

2010-01-01

Breaking The Silence: A Health Narratives Approach To Understanding Tuberculosis In El Paso, Texas

Angelica Forero-Quintana

University of Texas at El Paso, amforero@miners.utep.edu

Follow this and additional works at: https://digitalcommons.utep.edu/open_etd



Part of the [Sociology Commons](#)

Recommended Citation

Forero-Quintana, Angelica, "Breaking The Silence: A Health Narratives Approach To Understanding Tuberculosis In El Paso, Texas" (2010). *Open Access Theses & Dissertations*. 2485.
https://digitalcommons.utep.edu/open_etd/2485

This is brought to you for free and open access by DigitalCommons@UTEP. It has been accepted for inclusion in Open Access Theses & Dissertations by an authorized administrator of DigitalCommons@UTEP. For more information, please contact lweber@utep.edu.

BREAKING THE SILENCE: A HEALTH NARRATIVES APPROACH TO
UNDERSTANDING TUBERCULOSIS IN EL PASO, TEXAS

ANGELICA FORERO-QUINTANA
Department of Sociology and Anthropology

APPROVED:

Sara E. Grineski, Ph.D., Chair

Timothy Collins, Ph.D.

Eva Margarita Moya, Ph.D.

Patricia D. Witherspoon, Ph.D.
Dean of the Graduate School

Copyright ©

by

Angelica Forero-Quintana

2010

DEDICATION

I dedicate this thesis to my mother Nubia Castellanos and my father Enrique Forero, for giving me the opportunity to move to the United States and for supporting me in all of my dreams. To my husband, Juan Quintana for all of his guidance, help, and support. To my son Jacob Mathew Quintana, who has been my inspiration, and my source of strength in this thesis. To all, Thank You.

Dedico esta tesis a mi madre Nubia Castellanos y a mi padre Enrique Forero, por darme la oportunidad de venir a los Estados Unidos y por apoyarme en todos mis sueños. A mi esposo Juan Quintana por todos sus consejos, ayuda y apoyo. A mi hijo Jacob Mathew Quintana, quien ha sido mi inspiración y motivo de fuerza en esta tesis. A todos, gracias.

BREAKING THE SILENCE: A HEALTH NARRATIVES APPROACH TO
UNDERSTANDING TUBERCULOSIS IN EL PASO, TEXAS

by

ANGELICA FORERO-QUINTANA

THESIS

Presented to the Faculty of the Graduate School of

The University of Texas at El Paso

in Partial Fulfillment

of the Requirements

for the Degree of

MASTER OF ARTS

Department of Sociology and Anthropology

THE UNIVERSITY OF TEXAS AT EL PASO

December 2010

ACKNOWLEDGEMENT

I would like to acknowledge my thesis chair, Dr. Sara Grineski for guiding, and supporting me with this thesis. I would also like to acknowledge my thesis committee members Dr. Eva Margarita Moya for her guidance and encouragement during this semester, and to Dr. Timothy Collins for his support with thesis.

I would also like to acknowledge the TB clinic staff for helping me recruit the participants for this study, and the Graduate School for providing funding for this project. Lastly, I would like to acknowledge the fifteen participants who made this thesis possible. Their stories changed my life forever.

Gracias a cada uno de los quince participantes que hicieron esta tesis posible. Sus historias cambiaron mi vida para siempre.

ABSTRACT

Tuberculosis is a chronic illness affecting people in El Paso, Texas. TB continues to be a disease of great concern along the US-México border. The TB rates in El Paso for 2008 and 2009 were 5.4 and 8.9 per 100,000 and 13.5 and 13.3 per 100,000 in Ciudad Juárez. The number of new TB cases in 2008 and 2009 for El Paso were 40 and 67 cases and in Ciudad Juárez, they were 311 and 306 cases (Moya, 2010). This study relied on interviews with fifteen people undergoing treatment for TB (and three of their children) using a health narratives approach. Important themes from the narratives included delayed diagnosis, challenges in dealing with TB, and positive aspects that came out of recovering from the disease. In terms of explaining why people were delayed in diagnosis, reasons ranged from several misdiagnoses in a row, lack of awareness of TB by doctors', fear of immigration authorities, and fewer economic resources for health care. Once receiving a diagnosis, participants faced additional challenges including poverty and difficulties accessing social services (e.g., finding employment because of TB, and eligibility to qualify for social assistance such as unemployment compensation, food stamps or housing). Other challenges participants faced while undergoing treatment were a lack of knowledge about TB (e.g., sources of infection, treatments, and clinics where people can get tested) and stigma. At the end of treatment, some participants reported positive outcomes from being a person with TB illustrated by beneficial changes in behaviors (e.g., consuming healthier foods, stopping illegal drug use and exercising); a desire to give back to their community (e.g., volunteering); and positive changes in family relations (e.g., closer relationships). This study contributes to the understanding of the experiences of people with TB in communities with a relatively high burden of disease.

TABLE OF CONTENTS

ACKNOWLEDGEMENT	v
ABSTRACT.....	vvi
TABLE OF CONTENTS.....	vvii
LIST OF TEBLES	ixx
Chapter 1: INTRODUCTION.....	1
1. LITERATURE REVIEW	1
1.1 Background on Tuberculosis.....	1
1.2 Tuberculosis on the US-México Border	4
1.3 Health Narratives	7
1.4 Tuberculosis and Structural Violence.....	10
1.5 Delayed Diagnosis	13
1.6 Challenges Faced by People with Tuberculosis.....	17
1.7 Positive Aspects of Tuberculosis	23
1.8 Contribution to the Literature	24
Chapter 2: DATA & METHODS	26
2.1 Study Area	26
2.1 Data Collection	27
Chapter 3: ANALYSIS	33
3.1 Delayed Diagnosis	33
3.2 Challenges Faced by Residents with Tuberculosis	45
3.3 Positive Outcomes of Tuberculosis	60
Chapter 4: DISCUSSION	73
4.1 Structural Violence	78
4.2 Limitations	86
Chapter 5: CONCLUSION	88
5. Policy Recomendations.....	89
5.1 Delayed Diagnosis	89
5.2 Challenges Faced by People with Tuberculosis.....	90

5.3 Positive Outcomes of Tuberculosis	90
5.4 Structural Violence	91
REFERENCES	95
APPENDIX.....	100
VITA.....	120

LIST OF TABLES

Table 1.1: Analysis Themes.....	31
Table 1.2: Participants' Demographic Information.	32

CHAPTER 1

INTRODUCTION & LITERATURE REVIEW

The Centers for Disease Control and Prevention (CDC) reported that one-third of the world's population is infected with TB and nearly nine million people will become sick with the bacteria. There are two million TB-related deaths worldwide every year and TB is the leading cause of death for people with HIV (WHO, 2007, CDC, 2008). This thesis seeks to explore and explain the experiences of people with tuberculosis. Health narratives serve as a method for describing the impact of TB on people with the disease, and structural violence serves as a conceptual framework to understand tuberculosis, not only as an individual disease, but as a problem of social inequality affecting our border community.

In chapter 1, I will provide background information on TB, before reviewing TB on the US-México border, health narratives, structural violence, and three themes that emerged in combination from a review of the literature as well as through the process of conducting interviews. They include: 1. Delayed diagnosis, 2. Challenges faced by people with TB, and 3. Positive outcomes of TB. In chapter 2, I will provide information about the study area, and methods for the study. In chapter 3, I will provide an analysis of the three emerging themes. Chapter 4 will address a discussion of the significance of the findings, and chapter 5 will provide a conclusion for this study that relates to policy recommendations.

1.1 Background on Tuberculosis

TB is a disease caused by a bacterium called *Mycobacterium tuberculosis*. The bacteria usually attack the lungs but can attack any part of the body such as the kidneys, spine, and brain

(CDC, 2008). TB is spread through the air from one person to another. TB bacteria are put into the air when a person with active TB of the lungs or throat coughs, sneezes, speaks, or sings. People nearby may breathe in these bacteria and become infected, but not everyone infected with TB bacteria becomes sick.

As a result, two TB-related conditions exist: latent TB infection (LTBI) (i.e., TB infection without active symptoms) and active TB disease. With LTBI, TB bacteria can live in the body without making the person sick. This is the case for most people who breathe in TB bacteria and become infected; the body is able to fight the bacteria to stop it from growing. People with LTBI do not feel sick and do not have any symptoms; the only sign of TB infection is a positive reaction to the tuberculin skin test or the TB blood test. People with latent TB infection are not infectious and cannot spread TB bacteria to others, and may never develop the TB disease. However, if TB bacteria become active in the body and the bacteria multiply, the person will get sick with active TB disease (CDC, 2008).

People with TB disease may spread the bacteria to people they spend time with every day, such as family members, coworkers, young children, or friends. Some people develop the TB disease soon after becoming infected (within weeks), before their immune system can fight the TB bacteria. Other people may get sick years later, when their immune system becomes weak for another reason. For persons whose immune systems are weak, especially those with HIV infection, the risk of developing TB disease is much higher than for persons with normal immune systems (CDC, 2008).

Treatment for LTBI is a one drug regimen as LTBI is easier to treat than active TB, which requires a combination of drugs. For LTBI, Isoniazid (INH) is prescribed for nine months as the preferred regimen to kill the TB bacteria present in the body (CDC, 2009). In addition,

there are nine other drugs plus INH currently approved by the U.S. Food and Drug Administration (FDA) for treating TB (CDC, 2009). Some of the drugs used in combination to treat active TB include: isoniazid (INH), rifampin (RIF), ethambutol (EMB), and pyrazinamide (PZA). Regimens for treating TB have a more intensive phase of two months, followed by a continuation phase of either four or seven months (CDC, 2009). In addition, in the United States, the use of the BGC (*Bacille Calmette-Guerin*) vaccination in the prevention of TB meningitis is rare, as the vaccine does not completely prevent people from getting TB and it may also cause a false positive tuberculin skin test. However the BGC vaccination is still used in many countries including México, as the primary preventive method against TB meningitis (CDC, 2008).

In the United States, the total number of cases of TB in 2008 was 12,904, representing a rate of 4.2 cases per 100,000 persons (CDC, 2008). Both the number of TB cases reported and the case rate decreased (-2.9% and -3.8%, respectively) compared to 2007. The TB rate in 2008 was the lowest recorded since CDC began reporting rates in 1953 (CDC, 2008). The TB rate has been going down in the United States each year since 1992. Among the states, California was the number one state for TB cases with 6.4% of all cases in the US (California Health and Human Services Agency, 2009), followed by Texas, which had 6.2% of all reported cases (CDC, 2008).

This pattern of decreasing rates contrasts sharply with the developing world, whereby TB rates are still increasing and are much higher. For example, the World Health Organization (WHO) reported 21,283 new TB cases in México in 2007, reflecting a case rate of 20 per 100,000 populations (Border Health Commission, 2009). In México, every day there are 54 new TB cases, and about every six hours a person dies from TB, as TB continues to affect the most

vulnerable communities (Moya & Lusk, 2009). México was listed as the most common country of birth for foreign-born persons with TB in the United States; Mexican-born active TB cases comprise 25% of all foreign-born TB cases in the United States (Moya & Lusk, 2009). In addition, the National Health and Nutrition Examination Survey (1999-2000) found a higher prevalence of latent TB infection (LTBI) in people of Mexican origin (9.4%) compared with those born in the US (4.4%) as the total estimated number of persons with LTBI in the US was 11,213,000 or 4.2% of the civilian, non-institutionalized population (Border Health Commission, 2009). In the following section I will provide background information of TB on the US-México Border.

1.2 Tuberculosis on the US-México Border

Tuberculosis continues to be a disease of great concern along the US-México border, by maintaining its position in the top ten diseases that account for high rates of mortality and morbidity in this region (Pan American Health Association, 2007). The US-México border region, which stretches more than 2,000 miles, is characterized by differences in the level of infrastructure but similarities in terms of population growth, culture, lower socioeconomic status, limited access to health care, and low levels of health insurance coverage (Moya & Lusk, 2009, McEwen, 2005).

Immigration has changed the epidemiology of tuberculosis in the United States as the number of TB cases in the native-born population has declined and as the number of cases in the foreign-born population has increased (Deiss et al., 2009; De Heer et al., 2009; & Quitugua et al., 2002). The higher incidence of TB within the northern Mexican border area and the continuous cyclical migration of Mexican nationals to and from the US suggests that the strains of

“mycobacterium tuberculosis may be transmitted across the border” (Quitugua et al., 2002, p.2716).

In what follows, I will review four of the studies conducted on TB along the US-México border (Wells et al., 1999; McEwen, 2005; De Heer et al, 2009 & Moya, 2010) to provide important background information on the epidemic in this region of study. Despite the seriousness of the epidemic, few studies have been conducted in a bi-national setting (see also Moya and Lusk 2009, & Moya, 2010). Wells et al. (1999) studied tuberculosis among foreign-born Hispanics living in US states that border México from an epidemiological perspective. Wells et al. (1999) explained that the rates of TB in foreign born communities in the border states are “not necessarily a product of recent importation of active TB, but could represent infection and transmission occurring among persons after immigration to the US or reactivation of prior infection disease” (p. 836). In addition, the large number of periodic return visits of persons to México from the US increases the chances for infections in the US. In México, “the TB rate is estimated to be fivefold than that of the US, [which] increases the risk for exposure to TB and thus ultimate transmission of TB within the US” (Wells et al., 1999, p. 837). In conclusion, Wells et al. (1999) suggested that bi-national collaborations for TB control and prevention were essential (there were five CDC-funded projects in place at this time), and that they should also be expanded to non-border regions of México as well.

In addition to an epidemiological approach, tuberculosis in the US-México border has also been studied from a critical ethnographic approach. McEwen (2005) used a critical ethnographic study (and health narratives, to be discussed later) to explore the multiple and disparate explanations of latent tuberculosis infection (LTBI) in the US-México border region. McEwen (2005) explained that Mexican immigrants at the US-México border are confronted

with divergent explanations for TB from the two national professional health care sectors that contribute to their understanding and perceptions of LTBI. The divergent explanations in United States and México are rooted in the different TB policies in the two countries that reflect the disparities in economic resources, technology, and TB rates.

Findings from this study situated Mexican immigrants' understanding and experience of LTBI from "a historical, sociopolitical, and cultural context of the US-México border" (McEwen, 2005, p.351). Mexican immigrants' knowledge was represented by McEwen (2005) based on a taxonomy of categories and domains of cultural knowledge of LTBI. Participants identified both factors that facilitated their decision to initiate and complete preventive treatment (e.g., hope of avoiding TB disease, the influence of family and friends, and expectations about treatment) and the factors that were perceived as barriers to undergoing preventive treatment (e.g., length of treatment, medication side effects and the lack of clear explanations about LTBI from health professionals) (McEwen, 2005).

Tuberculosis on the border was also studied through a *photovoice project* in which "photographic interviewing gives a voice to individuals affected by TB" (De Heer et al., 2009, p. 58). De Heer et al. (2009) explained that this Photovoice project has been the only one conducted worldwide, and it includes the border cities of El Paso, Texas and Ciudad Juárez, Chihuahua. Photovoice, as explained by De Heer et al. (2009), served as a tool of empowerment, "enabling those with little money, power, or status to communicate to decision and policy makers" (De Heer et al., 2009, p.58). De Heer et al. (2009) points out that the social conditions of the border create a unique context for individuals with TB in the border region. In the border region "TB continues to be a stigmatized health issue" (De Heer et al., 2009, p.70), as participants reported feelings of stigmatization during the different stages of diagnosis, and

treatment. In addition, De Heer et al. (2009) identified several needs to be addressed in the prevention of TB, such as bilingual TB education and the targeting of “people at risk for TB and HIV, persons affected by diabetes, and migrant and mobile communities” (De Heer et al., 2009, p.71). Finally, the project demonstrates that empowering TB patients serves as a possibility for connecting those affected by the disease and those in power to change policy related to TB.

Tuberculosis on the border was also studied through an exploratory study (Moya, 2010) on health-related stigma from the experiences and perspectives of people affected by TB. Findings indicated that this study provides basis for the development of individual and structural stigma interventions with Mexican-origin groups to ensure preventive, diagnostic and treatment free of stigma and discrimination for persons affected by TB (Moya, 2010). In the following section I will provide background information on health narratives, the method used to explain the impact of TB on people in this study.

1.3 Health Narratives

In this section I will introduce a focus on the experience of illness, in this case TB, through health narratives. Bell (2000) defines the study of narratives and the experiences of illness as a discourse that consists of related events connected in a meaningful way for a particular audience in order to make sense of the world, and people’s experiences in it. Bell’s (2000) definition includes those events in life that occur in every imaginable setting in which knowledge can be produced, communicated and sustained; narratives, like the events they portray, take place in specific historical contexts and in shifting relations of power. Bell (2000) explains that narratives include rich and complex clues about the behaviors of members of

cultures, as they enable people to explain the multiple ways in which behaviors work and are connected to society.

The experience of illness refers as “how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms of disability” (Bell, 2000, p.187). By making a distinction between disease and illness, Bell (2000) argues that it is possible to turn the focus of analysis from the perspective of the physician (and the disease) to that of the patient (and the illness). This turn calls for empowering patients in medical encounters, and in the institutions of medicine as “medicine’s focus on disease not only systematically silences patients’ viewpoints but reproduces unequal relations of power” (Bell, 2000, p. 187).

Health narratives scholars have concentrated on studying chronic illnesses. The attention to chronic illness by health narratives scholars reflects the rise in the number of people living with chronic illnesses in comparison with those living with acute illness (Bell, 2000). Chronic illnesses have different impacts on people than acute illnesses (Bell, 2000, Conrad & Bury, 1997), and these differences occur because “chronic illnesses are more likely than acute illnesses to seriously disturb a person’s essential relationship and very sense of self” (Bell, 2000, p. 188). As Bell (2000) notes, some acute illness are minimally disruptive of life activities, while chronic illnesses have a trajectory, and are more distressing.

In the social sciences, there is an outpouring of narrative work. The word narrative “has become ubiquitous throughout the academic community, crossing disciplines, theoretical frameworks, methodological perspectives, and national borders” (Bell, 2000, p. 188). The popularity of narratives and qualitative research in health more generally, reflects criticisms of the biomedical tradition that has focused on disease as opposed to illness (Bell, 2000). This has

also led some scholars to turn their attention to the use of narratives “because narratives emphasize the plurality of truths that cultures and subcultures claim about themselves, instead of assuming that there is one set of indisputable truths that can be known and told” (Bell, 2000, p. 185). Bell (2000) also gives another reason to convey the value of narratives for understanding illness: the researcher is better able to understand the experiences of sick people that cannot be captured by other qualitative or quantitative methods of analysis. Some of the chronic illnesses studied through narratives include epilepsy, cancer, rheumatoid arthritis, multiple sclerosis, and tuberculosis (Good & Mary-Jo 1994; Kleiman et al., 1995; Bearison 1991; Eun Jeong et al., 2004; Drieger et al., 2004; McEwen, 2003; Araujo Paz & Moita Sa, 2009).

While TB is not the most common disease studied from this perspective, several studies have taken a narrative perspective on TB. McEwen (2003) conducted an ethnographic study (see also McEwen, 2005) using narratives to explore the understandings and experiences of LTBI in infected Mexican immigrants. Immigrant narratives centered on cultural themes as well as structural/policy barriers related to health care, both of which influenced the decision making of Mexican immigrants related to completing preventive therapy for LTBI (McEwen, 2003). Another study based on the experiences of people with TB was conducted by Araujo Paz & Moita Sa (2009). The study presented a phenomenological reflection on the daily care routine of patients in TB treatment in Belém, Brazil (Araujo Paz & Moita Sa, 2009). This study’s main objective was to understand the treatment routine delivered at a primary health care center, by conducting interviews with infected TB patients and the health care professionals (Araujo Paz & Moita Sa, 2009). Results from patient findings revealed that infected people feared the disease and its consequences, that care was usually provided in an impersonal way that reflected a “biomedical technical standard”, and patients were seen as responsible for their treatment

(Araujo Paz & Moita Sa, 2009, p.180). By analyzing patient narratives, Araujo Paz & Moita Sa (2009) concluded that there was a gap between the treatment offered at the clinic and what the patients expected and needed, in terms of more humanized treatment. Closing this gap could lead to more successful control of TB (Araujo Paz & Moita Sa, 2009).

Although TB has been studied from a narrative focus related to immigrants and LTBI (McEwen 2003) and delivery of treatment (Araujo Paz & Moita Sa, 2009), a general study of TB narratives has not been conducted in the US-México border region, which directs this thesis at the exploration of these areas. In addition, narratives of experiences of people with an illness, in this case people with TB, have the potential to connect the personal experiences of individuals with public issues of social structure (Bell, 2000), as has been done skillfully by Farmer (1998, 2003), to be discussed next. The narratives collected in this thesis represent the experiences of people with tuberculosis along the US-México border following Farmer (2003, 2004) and his work on the experiences of people in global contexts that suffer from unequal social structures, poverty, and inequality.

1.4 Tuberculosis and Structural Violence

In this section, I will define structural violence using Paul Farmer's framing, and provide a summary of key points related to TB and structural violence. Structural violence is an important aspect of this thesis as it helps explain the connections between social injustices, constraints on agency, and human suffering in persons affected by TB. A lens of structural violence also allows the researcher to make decisions as to what is morally wrong, and to recommend changes in scenarios where structural violence takes place.

Structural violence as explained by Farmer (2004) dates back to at least 1969 and has contributions from Johan Galtung and Latin American liberation theologians. Galtung (1969) used the term broadly to describe social injustices caused by social structures which include poverty and steep grades of social inequality, including racism and gender inequality (see Galtung, 1969). As an illustration of structural violence and TB, Galtung (1969) offers the following example:

Thus, if a person died from tuberculosis in the eighteenth century it would be hard to conceive of this as violence since it might have been quite unavoidable, but if he dies from it today, despite all the medical resources in the world, then violence is present according to our definition (p.168).

Farmer (2004), building off Galtung (1969), defined structural violence as: “sinful social structures characterized by poverty and steep grades of social inequality” (Farmer, 2004, p.307). In other words, structural violence is violence exerted systematically or indirectly by people with power. The use of the word “sinful” in Farmer’s (2004) definition implies that structural violence is also morally wrong. Structural violence includes a host of offenses against human dignity, including “extreme and relative poverty, social inequalities ranging from racism to gender inequality, and the more spectacular forms of violence that are uncontestedly human rights abuses, some of them punishments for efforts to escape structural violence” (Farmer, 2003, p.8). In addition, the concept of structural violence “is intended to inform the study of the social machinery of oppression. Oppression as a result of many conditions not the least of which reside in consciousness” (Farmer, 2004, p.307). These observations have led Farmer (2003) to ask questions about death, starvation, AIDS, tuberculosis, warfare, and medical practice in settings of great social inequality. In order to understand structural violence, Farmer (2008) indicated that we need to call not only on history and broad social context, but also on personal narratives and on personal experiences, which is the aim of this thesis.

In an analysis of Haiti, Farmer (2004) explained that in order to understand structural violence it is necessary to comprehend the roles played by history, geography, economic influences, and other forms of socialization that enable the existing conditions of structural violence to be present in contemporary Haitian society. For example, looking at the deprivation in Haiti, Farmer (2003) observes that “political and economic forces have structured the risk of AIDS, tuberculosis and indeed, most other infectious and parasitic diseases; social forces have structured the most forms of extreme suffering, from hunger to torture and rape” (p.16). Farmer skillfully connects these macro-scale processes to the voices of victims of structural violence in order to represent the existing global conditions of infectious diseases. Farmer (2003) illustrates, using individual cases of patients in poverty, the contrast between the lives of those who are affluent enough that they rarely see the lives of others affected by structural violence, and the poor.

In order to understand the relationship between structural violence and explore its contribution to human suffering, Farmer (2008) considers an analytic model in which various social axes “are used to discern a political economy of brutality” (p.337). These axes are: *the axis of gender*, in which Farmer (2008) examined gender inequality to help explain why women are victims of structural violence more often than men. The second social axis used by Farmer (2008) is *the axis of race and ethnicity*, which helps explain why racial classification has been used to deprive groups of basic rights throughout history and in present times. The third social axis used by Farmer (2008) is called *other axes of oppression*, in which any social or biological human characteristic is important to consider inequality, discrimination, and human suffering for persons who are victims of structural violence.

Returning to my focus, I will use the concept of structural violence to highlight the inequalities shaping the experiences of these usually unheard voices of people with TB in the border community. In order to do this, I will build off Farmer's analytic model of identifying important axes that shape people's experiences with structural violence (Farmer, 1993, 2006). Previewing my discussion section, I find that the experiences of people with TB in El Paso relate to the concept of structural violence through four axes: social factors including ethnicity (and race), gender, immigration status, and socioeconomic status (through access to health insurance). In my analysis, structural violence was important because it allowed me to determine these less recognized social factors, and social injustices that are embedded in the vulnerability of human suffering that contributes to the infection and spread of TB in the border community. In the next section, I will move from TB and structural violence to the themes in this study: delayed diagnosis, challenges faced by people with TB and positive outcomes of TB.

1.5 Delayed Diagnosis

Little is known about the prevalence of delayed diagnosis or about the roots of delaying care among people affected by TB. Delays in the diagnosis of TB can result in progression to advanced illness (Wallace et al., 2009; Gaviria et al., 2010; Tsai et al., 2008; Deis et al., 2001; Moya & Lusk, 2009). Based on county reports to the National Tuberculosis Surveillance System (NTSS) Wallace et al. (2009) compared pulmonary TB cases in persons older than 15 years of age with advanced disease to those without TB disease in a binomial regression analysis. Wallace et al. (2009) explained that the proportions of total TB cases each year that were advanced (i.e., active pulmonary TB) increased from 18.5% in 1993 to 26.1% in 2006; the increase in the proportion of pulmonary TB was most notable in counties with low TB rates (i.e.,

below 6.6 per 100,000) (Wallace et al., 2009). This finding indicates that active pulmonary TB cases were found in areas with low prevalence rates and among subgroups less “at risk” (e.g., whites, employed US- born and non-alcohol abusers); part of this increase in serious cases, as explained by Wallace et al. (2009), was a consequence of TB becoming an uncommon disease leading to delayed diagnoses for these groups. This study highlights the need for TB diagnosis at early stages of the illness to minimize advanced pulmonary TB and decrease the risk of transmission for groups with low prevalence rates (Wallace et al., 2009). Wallace et al. (2009) indicated that additional efforts should concentrate on reducing time to treatment initiation in low-incidence areas and among groups traditionally seen as being at low risk for TB.

Delayed diagnosis of active pulmonary TB is often related to patients first being diagnosed with pneumonia. Tsai et al. (2008) investigated the clinical characteristics and factors in patients with delayed diagnosis of active TB in an emergency department in Taiwan. Based on a review of the medical records of the 103 patients with discharge diagnosis of pulmonary TB from December 2003 to March 2006, Tsai et al. (2008) found that for those with a delayed diagnosis, 68.4% were first diagnosed with pneumonia. Tsai et al. (2008) indicated that it is important to highlight the differences between TB and pneumonia, because emergency physicians gave erroneous diagnoses of pneumonia based on the similar clinical, radiologic and laboratory characteristics of both illnesses. Tsai et al. (2008) suggested that emergency physicians keep pulmonary TB as a possible diagnosis for patients suspected to have pneumonia.

Also in relation to delayed diagnosis, Gaviria et al. (2010) examined the role of health care providers in the delayed diagnosis of pulmonary TB among adults in the city of Medellin, Colombia. Gaviria et al. (2010) surveyed 89 doctors and nurses about their pulmonary TB related knowledge and practices. Findings indicated that the lack of knowledge and patient

stereotyping by doctors and nurses were the leading causes of the misinterpretation of symptoms (Gaviria et al. 2010). In terms of lack of knowledge, Gaviria et al. (2010) reported that 88.8% of doctors and nurses did not know that weight loss was not frequent during the initial phases of the disease; 50.6% said that not all patients with pulmonary TB coughed; and “30.3% of the respondents thought that respiratory symptoms could be momentarily cured with antibiotics” (p.87). The provider’s lack of knowledge regarding risk factors and clinical protocols made diagnosis difficult when the patients did not match the stereotype or exhibited symptoms of a more well-known illness. Gaviria et al. (2010) indicated that in relation to the participant’s survey, findings concentrated at the misinformation about pulmonary TB, transmission and inappropriate treatment that led to discriminatory practices. Gaviria et al. (2010) also indicated that social isolation of people with TB reinforced stereotypes and stigma, which discouraged the patients from seeking medical attention.

Returning to my focus on delayed diagnosis, it is important to mention the duration of symptoms for persons prior to getting a diagnosis of TB. Gaviria et al. (2010) indicated that the average duration of symptoms at diagnosis was four months, and prior to diagnosis, patients had been symptomatic for six months or longer. This demonstrates a serious delay in diagnosis of symptomatic persons which increases the risk for TB transmission as they are in active disease (and contagious) longer. In addition, little is known about repeated misdiagnosis (see Moya and Lusk, 2009 and Tsai et al., 2008), which directs my attention in this study at examining the process of delayed diagnosis.

In addition to the health care provider issues already discussed, behaviors and challenges for the persons with TB also contribute to their delayed diagnosis. First, immigrants may have delayed diagnoses because of not seeking care when experiencing symptoms due to fear of

immigration authorities. This theme has been addressed more in-depth in the access to care literature than it has in the TB literature. Concerns about deportation when seeking care are likely rising due to changes under the 1996 welfare reform legislation (see Proposition 187 as explained in Berk & Schur, 2001) and the related amendments that affect eligibility of immigrants for public programs and states' abilities to provide care to undocumented immigrants. Berk and Schur (2001) conducted 973 in-person surveys of undocumented Latinos in Texas (Houston and El Paso) and California (Fresno and Los Angeles) neighborhoods with a significant concentration of Latinos. Findings from this study indicated that 39% of the undocumented adult immigrants expressed fear about receiving medical services because of their undocumented status. Those who reported fear were likely to report being unable to acquire medical and dental care, prescription drugs, and eyeglasses. In sum, they found that concern about immigration status decreases the likelihood of receiving care (Berk & Schur, 2001).

In El Paso, TX, the site of my study, Heyman, Nunez & Talavera (2009) studied health care access amongst 84 unauthorized [undocumented] immigrants. The study found that fear of authorities, obstacles to movement by immigration law enforcement, and hierarchical social interactions in health care settings influenced the immigrants' lack of access to health care (Heyman, Nunez, & Talavera, 2009). Barriers were not discrete factors but rather occurred as webs that made solving the challenges more difficult than if the individual barriers were experienced alone (see Heyman, Nunez, & Talavera, 2009). Heyman, Nunez, & Talavera, (2009) indicated that while seeking health care, their participants were at constant risk of being arrested and deported, so unauthorized immigrants may not be willing to take the risk to seek health care and may fear formal health care providers.

A second reason that people delay care is because of few economic resources. Asch et al. (1998) sought to determine what perceived access barriers delayed symptomatic TB patients from obtaining care. Asch et al. (1998) conducted a survey in Los Angeles, California using a sample of 248 patients undergoing treatment with active TB based on self-reported delay in seeking care and access barriers. Asch et al. (1998) found that one in five of the participants reported delaying care for more than 60 days, 25% of the total sample delayed care because of unemployment as participants worried about the cost of care or could not afford it, 26% of the participants believed they could treat themselves, and 28% did not know where to seek care. Asch et al. (1998) concluded that unemployment and a lack of knowledge about where to obtain care were most closely associated with clinically significant delays. This suggests that improving the availability of care for high risk groups may reduce TB patients' delay in obtaining care, while limiting the spread of the disease.

1.6 Challenges faced by people with TB

There are many challenges faced by people with TB. Some key challenges, to be discussed in this section are: poverty, lack of knowledge and stigma.

1.6.1 Poverty

Tuberculosis is known to be associated with poverty (Farmer, 2008, Holtgrave & Crosby 2004, Cantwell et al, 1997). Holtgrave & Crosby (2004) measured the state-level relationship between social capital, poverty, income inequality, and case rates of TB in 1999. Higher rates of poverty, higher levels of income inequality, and less social capital were all significantly correlated with higher TB rates (Holtgrave & Crosby 2004). In a related study of all TB cases reported to the CDC between 1987 and 1993, Cantwell et al. (1997) explored the

relationship between the increased risk of TB and demographics, socio economic status (SES), race/ethnicity and birthplace by using multivariate regression models. Findings indicated that low SES (i.e., income and education, among others) increased the risk of TB, especially for those living in crowded settings, and that other indicators of low SES such as poverty, receipt of public assistance income, and unemployment were also associated with an increase in TB (Cantwell et al., 1997). These studies about poverty were largely quantitative; my narrative approach will add the qualitative details about how people cope with poverty-related challenges.

1.6.2 Lack of knowledge

The lack of knowledge about TB is a challenge for those diagnosed with the disease as they and their families, and sometimes their health care providers, are not very aware of the disease. People in the United States, especially in border areas such as El Paso, Texas where rates of TB infection are higher, are lacking awareness of the seriousness of TB (Moya, 2010). In a national level survey, Ailinger, Laus, & Dear (2003) discovered that Americans do not know enough about TB. They examined knowledge and perceived risk of TB using the 1994 National Health Interview Survey. Results from this study, demonstrated some general knowledge about TB, several misconceptions, and low concern regarding the risk of contracting TB (Ailinger, Laus, & Dear 2003). They indicated that 89.8% of the sample did not perceive any personal risk of contracting TB. In addition, respondents reported being knowledgeable about TB but their actual knowledge of the disease was lower than their perceptions (Ailinger, Laus & Dear 2003). Ailinger, Laus, & Dear (2003) reported that gender was slightly associated with knowledge of perceived risk, 23.8% of men and 25.7% of women answered all questions correctly. Education was a factor in knowledge as 15.4% of the respondents with less than a high school education

versus 26.9% with a high school education responded correctly to the question on how TB was spread (Ailinger, Laus & Dear, 2003). In relation to family income, Ailinger, Laus, & Dear (2003) reported an association with TB knowledge; 26.1% of those people at or above the poverty line answered all the questions correctly, compared with 17% of those people below the poverty line. Ethnicity was also a factor associated with knowledge and perceptions of TB, Ailinger, Laus & Dear, (2003) reported that 25.4% of non-Hispanics and 18.4% of Hispanics respondents answered all TB questions correctly. An important conclusion and recommendation from this study was that public health nursing efforts needed to be redirected toward health education regarding TB risk, spread, screening and testing programs (Ailinger, Laus, & Dear 2003).

As opposed to studying the American public as a whole, Wolfe et al. (1995) conducted a study on a high risk group (i.e., intravenous drug users) of 394 in New York City to measure TB knowledge. Wolf et al. (1995) reported that while most respondents understood the mechanisms of TB transmission, 75% did not understand the difference between active and latent disease. Other findings indicated that 40% of the participants did not understand the importance of medication adherence, and one third were unaware of the problem of drug-resistant TB (Wolfe et al., 1995). Wolfe et al. (1995) also indicated that the absence of TB education among this group of drug users reflected a population-wide lack of TB-related knowledge, which interferes with efforts to control TB.

Looking specifically at knowledge among racial/ethnic minorities, Marinac et al. (1998) conducted face-to-face surveys that examined self-perceived and [actual] TB knowledge in 505 people in the Kansas City Metropolitan area. Marinac et al. (1998) explained that self-perceived knowledge about TB was rated as “little or nothing by 60% of the respondents” (p.804). The

correct response average score when asked specific questions about TB were 61% (Marinac et al., 1998). Participants knew more about symptoms (89%) than forms of transmission (55%), etiology (53%), identification of high risk populations (57%) and treatment (49%). Results indicated knowledge deficits in the etiology, transmission and treatments of tuberculosis, and that efforts at developing educational programs must be directed at reducing the incidence of active TB cases and increase preventive interventions (Marinac et al., 1998). This lack of knowledge in the general public becomes a challenge when one is diagnosed with TB, and the specific ways this is challenging will be discussed using my data. In the next section I will provide background information about stigma.

1.6.3 Stigma

Stigma is known to affect people with TB, as it contributes to the suffering of those affected by the illness (Soma et al., 2008). In terms of the theoretical background for the concept, Erving Goffman's (1959) definition of stigma relates to the gap between what a person ought to be, the "virtual social identity," and what a person actually is, the "actual social identity". Anyone who has a gap between these two identities is stigmatized (Ritzer, 2007). However, the dramaturgical interaction between stigmatized people and others depends on which types of stigma an individual has. In the case of discredited stigma, the person assumes that the differences are known by the audience members or are evident to them. A discreditable stigma is one in which the differences are neither known by audience members nor readily perceivable by them (Ritzer, 2007).

Having TB would usually be a discreditable stigma, as the person who is sick can hide or negate symptoms, avoid or delay seeking care, and/or default from treatment (Soma et al., 2008).

In the case of a sick person with TB, infecting the rest of his/her family could be also a source of discredited stigma. Once infected, the family as whole is confronted with dealing or managing the social rejection of a communicable disease.

Tuberculosis has been studied in relation to stigma (Soma et al., 2008; Moya 2010 and Moya & Lusk, 2009). Soma et al. (2008) studied gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. In this study, Soma et al. (2008) assessed the different indicators of TB-related stigma that may lead someone with TB to hide symptoms, avoid or delay seeking care, hide a diagnosis, or default from treatment. These indicators included overt social exclusion as patients face various levels of isolation and rejection including fears of losing employment, divorce, and isolation within the household that impedes the sharing of common household items such as utensils, food, or sleeping areas. Soma et al. (2008) explained that TB stigma was worse for women as compared to men, resulting in divorce or separation more often for women. Limited mobility and financial dependency may discourage women with TB from seeking care because they fear the effects of public disclosure of the diagnosis (Soma et al., 2008). Findings from this study conclude that stigma influenced the effectiveness of TB treatment and control (Soma et al., 2008).

Specifically related to the US-México border, Moya (2010) examined stigma in the perspectives and experiences of Mexican-origin persons affected by TB in treatment or who had completed treatment in Ciudad Juárez, México and El Paso, Texas. Findings from this study revealed that the majority of participants experienced stigmatization related to TB. Moya (2010) found the stigmatization of TB and HIV/AIDS was associated with beliefs that the disease is linked to poverty, homelessness, and addiction. Stigma caused fears and distancing from family members, children, and/or work peers. Moya (2010) also found that negative impacts of stigma

for these participants included low self esteem, poor morale, depression, sadness, fear of transmitting the disease to others, shame and guilt. Moya (2010) concluded that the results of this study offered opportunities for advocacy, communication, and social mobilization activities.

Another study concentrating on stigma was Moya and Lusk (2009) who explained that in order to understand individuals affected by TB, one must understand stigma. Examining stigma can provide important insights into how TB is experienced, not only because stigma deters people from seeking care, but because there is lack of understanding of the disease, prejudice toward those infected, and irresponsible media reporting (Moya & Lusk, 2009). Based on qualitative interviews conducted by Moya, one female participant from El Paso, Texas and one female from Ciudad Juárez, Chihuahua were interviewed to uncover their perceptions of TB, and their TB-related stigma experiences (Moya & Lusk, 2009). For the El Paso participant, these were some of the emerging themes from the interview: “guilt, avoidance, culture of silence, rejection, disbelief, stigma, isolation, misdiagnosis, fear, and co-infection” (Moya and Lusk, 2009, p.53). For the Juárez participant, her emerging themes were: “secrecy, banishment, shame, rejection, death, malpractice, isolation, and poverty” (Moya and Lusk 2009, p.56). These two cases illustrate the social implications of TB in a low income border region and point to the need for research to systematically identify those factors that contribute to the negative effects of stigma and the positive factors used to overcome stigma in the lives of TB sufferers. My proposed study will contribute to this project.

1.7 Positive aspects of TB

While we tend to think of TB as a negative occurrence in someone’s life, positive outcomes can be possible. Shih (2004) argues that individuals successfully managing their stigma tend to adopt an empowerment model as opposed to a coping model when dealing with

stigma. Coping models propose that stigmatized individuals adopt strategies to cope with stigmas to avoid the negative consequences, by adopting a prevention model that guides the individuals to avoid negative consequences instead of seeking positive ones (Shih, 2004). On the other hand, in the empowerment model, stigmatized individuals are not passive targets of prejudice that focus only on avoiding negative outcomes, but they actively participate in society to understand their social world and create positive outcomes (Shih, 2004). In this model “overcoming adversity is not a depleting process but rather a replenishing and enriching process, as individuals who overcome adversity develop a sense of mastery and self-efficacy at their accomplishments” (Shih, 2004, pp. 180-181).

Positive impacts of stigma related to TB were described by Moya (2010) as participants who overcome TB and the associated social stigma, fostered positive attitudes about life, cared more for a person’s own health, developed more emotional strength, and had more appreciation for their health and families. On the other hand, De Heer et al. (2009) explained that in the Photovoice project, participants were empowered by sharing their stories, which in turn secured public commitments from decision makers to contribute to TB awareness and eradication (De Heer et al., 2009). This empowerment aspect of Photovoice is positive as it enables the participant to take an active learning role and to take part in community social action programs, and influence policy decision (De Heer et al., 2009).

I will use Shih’s (2004) coping/empowerment model in my project to explore the positive outcomes of TB. Apart from the benefits of positive impacts (Moya, 2010) and Photovoice (De Heer et al., 2009) and the general ideas from Shih (2004) that one can overcome stigma in a positive way, there have been few studies on the positive impacts that overcoming TB might have on a person. My study will address this.

1.8 Contribution to the Literature

I decided to concentrate on TB because it continues to be a disease of great concern along the US-México border, by maintaining its position in the top ten diseases that account for high rates of mortality and morbidity in this region (Pan American Health Association, 2007). The US-México border is a unique site for this study as no other border in the world exhibits such inequality of power, economics, and human conditions (Moya & Lusk, 2009). Health narratives serve as an important instrument to understand the complexities of structural violence. Building on Farmer's macro- and micro-scale approach to give voice to the victims of structural violence, I will work to provide a voice to people with TB being treated in El Paso, Texas.

There are some gaps that can be noted based on this literature review that have informed my study design and themes. First, there are no studies conducted on the US-México border that include experience of illness related to TB in a contextual perspective related to structural violence. Second, there are only a few TB studies (McEwen, 2003; Moya & Lusk 2009; & Moya, 2010) that contribute to the literature on narratives and the experience of illness for people with TB. In addition, there are few studies that examine the experience of the process of delayed diagnosis and little is known about the challenges people face when they have active illness and undergo treatment (e.g., poverty, challenges accessing social services, lack of knowledge and stigma). Lastly, there are very few studies that concentrate on the positive outcomes of TB which makes this study a complementary concept for a better understanding of TB. Using a health narratives perspective, this project will address the gaps by achieving answers to these research questions related to how people seeking treatment in El Paso are affected by TB:

1. Why do people experience delayed diagnosis of TB?
2. What are the challenges faced by people with TB?

3. What positive impacts can come from being a person with TB?

CHAPTER 2

DATA AND METHODS

2.1 Study Area

The location of El Paso Texas is a unique context for examining through health narratives the impacts of being a person with TB, as this city is located at the border of two highly unequal nations. The sister cities of El Paso and Ciudad Juárez are located in the Rio Grande/Bravo basin in the Chihuahuan Desert. El Paso County has a population of approximately 740,000 while Juárez has nearly 1.5 million residents. El Paso County has a population whose majority is an ethnic minority, with 82% being Latino, in addition, 4% are African American and 14% are non-Latino white. The city is generally working class, with a median household income (in 2007) of \$35,000 (US Bureau of the Census, 2008). Forty percent of adults do not have health insurance (Rivera et al., 2009), meaning the County has one of the highest rates of uninsured residents in the state of Texas, the state with the highest rate in the US.

TB is a serious health concern in these two cities. For 2008 and 2009 the TB rates in El Paso were 5.4 and 8.9 per 100,000, and in Ciudad Juárez, 13.5 and 13.3 per 100,000. The number of new TB cases in 2008 and 2009 for El Paso were 40 and 67 cases and for Ciudad Juárez, they were 311 and 306 cases (Moya, 2010). Possible reasons that account for these changes in rates are that in Ciudad Juárez, people affected by TB might fear to seek care as moving throughout the city is dangerous, or are leaving the city and moving into El Paso, Texas (if they have the option to seek care in the US) because of fear of the current violence. In terms of important risk factors, the percentages of TB cases for the population ages 18 years and up in 2009 in El Paso were: 76.2% foreign-born, 35.5% alcohol use, 15.2% diabetes, 11.8% HIV/AIDS, 3.1% homelessness, and 11.8% incarceration. For Ciudad Juárez, the important risk

factors were: 17% diabetes, 5% alcohol abuse, 7% HIV/AIDS, and 11% malnutrition (Moya, 2010).

Narratives collected during this study represent the perspectives of Mexican immigrants, and Mexican Americans seeking treatment for tuberculosis at the TB clinic in El Paso, Texas. The TB clinic is funded by the Department of Health and Human Services of Texas. Its main mission is to promote, ensure and improve the control and the spread of TB in El Paso by identifying and providing appropriate treatment to persons infected with TB and to those within groups at high risk of progressing from latent TB to the active disease and from spreading the disease. The TB clinic also offers screening, testing, and education services. Treatment is based on income and residence eligibility (See www.ci.el-paso.tx.us/health/tb). For income eligibility and/or health insurance, if a person does not have any type of health coverage, there is a minimum payment of \$5 dollars per visit. Patients also have a possibility of billing their own health insurance until treatment is completed. In terms of residence eligibility, people who do not have legal documents can still receive the services of this clinic as long as they have an El Paso address. Patients diagnosed with TB are treated through a Direct Observed Therapy (DOT) system, meaning that a trained health care worker delivers TB medication and watches the person swallows the medication to confirm that the person is complying with treatment.

2.2 Data Collection

Data were collected through one pilot in-depth interview followed by fourteen in-depth interviews of persons with tuberculosis (the primary interviewees were these fourteen individuals, but three daughters also participated in the interviews with their parent) conducted between June and August 2010 at the TB clinic in El Paso, Texas. The majority of the

participants in this study were at the end of their treatment, five participants were two to three weeks away from completing treatment, five participants were three months away from completing treatment, two participants completed treatment the day of the interview, and only one participant still had another six months to go to complete treatment.

The TB clinic in El Paso was selected because it treats all TB patients in El Paso. The TB clinic also facilitated the research process by allowing me to interview the participants in a private and secure space where the participants could feel comfortable without the pressures of having an interview at their residence in the presence of family members, children, or friends. During the interview process, I was able to make a solid connection with several staff members of this clinic, who taught me relevant information about TB (such as showing me how to read chest x-rays, sharing personal experiences about their jobs, and their interactions with patients which generated several ideas for future research). Participants were recruited through the TB clinic staff, participants were given a study flyer by the nurses with a phone number section which they were asked to fill out with their contact information if they were interested in participating in the study. TB Clinic staff then contacted me and provided me with each patient's contact information. Participants were contacted within a 48 hour period to schedule an interview. The total number of people contacted by phone was 14. I did not have any difficulties reaching them over the phone and none of the persons refused to be interviewed or cancelled the interview.

The fourteen interviews took place at the TB clinic, and the pilot interview took place in my office at UTEP. The fourteen respondents were provided with \$25.00 to compensate them for their time, and to thank them for their participation in this study. The \$25 incentives were provided thanks to funding from the Graduate School at the University of Texas at El Paso. All

but one of the interviews was conducted in Spanish. All 15 interviews were digitally recorded, with the respondent's consent, and averaged 60 minutes in length. All 15 interviews were transcribed in the language they were conducted in and analyzed using N*VIVO qualitative analysis software.

During the interview, a variety of themes were discussed (see Interview Guide in Appendix A). In the first section, the participant was asked about his/her story with TB. In this section, the participant was asked about his/her initial symptoms, length of time with symptoms, time spent waiting to seek health care, sources of infection, and other health conditions. Also discussed was the impact of TB on his/her life, the process of being diagnosed, seeking treatment, if he/she sought care in México and/or the US, feelings about medications, side effects of medications, infecting others with TB, process of finding the TB clinic, experience of receiving treatment at the TB clinic, and resources offered to the participant by the TB clinic.

The second theme discussed with participant was personal changes. In this section the participant was asked about personal changes occurring after he/she was diagnosed with TB; these included those related to depression, self-esteem, emotions, and religious faith. The third theme discussed was social interaction. Topics discussed in this section were changes in activities, experiences at work or school and with family; and reactions when informing partners, family, friends, and co-workers about the infection. The fourth theme discussed with participant was about his/her living conditions, including a description of the home, number of people living in the home, description of the neighborhood, and changes made to the home because of TB. The fifth theme was diet, including a description of foods consumed because of TB, the cost of healthy foods, and if he/she received any social assistance to pay for food. Then, we discussed transportation and the participant was asked to describe his/her mode of transportation,

ownership of a vehicle, and difficulties of not having a vehicle (if applicable). Seventh, the participant was asked about their economic situation, specifically about if he/she worked outside the home, who provided the primary source of income, the impacts of TB in his/her place of employment, and financial support received while the person was in quarantine and treatment.

Challenges (e.g., impact of violence in Juárez on experiences, not speaking English, poverty, seeking health care) were the eighth theme discussed with participants. In regards to discrimination, the ninth theme, the participant was asked about hiding their TB diagnosis, feeling less because of TB, managing TB-related complications, and comparing discrimination between México and the US. The last theme discussed with the participant was about the positive outcomes of having TB. Each participant was asked if he/she had experienced positive changes in personal behaviors or had examples of positive ways in which discrimination could be overcome and if she/he was interested in serving as role model for the community and educating the public about TB.

The three primary themes for my thesis: delayed diagnosis, challenges faced by people with TB, and positive outcomes of TB, which relate to my research questions, served as the initial codes, which I created using N-Vivo qualitative analysis software. Then, I created sub-codes (child nodes) within each of the three nodes, which are described in Table 1.1, along with which participant's narrative will be highlighted related to that theme.

Table 1.1 Analysis Themes

<u>Themes</u>	<u>Narrative Featured</u>
Delayed diagnosis of TB	
Repeated misdiagnosis after seeking care	Beatriz
Lack of awareness of TB by doctors	Alexandra
Fear of immigration authorities	Jorge
Few economic resources for health care	Marcela
Challenges people faced with TB	
Poverty	Dianna
Challenges accessing social services	Esperanza
Lack of information	Ivan
Stigma	Julieta
Positive aspects of TB	
Change of behavior because of TB	Sebastian
Desire to give back to community	Samuel
Change of family relations	Beatriz's Daughter

This study was approved by the University of Texas Institutional Review Board, and by the Texas Department of Health (i.e., TB clinic). Information regarding each participant is presented in Table 1.2.

Table 1.2 Participants' Demographic Information

Pseudonym	Age	Country/Place of Birth	# Of Years in EP	English Speaker	Type of Health Insurance	Annual Income	Level of Education	Referred to TB Clinic by
Jorge	24	MX/Cd. Juarez	14	No	None	5,000-10,000	Elementary/MX	Health care provider
Ivan	66	MX/Durango	4	No	Medicare/Edna	5,000-10,000	Elementary/MX	Lung Specialist
Esteban & Amanda	80	MX/Durango	19	No	Medicare/Medicaid	5,000-10,000	None	Health care provider/Providence
Dianna	19	U.S./El Paso	19	Yes	None	Less < 5,000	Some College/US	Health care provider
Mercedes	52	MX/Durango	34	Yes	Tricare Ft. Bliss	5,000-10,000	Part of High School/MX	Health care provider
Fernando & Valencia	75	MX/Chihuahua	3	No	None	Less < 5,000	Elementary/MX	Health care provider/Texas-Tech
Samuel	63	MX/Cd. Juarez	18	No	None	Less < 5,000	High School Degree MX	Family/Daughter
Beatriz & Ximena	83	MX/Zacatecas	20	No	Medicare/Medicaid	5,000 - 10,000	Elementary/MX	Health care provider
Julieta	70	MX/Durango	24	No	Medicare/Medicaid	10,000-14,000	Elementary/MX	Health care provider
Daniel	72	MX/Chihuahua	40	No	Medicare/Medicaid	Less < 5,000	Part of High School/MX	Health care provider
Marcela	47	U.S./El Paso	4 Mo.	No	Medicaid	Less < 5,000	Some High School in MX	Health care provider
Sebastian	24	MX/Cd. Juarez	6	Yes	None	10,000-14,000	Some College/US	ICE Agents
Alexandra	23	MX/Durango	12	Yes	None	15,000-19,999	Some College/US	Health care provider
Mia	24	MX/Cd. Juarez	13	Yes	None	10,000-14,000	B.A. US	Health care provider
Esperanza	42	MX	39	Yes	None	Less < 5,000	B.A. US	Health care provider

CHAPTER 3

ANALYSIS

The analysis section will focus on answering the research questions. First, I will focus on why people with TB experience delayed diagnoses (research question 1). Then, I will address the challenges faced by people with TB (research question 2). Finally, I will discuss positive impacts that came from having TB (research question 3).

3.1 Delayed Diagnosis

Residents living in El Paso, Texas with tuberculosis had different experiences during their diagnosis process. In this section I will explain how the process of being diagnosed unfolds. The pre-defined code for this section is “*Delayed Diagnosis*” and it was sub-coded into four child nodes: repeated misdiagnosis after seeking care, lack of awareness of TB by doctors, fear of immigration authorities, and few economic resources for health care. In the following sections, I will illustrate the stories of delayed diagnosis in each of these four categories for El Paso residents with TB.

3.1.2 Repeated misdiagnosis after seeking care:

Nine out of 15 participants were diagnosed with illnesses other than TB until their doctors finally determined it was TB, making misdiagnosis a common occurrence for participants in this study. Five females ranging from ages 19 to 83 were diagnosed with asthma, allergies, cancer, pneumonia, bronchitis, thyroid cancer, and/or severe colds. Three men ranging from ages 60 to 75 were also diagnosed with cancer, bronchitis and/or severe colds. The time frame for diagnosing TB among these participants was between six months and three years. These participants reported that during their initial health care visits, they were not tested for TB, were not asked for a sputum test (i.e., when the phlegm of the persons is tested for TB) and did

not receive a chest X-ray. Participants reported that after doctors diagnosed them with an illness, they were prescribed medication to treat their presumed condition. In addition to being diagnosed with other illnesses, doctors' referred participants to specialists such as a pulmonologists and oncologists.

To illustrate the theme of "*repeated misdiagnosis after seeking care*", I will draw on the case of Beatriz, an 83-year old woman born in Zacatecas, México, with 20 years of legal residency in El Paso, who was interviewed with her daughter Ximena. Beatriz was selected because, while her time to diagnosis of three months was shorter than the others with misdiagnosis, the number of diseases she was misdiagnosed with was quite high. Three months before being interviewed, Beatriz began experiencing shortness of breath, coughing, and fatigue. She decided to go to her general practitioner to ask about her symptoms. Her doctor told her that she had severe bronchitis and provided her with antibiotics; but a few days later, Beatriz's symptoms continued. Beatriz then decided to go the hospital because she could not tolerate the symptoms anymore. At the Del Sol Medical Center, Beatriz was first admitted to the emergency room, and after staying overnight, she was told that she had bronchitis and was treated with several inhalers. Beatriz was released from the hospital, and a few days later, the symptoms continued.

Ximena then decided to take her mother to see a doctor in Juárez, because they both felt that the doctors in El Paso had not been helping Beatriz. The doctor in Juárez diagnosed Beatriz with asthma and allergies and gave Beatriz two shots. The mother and daughter returned to El Paso, but none of Beatriz symptoms went away. Beatriz returned to her primary caregiver in El Paso, and mentioned to her doctor that she had gone to Juárez, where they had given her two shots for asthma and allergies. Beatriz's doctor told her that there was no such a thing as shots

for asthma and what she really had was pneumonia. Beatriz could not believe she had pneumonia, but her doctor prescribed her a medication and she returned home.

Beatriz's symptoms did not go away. Ximena said that her mother had been experiencing those symptoms for more than two months by this time, and since the symptoms were worsening, Ximena decided to take her mother to another hospital. At Providence Hospital, Beatriz was treated with inhalers and was told once again that she had pneumonia. After being admitted to the hospital and staying overnight, Beatriz was told that they were going to perform a biopsy because she did not have pneumonia. To do so, they were going to insert a tube through her throat (endoscopy) because they could not identify what she was suffering from.

Three days after being admitted to Providence, the doctor told Ximena that her mother had cancer:

Cuando salió el doctor de hacerle la endoscopia, me dijo ¡Te tengo malas noticias!, le dije ¿Qué está pasando? Tu mamá tiene un tumor canceroso, que era como un chícharo en su pulmón ¿Esta seguro? Y me dijo si.... Es cáncer y le dije ¿Qué va a pasar? No, dijo vamos a hacerle unos estudios, y haber que tratamiento le vamos a dar. Entonces le dije, pero ¿Si es cáncer? Si, si es cáncer... Yo, soy muy ignorante, pero yo se que para diagnosticar cáncer se necesita varios procesos ¿Verdad? Pero así decirme tu mamá tiene un tumor canceroso, eso una noticia muy impactante para mi, muy fuerte. El doctor me dijo todavía no le digas nada a tu mamá, déjame hacerle otros estudios, haber que vamos a hacer, y yo le insistía ¿Pero doctor si es cáncer? Y él me decía que si, que ya era el pulmón que estaba canceroso, este es el tumor que esta cancero. Entonces cuando nos dijeron, a los tres, cuatro días, no, no, no es cáncer, es tuberculosis, dijimos... ¡Bendita tuberculosis!...

When the doctor came out of the endoscopy, he told me, "I have bad news!" I said, "What's happening?" "Your mother has a cancerous tumor, which was like a pea on her lung." "Are you sure?" And he said, "Yes... It is cancer." And I said, "What will happen?" "No," he said, "let's do some more studies and let's see what treatment we are going to give her." So I said, "But is it cancer?" "Yes, it is cancer"... I am very ignorant, but I know that to diagnose it, there needs to be various tests, right? But, just telling me, your mother has a cancerous tumor, that was very shocking news to me. The doctor told me not to say anything to my mom, he said "let me do other studies, to see what we are going to do", and I kept insisting "But doctor is it cancer?" And he told me

that it was already the lung, which was cancerous, the tumor is cancerous, so when we were told, three, four days later, no, no, it is not cancer, it is tuberculosis. I said bless tuberculosis!

Beatriz and Ximena did not quite know how Beatriz was finally correctly diagnosed with TB.

Ximena only remembered that one day the doctor told her that her mother had cancer and few days later, Ximena was told that her mother had TB. Ximena did not know how this diagnosis was finally confirmed. She never asked the doctor what he did to determine that it was TB.

However, prior to the diagnosis of TB, Beatriz received five different diagnoses: bronchitis, pneumonia, asthma, allergies, and cancer. Ximena said that having her mother diagnosed with TB was a blessing because she knew that TB was curable, and that her mother was not going to die from cancer. Beatriz has begun her treatment for pulmonary TB, and she is scheduled to complete her treatment by November of 2010.

3.1.3 Lack of awareness of TB by doctors

In addition to repeated misdiagnoses, lack of awareness of TB by doctors also led to delays in being diagnosed with TB, as participants who were aware of TB, and sought care were not tested for TB prior to determining other illnesses/conditions. On February 2010, Alexandra, a 22-year old woman born in Durango, México found out that she had TB. Alexandra was selected to represent “*lack of awareness of TB by doctors*” because while seeking care, Alexandra repeatedly asked her doctors to perform a TB test, because she has family members who have had TB in the past, but they did not. Alexandra’s diagnosis was not easily confirmed because she did not receive a skin test, a sputum test, or X-rays during several visits to the emergency room with symptoms of TB. During the summer of 2009, when Alexandra began to feel sick, she went to Thomanson hospital (the county hospital in El Paso, Texas), where she

mentioned she had night sweats, coughing, and loss of appetite (which are all TB symptoms). In the emergency room, they told Alexandra that she had pneumonia, and they prescribed her with a ten-day course of antibiotics.

Years before, Alexandra's mother had been very concerned because she had an aunt who died of TB when Alexandra was 10 years old. After her aunt's death, her mother took her to Tillman Health Center (a local clinic in downtown El Paso, where people can get TB testing for free) for a TB skin test. In a skin test or PPD, the practitioner puts a small amount of TB protein (antigens) under the top layer of the skin in the inner forearm. The skin will react to the antigens by developing a firm red bump at the site within two days if the person has been exposed to TB bacteria. At Tillman Health Center, Alexandra's test was positive (indicating LTBI), but they told Alexandra's mother that they could not give her preventative treatment for TB because Alexandra also had Spina Bifida, a condition that does not allow her to have control over her bowel movements.

Thirteen years later, Alexandra's mother kept insisting that Alexandra go and get checked again for TB, so Alexandra decided to get another skin test at Tillman Health Center. At Tillman, they performed a skin test, and Alexandra was told that she did not have TB, but that she should go to the TB clinic for measurement of her spot and confirmation of TB. Alexandra remembers her spot being so big and red that her mother was concerned about it. Alexandra remembers the spot being about 18 millimeters in diameter. In a skin test, if the spot is bigger than 10 millimeters, the person is diagnosed with TB. She said that when she arrived at the TB clinic, they told her that she did not have TB, and that she could go home. Based on Alexandra's account, it appeared as if the TB clinic missed diagnosing her with TB at that time.

Then, Alexandra left the United States to visit her family in Durango, México with the same symptoms of night sweats, and coughing, still believing it was a severe cold. In hindsight, this was very risky, because she could have infected others with her yet undiagnosed active TB disease. When she returned, Alexandra continued some semblance of a normal life until January of 2010, when her symptoms began to worsen. Alexandra returned to Thomason Hospital, with the same symptoms and they told her she had pneumonia. Alexandra also told the doctors at the hospital that she had been tested for TB and that her aunt had died from TB, but Alexandra did not receive an X-ray or further examination to see what she was suffering from. Alexandra was released from the hospital and she returned home with antibiotics for ten days.

Two weeks later, Alexandra once again returned to Thomason. She explained:

I came back to the E.R. and I told them the same thing! You know what, I have been coughing, I have night sweats and I lost ten pounds, and I couldn't eat anymore! Everything that I ate, I would just throw up, because I had a pain in my stomach, and that was the reason I went in... And they told me, you have gallstones and then they asked me, "when was the last time you went to see a doctor?" And I told them, "I was here two weeks ago, for pneumonia!", and they were like okay... I kept telling them, "I have night sweats, I have been coughing for more than a year." And, when I told my doctor, because she happened to be there, she told me, "What do you mean by night sweats?" And then I told her that I was feeling like that for over a year, and that's when they were like, we need to do more testing.... That was when they told me that they were going to keep me there, just to do all this stuff. Two or three days later, Dr. Bohorquez went in to see me, because I saw a lot of doctors, and they didn't know what it was... And Dr. Bohorquez went and touched my neck and said "Oh, okay, yes, you have TB" and then he told me "I just want for you to give me some sputum, but for sure you have that... and that is when they told me I had TB...

Alexandra's confirmed diagnosis took about a year and a half. This was in spite of the fact that Alexandra knew that TB was a possibility for her, as her aunt died, and her mother insisted she get checked more than once. It seemed that those associated with the public health system at the TB clinic and the Tillman Health Center ignored the results of her skin test, thus making Alexandra's a case of lack of awareness of TB by doctors, because her symptoms were

apparently actively disregarded.

3.1.4 Fear of immigration authorities

The next sub-code within “*Delayed Diagnosis*” to be discussed was fear of immigration authorities, which was accompanied by a lack of health insurance. Fear of immigration authorities kept undocumented participants from seeking care because of the belief that immigration authorities were in hospitals and clinics.

To illustrate the theme of “*fear of immigration authorities*” I will draw on the case of Jorge, who experienced acute fear, which led to his delayed diagnosis. During the fall of 2009, Jorge, a 24-year old born in Ciudad Juárez, who has lived 14 years in El Paso, went to visit his brother who had been released from jail in Ciudad de Chihuahua. Jorge recalled that his brother had some gang-related problems in jail. Jorge was aware that being with his brother put him at risk of being attacked too. Jorge said that one day after his brother was released, they were walking, and they were picked up by some men and tied up. The men took the siblings to another place where Jorge and his brother were severely beaten. Telling the story of his brother was not easy for Jorge, in simple terms, he said: “mataron a mi hermano en frente mio y a mi me dejaron ir” (“they killed my brother in front of me and they set me free”).

Jorge said that after the death of his brother, he returned to El Paso where he began having health problems. His back hurt most of the time, he was tired and wanted to sleep most of the day, he had no appetite, he was dizzy, and his nose bled frequently. Jorge did not seek medical attention for these symptoms at any time; in fact he was feeling these symptoms for six months until one day, when he could not get out of bed and walk, his wife called the ambulance. At Providence Hospital, Jorge was rushed to surgery, where the doctor discovered an abscess and

TB in his spine. During our interview, Jorge showed me his wound. He had a scar from the surgery and remains of the abscess, which made his back look very swollen. Jorge received antibiotics for his abscess at this hospital and began treatment at the TB clinic when he was interviewed.

Jorge asserted that an important reason for him not going to the hospital sooner was fear of immigration officers because he was an undocumented immigrant. Even at his appointments at the TB clinic, Jorge expressed his fear of immigration officers:

¿Que si por ilegal y me van a detener ahí, uno de inmigración? ¡Enserio! A mi me daba miedo de venir a mis citas, no más que empecé a investigar con la doctora que iba a medicarme, ¿oiga no cree que me vallan a detener ahí o algo? Y ella me decía ¡noooo, no, se preocupe, nada de eso va a pasar ahí Jorge!, ándele valla, porque el doctor lo tiene que ver una vez por mes, eso va a hacer por el resto del año, para que tome su medicamento. Pero le digo que si tenía miedo, porque nunca me explicaron, que aquí no corría riesgo de eso, o algo, y eso era mi temor porque nunca me había atendido aquí ni en ningún lado. La vez que me llevo la ambulancia del centro al hospital, fue porque de verdad ya no me pude levantar, y tuvo que llegar la ambulancia por mí... Tenía miedo, que me curaran y de ahí me mandaran a Juárez, o algo así, y por eso es que yo ya ni voy a México.

What if because I'm illegal? Am I going to be detained there by one of the immigration officers? Seriously, I was afraid of coming to my appointments. I began to investigate this with the nurse who would go to give me my medication; "Do you think they are going to detained me there or something?" And she said, "noooo, no, don't worry, none of that will happen there Jorge. Go, because the doctor has to see you once a month that will happen for the rest of the year, to take your medicine". But, I tell you, I was afraid, because nobody explained to me that here there was no risk of that, and that was my fear because I have never sought care here or anywhere. That time that the ambulance took me to the hospital from downtown was because, really, I could not get up, and the ambulance had to come for me ... I was afraid that they would cure me and then send me to Juárez , or something, and that's why I do not go to México.

Jorge's fear of immigration officers being in hospitals is still present. When he finally sought care for his spine, it was the first time Jorge had seen a doctor since he moved to the US. Jorge considered his doctor at the TB clinic his primary source for care, and he wonders about his health care after he completes his treatment.

During our interview, Jorge indicated that he was worried about his future. After the surgery, Jorge's doctor told him that he could not do any physical activity for two years because that much time was needed to allow his back and body to fully recover from the surgery. As an undocumented immigrant, Jorge used to work picking up rocks at Fort Bliss; he said that he could not return to that job anyway because it was physically demanding and his body was not the same. He reported feeling weak and that he does not have full strength in his back. Jorge did not know what to do to earn an income to support his wife and his children, a five-year old and a one and a half-year old. In the meantime, Jorge helped his sister with her yard work and painted restaurants every once in a while when someone hired him, but he did not have a secure source of income. Jorge was not eligible to receive any type of government assistance such as unemployment because of his immigration status. All he hopes for is to recover fully, and to feel healthy again to start looking for a job to support his family.

3.1.5 Few economic resources for health care

Participants who did not have sufficient economic resources waited until symptoms were severe to seek medical help because of the cost. Because of their lack of economic resources, participants believed that their symptoms were a common cold that could cure on its own. Participants reported that symptoms needed to be severe enough (e.g., began to cough blood, could not sleep anymore, or the cough interfered with regular activities) for them to seek care. Eight participants ages 19 to 75 also reported that the primary reason for not seeking care when they first began to have symptoms was not having insurance and/or not being able to afford medical services or prescribed medications.

To illustrate the theme of "*few economic resources for health care*," I will describe the story of Marcela. Marcela is 47-years old and an American citizen residing in Juárez. She is a

mother to five children: Daniel (21) and Teresa (16) (both American citizens), Mario (28), Maria (13) and Julian (11), who are Mexican citizens. She was selected because she had the fewest economic resources to pay for health care in Juárez, which contributed to a delayed diagnosis.

In 2008, Marcela began experiencing weight loss, weakness, hair loss, dehydration, and loss of appetite. At first, Marcela thought it was anemia caused by severe menstrual periods and the extreme heat from that summer because they did not own an air conditioner. After six months of experiencing these symptoms, Marcela began to have high fevers that would cause her to have lapses of unconsciousness and fainting, so she would stay in bed most of the time. Seeing his mother feeling weak and losing weight, her son Mario told her that she needed to see a doctor, but Marcela refused to go because paying the doctor would take the weekly salary from her son, the only provider in the family. Marcela explained:

No tenía con que dinero hacerme los estudios, o era de que comíamos, de que comían mis hijos, porque yo dejaba de comer para que mis hijos comieran, o hacerme los estudios. Y cuando yo ya fui a hacerme los estudios fue porque yo empecé a sentir temperatura muy alta, mi niña le hablo a mi mamá y ella vive en Juárez, y le dijo: ¡Mi mamá está muy mal, ya no se quiere levantar, ni comer! Entonces mi mamá va a la casa y me ve como estoy y me dijo que me tienen que llevar con el doctor. La primera cita con el doctor, que me hacen los exámenes, se llevo el sueldo de mi hijo el mayor de toda la semana, todavía mi mamá tubo que conseguir prestado, y por eso yo no quería ir a hacerme los análisis porque se me hacia injusto que ellos trabajaran toda la semana para pagarme a mí. Yo pensaba que era una anemia, es una deshidratación, yo decía que tenía anemia, de tanto sangrar...

I had no money to pay for the medical testing; it was that, or we ate, that my children ate, because I stopped eating so that my children could eat, or so I could get the medical testing. And when I finally went for the medical testing, it was because I started having a very high temperature. My little girl called my mom, who lives in Juárez, and said: “My mom is very ill, and does not want to get up or eat!” Then my mom came to my home to see me and she said, “I have to take you to the doctor”. At the first appointment with the doctor, they did the examination, which took all of the weekly salary of my oldest son and still my mom had to borrow some money. So that’s why I did not want to go to get tested, because it was unfair to them to work all week to pay for me. I thought it was anemia, dehydration, I said I had anemia from bleeding so much. After her son Mario paid for the first appointment, Marcela decided not to return to the

doctor because they could not afford all of the testing that her doctor requested. Marcela returned home, and her symptoms got worse and worse. Mario, the provider of this family, then took his mother to see another doctor in Juárez, where they were living at the time. Mario did not want to take her mother to a hospital, because they did not have enough money to pay for the testing, and were uninsured. Mario decided to take Marcela to a local pharmacy where they ran some tests but the pharmacist told them that it was best to take her to a hospital because they did not have the equipment to conduct the necessary exams to determine what Marcela had. Mario told his mother that it was best if they called Daniel, who lived in El Paso, and for him to bring Marcela to the hospital in El Paso, since Marcela is an American citizen.

Having no other option, Marcela decided go to El Paso. At the port of entry, Marcela was arrested because she had a warrant for not completing her time in a half-way house after being released from prison. Marcela had been arrested in the past for illegally smuggling people into the United States on the San Diego/Tijuana border. After being arrested, Marcela was detained and two weeks later, she was sent to San Diego, where her case originated. Marcela said that at that time she weighed 60 pounds, and while in court, the hand-cuffs were so heavy that she had difficulty walking. Once in federal prison, Marcela was unable to eat because she was weak, was unconscious most of the time, had little hair, and not enough energy to move on her own. Marcela indicated that thanks to the help of other inmates, she was able to receive medical attention. One of the other inmates noticed that Marcela was not eating and was very sick. Marcela said that after several months in prison, one day, she fell unconscious and the other inmates called the guard who was able to get medical help for Marcela.

Marcela was transferred to a hospital outside the prison. At the hospital, Marcela was diagnosed with TB, HIV and syphilis. The doctor told Marcela that she had the HIV virus for

more than 15 years, and since she was not eating healthy or getting the proper care for HIV, her immune system had weakened and TB developed. Marcela did not know she had HIV until that moment and wondered how she could have gotten infected. During our interview, Marcela indicated that she had never done intravenous drugs, and that she only had had only two sexual partners in her life, both of whom were her ex-husbands. Marcela believed that she got infected with the HIV virus from her second partner, and she wondered about her two youngest children and whether they were also HIV positive.

After completing her treatment at the hospital, Marcela returned to prison to finish her sentence. Marcela was released from prison and was able to return to El Paso, where she continued her TB treatment at the TB clinic. Unfortunately, neither Marcela nor her son Mario were told by the doctors or pharmacists in Juárez that there are places where uninsured people with few economic resources can seek care and receive free treatment and medication for TB-HIV/AIDS in Ciudad Juárez.

Marcela will complete her treatment in the fall of 2010. At the end of our interview, Marcela indicated that she needed help from an organization in El Paso that could help her test her children for HIV. I was able to refer Marcela to some organizations in El Paso. Marcela also indicated that she wanted to learn English and get a job because she did not have any money to support her children. Marcela looks forward to beginning a new life after completing her TB treatment and finishing the remaining months of her probation.

The narratives presented above illustrate how the different aspects of delayed diagnoses impact participants living in El Paso. In addition to delayed diagnoses, some people with TB are confronted with some challenges while dealing with TB. In the next section, I will describe the theme of challenges faced by residents with TB, and I will incorporate four different narratives

of how TB can affect one's life.

3.2 Challenges Faced by Residents with TB

In this section I will explain the challenges that residents with TB faced while undergoing treatment. The pre-defined code for this section is "*Challenges*", and it was defined as those personal, social, economic and cultural difficulties that the person encountered after being diagnosed with TB. The pre-defined code was sub-coded into four child notes: The first sub-code is "*poverty*", the second sub-code is "*challenges accessing social services while having TB*", the third sub-code is "*lack of information*", and the fourth sub-code is "*stigma*".

3.2.1 Poverty

Poverty was defined as the challenges participants faced from being low income persons with TB. This included, for my participants, challenges because of not speaking English, lacking transportation, finding employment because of TB, and immigration issues, as some participants, their spouses, and/or children did not have legal immigration status in the U.S. These challenges were included as part of the poverty code because poor participants faced these difficulties, which were due to, or associated with, their poverty. Eleven participants reported monetary challenges, which included not having enough money to buy groceries, struggling to pay \$5 for visits at the TB clinic, not having medical insurance, being unable to afford health care or medications, and not being able to move into a different home with more space and better ventilation. Eight participants, who all had low incomes, reported that not speaking English was a challenge for them because they had to wait for nurses to translate during their clinic visits. They could not communicate with doctors directly and read the information on TB medication labels and the information about the side effects. Eight participants reported challenges with transportation as some did not own a car, relied on family members or friends to visit to the

doctor, and used the bus or a bicycle as the only mode of transportation.

Four participants mentioned that immigration status was a challenge while having TB. For example, TB was an obstacle for a participant to visit her children in México, as her children could not come visit her in El Paso because they did not have the ability to legally cross the border. Another example was concerns about how TB would impact the process of legalizing one's status for a non-citizen, because immigration officers require physical examinations to make sure that a person does not have TB, and because one had accessed assistance from social services in the past. The last challenge mentioned by four participants was the obstacle of finding employment because of TB. Four of these participants feared being tested for TB again if an employer requested a test or if an educational field, like nursing, required a TB test to be allowed to practice the career. This challenge was part of the poverty theme, because these participants felt they could not earn an education or earn more money because of TB.

To better illustrate the theme of "*poverty*", I will present the story of Dianna, a 19-year old U.S. citizen. Dianna was selected because during the interview she expressed most of these poverty-related challenges. Dianna was a student at a local high school in northeast El Paso when she was diagnosed with TB. As a student, Dianna was involved in school activities, was a member of a sport's team, and held a part time job as a server in a Mexican restaurant. Dianna got married at 17, and at 18 she gave birth to her daughter Paula, while she was still in school.

After the birth of her daughter, Dianna began experiencing night sweats, coughing, and weight loss. She did not seek medical attention right away because she was uninsured and did not have money to pay for a doctor's visit. During Dianna's pregnancy, she was covered by Medicaid, but since coverage was no longer offered to mothers after the birth of her child, Dianna lost her coverage. The loss of her coverage unfortunately coincided with the onset of her

TB-related symptoms. Dianna had these symptoms, which increased in severity over time, for four to five months before taking action.

In the early months of 2010, Dianna was diagnosed with TB. At this time, Dianna immediately had to quit working and she also dropped out of school. Dianna also found out that both her mother and daughter had to take preventive medicine for LTBI. Dianna said that at that point her whole world crumbled into little pieces. Her husband, who was undocumented and worked in construction, had difficulties paying their bills and affording the baby's needs without the extra income that Dianna had been bringing home from her part-time job. Dianna's mother was unable to help them financially because she also worked as a server in a Mexican restaurant and earned very little. Dianna said:

Iba a la escuela, mis planes eran ir al colegio, pero las enfermeras me dijeron que no podía ir a la escuela y que ya no podía trabajar, y pues yo deje de trabajar y me atrase un año en la escuela. Yo necesitaba trabajar y mi esposo también, batallamos mucho en ese tiempo por esto, porque no la hacíamos con mi niña y las cosas de la casa, fue un problema grande, mi mamá lloraba mucho... Y como ella se separo de mi papá estaba sola, y lloraba junto conmigo...

I used to go to school, my plans were to go to college, but the nurses told me that I could not go to school and that I could not work. I left work and I fell behind one year in school. I needed to work and my husband too, we struggled a lot during that time because of this, because we could not make it with my daughter and the things for the home, it was a big problem, my mom used to cry a lot... And since she is separated from my father, she was alone, and I used to cry with her...

When Dianna quit working, they could barely pay the rent of her one-room apartment.

Dianna started having fights with her husband because they could not make ends meet; this is how Dianna said that poverty affected her while having TB:

A nosotros si nos afecta mucho porque mi esposo no gana mucho, como él no tiene papeles... Y luego las cosas de la niña, porque como a mí me quitaron el medicaid después de que la tuve, yo la tengo que llevar al doctor y a mí me toca que pagar. Cuando vengo a la clínica, acá me cobran porque me quitaron el medicaid... Y luego por mí, acá son \$5 dólares y por la niña \$5 dólares, pero igual son \$10 dólares cada vez vengo, y esos \$10 dólares yo los puedo usar para lavar, como no tenemos lavadora, nos

tenemos que ir a lavar a otro lado. A nosotros si nos afecta mucho... Batallamos mucho para pagar la renta, los biles, el cable y el resto...

It does affect us, because my husband does not earn much, since he does not have documents... And the things for the little girl, because they took my Medicaid away after I had her, I have to take her to the doctor, and I have to pay. When I come to the clinic, they charge me, here, it is \$5 dollars for me, and \$5 dollars for my daughter, but its \$10 dollars every time I come, and those \$10 dollars, I could use them to wash, since we don't have a washer, we have to go wash somewhere else. It does affect us very much... We struggle a lot to pay the rent, the bills, the cable, and the rest...

While \$5 is a relatively low fee for health care, Dianna illustrates how paying \$10 dollars takes money away from other expenses, like laundry. Dianna depends on the salary of her husband, and paying for medical services is something that she cannot afford since they do not have medical insurance.

Once she was out of quarantine¹, Dianna returned to high school and eventually received her degree. Dianna's career goal is to become a nurse. If she were to achieve this goal, it would be a way for her to earn a steady income and move out of poverty. However, Dianna has fears about not being able to become a nurse because she received TB treatment in the past. She said:

Quiero ser enfermera, pues no sé si esto, según te hacen pruebas y todo eso para estudiar lo que quieres, como yo enfermería. Como ahora que fui a la escuela, me dieron un papel que cada enfermera se tiene que hacer una prueba para ver si no tiene TB o lo que sea. Mi pregunta es ¿si yo lo tuve, yo puedo ser enfermera?
I want to become a nurse, but I don't know, since they do testing and everything so you could study what you want, like nursing. Like today, I went to school; they gave me a paper that said that every nurse has to get tested for TB. My question is "If I had it, can I still be a nurse"

Dianna does not know that she cannot be discriminated against by an employer or educational institution for being a person who completed treatment for TB. Dianna also had fears about getting re-infected with TB, and not achieving her dream of becoming a nurse. The day of our

¹ Quarantine and isolation are used to separate and restrict the movement of persons with TB from those that are healthy. Quarantine usually lasts a period of 90 days to complete, or until the person receives a negative sputum test that indicates that there is no active bacterium.

interview, Dianna said that she had completed her Federal Financial Student Aid application (FASFA) and that no matter how many obstacles she still had to face, she was going to try to become a nurse.

3.2.2 Accessing social services while having TB

In this section, challenges in accessing social services while having TB will be discussed. They are defined as the obstacles participants faced when accessing social services provided by the government and non-profit organizations related to housing, groceries, transportation, guidance from a social worker, and unemployment compensation that would have helped them better cope with TB-related challenges. Eleven out of 15 participants reported experiencing one or more of these obstacles. A key factor is that the TB clinic does not have a full time social worker to help link people undergoing treatment for TB with other social service providers. The clinic's main concern is to provide medical attention and treatment, but it does not offer any type of psychological or social work services to help people undergoing treatment for TB. They do have a few community outreach workers at the clinic that provide some assistance. "*Challenges accessing social services*" include a host of challenges, including lack of knowledge about social services available, lack of knowledge about how to navigate the system, not meeting the qualifications for social services because of immigration status or because recently receiving legal U.S. residency (people who recently became legal residents of the United States have to wait 5 years before applying for social services from the government), and fear of abusing the system or becoming a public burden for the system.

To exemplify the theme of "*challenges accessing social services*" while having TB, I will describe the story of Esperanza, a naturalized US citizen. Esperanza is a 42 years old

woman that was born in Ciudad Juárez, México, but has lived in El Paso for the last 39 years. Esperanza was selected because while she was in quarantine, she did not receive any social services and did not know how to access the system to ask for help, despite being in great need. Esperanza was diagnosed with TB three years ago. Her diagnosis was not easily confirmed because she spent three years prior to her diagnosis in the United States and México looking for answers to her unknown illness. During the three year journey before her diagnosis was confirmed, Esperanza went to three different doctors in the US, and two doctors in México, including an ear, nose and throat specialist. Esperanza was finally told that she had TB at the TB clinic, after being referred to the Tillman Health Center by her local clinic, since they did not have the proper equipment to perform X-rays on Esperanza.

Prior to her diagnosis, Esperanza worked in the public schools as a substitute school district employee. Esperanza said that she really liked her job, and that her work-life, family, and friends were normal. When TB came into Esperanza's life, it all stopped completely as she had to quit her job, and leave friends and daily activities. When Esperanza was placed in quarantine, she said that no one at the TB clinic told her about the possibility of receiving public or non-profit assistance once she started the treatment. At the time, Esperanza did not qualify for family leave or FMLA (Family Medical Leave Act), or any other type of employment benefit that could have helped her during the time she was placed in quarantine. Because of the temporary nature of her job, benefits are not offered to part time employees, like in the case of Esperanza. Esperanza did not know that she was eligible to receive social assistance, since her annual income was less than \$5,000 dollars a year after she quit working.

Esperanza said that at the TB clinic they concentrated on the medical aspect of her case, but that there was no one available to offer social, public, or psychological assistance. She was

also isolated from assistance because she lived in a colonia on the Far East side of the county.

This is how Esperanza expressed her feelings of not being offered public assistance:

Nunca me preguntaron ¿Quién te va a mantener en ese tiempo que iba estar en cuarentena? Porque cuarentena implica no poder ir al trabajo, no poder ir ninguna parte fuera de tu casa sin el cubre boca. En verdad yo ya estaba muy débil, para entonces yo ya no trabajaba, tenía como seis meses de tan mal que me sentía. Y tampoco lo pensé, es mas cuestión del orgullo de la familia, que nunca lo hemos hecho... En ese momento, no se si no tenia cabeza para pensar en eso, o simplemente no fue una opción porque decíamos estamos bien y entre mas agencias, tenemos que contarles, tenemos que decirles lo de mi enfermedad ¿por qué y para qué? Gracias a Dios teníamos donde vivir, que comer, pero para muchas personas especialmente si se les forza a dejar de trabajar, ¿quién mas va a proveer en la casa? Y muchos pierden sus trabajos, no se les garantiza ese mes de cuarentena para cuando termine va estar su trabajo esperándolos. Muchos tuvieron que dejar su trabajo, no tienen cobertura médica o la pierden al perder el trabajo. Para muchas personas les causa más trabajo, más estrés, preocupación, muchos hasta prefieren no tomarse el medicamento, o no diagnosticarse, no empezar la cuarentena, porque pierden su trabajo, tienen que escoger entre el tratamiento o el trabajo.

They never asked me “Who is going to provide for you during the time that you will be in quarantine?” Because quarantine implies that you are not going to work, not going anywhere outside your home without your mask. I was too weak, by then I didn’t work, I had six months of feeling that bad. And I didn’t even think; I don’t know if I didn’t have the mindset to think about that, or it was not an option for me because we were okay, and the more agencies involved, we had to explain to them about my illness “why and what for?” Many [people with TB] lose their jobs, it is not guaranteed that when they finish their quarantine, their jobs will be there waiting for them. Many had to leave their jobs, they don’t have medical insurance or they lose it when they lose their jobs. For many people this causes more work, more stress, and worries. Many prefer not to take the medication, not to get diagnosed, not to start the quarantine, because they lose their jobs, they have to choose between treatment and work.

During the time Esperanza was diagnosed with TB, she was living with her parents, who were retired and receiving social security. With their income they were able to support Esperanza and provide for the rest of her needs during the time when she could not work. Esperanza was fortunate to have her family, who in this case were able to help her and provide for her. In some cases, this is not a possibility. If Esperanza were not to have her family, getting treatment for TB would have been much more difficult, because as Esperanza said “you either choose between treatment or work”.

In addition, one of the reasons that Esperanza did not ask for social assistance was because her family feared explaining that TB was the main reason they were requesting social assistance. They were very concerned about the stigma. They feared that more people were going to find out about her TB in their community if they asked for help. Esperanza and her family did not know that there were agencies that could provide assistance while protecting their right to privacy. Esperanza completed her treatment in 2007, and has returned to her normal activities with her family, friends, and work.

3.2.3 Lack of information

In this section I will discuss participants' lack of information related to how people acquire the illness; what sorts of treatment options are available; that the TB clinic has free treatment regardless of legal status; and the fact that there is little general public outreach information about TB provided in public and private clinics, hospitals, health centers, and community centers. Some also had misperceptions about TB. In addition, participants noted that people, in general, did not know anything about TB, and that the media such as television, radio, and newspapers did not provide any information. Fourteen out of 15 participants mentioned they did not know that El Paso had a free TB clinic. Twelve out of 15 participants shared the following incorrect beliefs about the transmission of TB: TB was an illness transmitted by kissing, hugging, sharing utensils such as spoons, forks, plates and glasses and/or using the same clothes. Few participants had information about how TB is transmitted until they began treatment at the clinic. Even after completing treatment, some participants did not remember the causes of TB or how it is transmitted.

To illustrate the theme of “*lack of information*”, I will draw on the story of Iván, a 66-year old male old born in Durango, México, with four years of residency in El Paso. Iván was selected because his understanding about TB relates to his experiences 37 years prior to when his sister was diagnosed with TB while living in México. His lack of information becomes obvious because he could use these past experiences to frame his current experiences. Iván found out he had TB in February of 2010. Before this diagnosis, Iván thought that TB was a cough that could be cured by buying cough syrups in Ciudad Juárez. Iván said that at the beginning, some of the cough syrups and antibiotics he was purchasing without a prescription were helping as the cough and the phlegm decreased during some periods of time. As time went by, Iván said that the cough and the phlegm did not go away. As he thought it was nothing serious, he did not seek medical attention until he began coughing blood. When Iván coughed blood, he thought that one of the veins in his throat had ruptured from so much coughing.

Iván never imagined his cough and phlegm were some of the symptoms of TB, since the only person who he believed could have infected him was his sister, who had completed treatment 37 years ago. During our interview, Iván indicated that his sister never infected any members of her family, and that TB was an illness of the past. Iván also mentioned that another possible place that he could have gotten infected with TB was in Ciudad Juárez, because he was a frequent customer of a crowded restaurant in central Juárez, and a member of a busy fitness gym where he used the sauna two or four times a week. Iván said that at the restaurant there were approximately 100 people at a time, and at the gym, 20 to 25 people shared the space of a sauna, where he and others frequently coughed. Those were Iván’s thoughts about how he got infected with TB since he did not believe that he could have gotten it from his sister. However,

there is the possibility that he got a latent infection from her that only became active 37 years later.

Iván said that when his sister got infected, the family and members of the community piled and burned all of her belongings, including her mattress, bed, clothes, shoes, and utensils. He believed that since everything was burned, no one else in his family could have gotten infected (which is not true). When Iván found out he had TB, he thought that he was going to go through what his sister did 37 years ago. He reported:

Cuando mi hermana se enfermo de TB, en ese tiempo en México yo oía, que TB ¡Ha mira de se murió de tuberculoso, mira es que está tuberculoso! yo recuerdo que en aquel tiempo quemaban todo, cuando decían que un tuberculoso quemaban toda su ropa ¡En aquel entonces lo hacían he! Yo lo veía, quemaban la ropa, donde se acostaba, la cama, los trastes donde comían y después los tiraban, así como hicieron con las cosas de mi hermana. Pero las personas se morían antes... yo recuerdo... entonces yo hable con Efraín, un muchacho que está aquí,[en la clínica de la TB] y él fue el que me atendió la primera vez, el fue el que me dijo, tú tienes TB y vas a tener que hacer el tratamiento. Entonces cuando ya fue él con mis hermanas aquí, a chequearlas a decirles que yo tenía TB, una hermana mía le dijo ¿Oiga, tenemos que quemar todo lo de mi hermano, su ropa, todo? Y Efraín le dijo: No, no, eso lo hacían antes. Y ya les explico que no, pero yo tenía la misma idea; porque a lo mejor la TB le queda a esas cosas, y por miedo de contagiar a alguien...

When my sister got sick with TB, at that time in México, I heard about TB: Oh, look he died because of TB, look he has TB! I remember at that time they would burn everything, because they would say TB and they would burn all of the clothes. At that time they would do it! I saw it, they would burn the clothes, the bed, the dishes, and then they would throw it away, just how they did with my sister's belongings. But people died before, I remember, so I talked to Efraín, a guy that is here [at the TB clinic], he was the first one to see me, he told me, "you have TB, and you need to start your treatment." Then, he went to check my sisters, he told them I had TB, and one of my sisters asked him: "Do we need to burn all my brother's belongings, his clothes, everything?" and Efraín said, "No, no, they used to do that before". And he explained that no, because I had the same idea, because TB might stay in those things, and I was afraid of infecting someone else.

This quote illustrates how little Iván and his sisters knew about TB; they did not know how it is spread, and how the recommended actions have changed in the last 40 years. We now know that people cannot become infected from clothing.

Iván said that when he began his treatment, he learned about TB in a formal setting for the first time. Iván mentioned that he worked in California for over 40 years, while regularly visiting México and El Paso, and he never saw any type of information regarding TB:

Sabia de la TB por mi hermana, pero nunca vi información en las propagandas o algo así, no. Ni en Juárez, ni en California, nunca mire nada en ninguna parte sobre la TB, que yo recuerde no. Y aquí es la primera vez que si le hablan a uno de eso, pero ya cuando agarra la TB pues, cuando ya está enfermo uno.

I knew about TB because of my sister, but I never saw information in commercials or something like that, no. No even in Juárez, or California, I never saw anything about TB, not that I remember, no. Here, is the first time that they talk to you about that, but once you have TB, once you are sick.

Iván had little information about TB, and the only knowledge he had came from his experience with his sister when she got sick in México years ago.

Iván asserted that there was a need to inform people about TB, because it is not enough to give the information once the person is sick; there is a need to inform people no matter if they have TB or not. He said:

Debería de haber más información por parte de los institutos de salud, departamentos de salud, de que tengan gente que compartan con enfermos, aunque los enfermos no tengan TB, que compartan con ellos que les expliquen en los hospitales, a los que están enfermos de otra cosa, o a los que estén ahí, los que tengan una pierna quebrada, explicarles la enfermedad de la TB... Con mas educación, y explicándoles, diciéndoles como me sentía, lo que mire cuando estaba joven y decirles como trataban a la gente y decirles que la gente si se moría, porque la gente si se moría de TB, y luego ya de repente me pego a mí y explicarles que me pego a mí, que me sentía con vergüenza, temeroso de contagiar a los demás, pero se puede curar y decirles que no se hagan de apurar porque si hay medicina que cura la TB.

There should be more information, more information, from health centers, from the departments of health, to share with the people who are sick, with those that are not sick

with TB, to share with them, to explain to them at the hospital, to those who are sick with something else - those with a broken leg - to explain to them about the illness of TB. With more education, and explaining to them, telling them how I felt, what I saw when I was young and to tell them how they used to treat people, and to tell them that people did die, because people did die of TB, and then I got it, and to explain to them that I felt ashamed, I feared getting others sick, but you can cure it, and to tell people not to wait because there are medicines that cure TB.

These statements illustrate that Iván sees the lack of information as unfortunate, and something that could be improved in order to save others the troubles that he went through. Lastly, Iván knows what TB is, but unfortunately, it took him more than 40 years, and a positive diagnosis, to receive the proper education for TB.

3.2.4 Stigma

Stigma was defined as the discrimination participants felt by family members, spouses, friends, and members of their community because of their TB. Stigma-related challenges for participants included negative changes in intra-familial relations because of TB, hiding the diagnosis because of fears about the reactions of others, negative feelings and thoughts about wearing the mask while in active disease, negative feelings about quarantine, isolation, depression, being blamed because of TB, and feeling less as a person. Thirteen participants mentioned at least one of these forms of stigma.

To illustrate the theme of “*stigma*”, I will describe on the case of Julieta, a 70-year old woman born in Durango, México, who had lived 24 years in El Paso. Julieta was selected because she experienced the most stigma out of the 15 participants. Julieta is now retired, but before her health began to worsen six years ago, she worked as a housekeeper in a hotel in El Paso. Julieta began experiencing health problems six years ago when she had a pulmonary embolism, caused by blood clots in her lungs. Julieta said that when she had the pulmonary

embolism she was “cerca de la muerte” (close to death) and after that, she never felt healthy again. In April of 2010, Julieta was diagnosed with pulmonary TB. Julieta said that her doctor told her that her TB was caused by the aftermath of the pulmonary embolism, as it was likely that her latent TB infection was activated after her embolism.

Julieta lived with her husband and three great-grandsons, Mateo (10), Julian (5) and Alejandro (2), for whom she provided primary care. The father of these children was deported to México, where he lives with the mother of these children. When they told her she had TB, Julieta’s main concern was if she had gotten the children sick. She said:

Y todavía le dije yo ese día, como por precaución a los niños, le dije yo ¿Oiga yo tengo a mis niños? ¿Qué va a pasar con mis niños? A lo mejor ya los tengo a todos enfermos, y él me dijo, no, no se preocupe, su enfermedad no es contagiosa, usted la tiene adentro, no la tiene afuera, así me dijo...

And I even said that day, as a precaution for the kids, and I said, “Listen, I have my kids? What is going to happen with my kids?” Maybe they are all sick, and he said, “No, don’t worry, your illness is not contagious, you have it inside, not outside,” and that is how he told me.

Given what her doctor had told her, which is not correct information, Julieta did not know that TB was a contagious illness until she began to receive treatment at the TB clinic. After learning this, she felt sad and depressed, not because she had TB, but because she was putting her children at risk of getting TB.

When Julieta informed her family that TB was a contagious illness, her husband was not supportive. Julieta said that he often leaves on trips to México or Houston, and that he was not supportive in this moment of her life. When Camilla, the mother of Julieta’s grandchildren found out that Julieta had TB, she took the children to México for the summer, as a precaution. Camilla did not want to have her children near Julieta because it represented a risk for infection to her children, even though Julieta was wearing her mask and making sure that her

grandchildren did not sleep in her room. Julian, one of the grandchildren, used to share a bedroom with Julieta.

Julieta said losing the children was the worst thing in her life. These three children meant everything to her and her life did not have meaning without these three children because her life revolved around them. She explained:

Me he sentido triste por la enfermedad, porque es una enfermedad contagiosa. Que si no fuera contagiosa, la tomaba como nada, pero como si es contagiosa, eso si me preocupa a mí... y eso es lo que me pone triste y más triste cuando estoy sola sin mis niños, mas me siento sola. Pienso que cuando tenía a mis niños no tenía tiempo de pensar porque uno me pedía una cosa y el otro me pedía también, y danos esto, y haznos lo otro y ya me salía con ellos a jugar. Y por eso me siento tan triste.

I have felt sad because of the illness, because it is a contagious illness. If it was not contagious, I would take it like nothing, but since it is, that is what worries me... and that is what makes me sad, and even more when I'm without my children, I feel lonelier. I thought when I had my children, I didn't even have time to think, because one would ask me for something and the other one too, and give us this and that, and then I would go outside to play with them. And that is why I feel so sad.

In addition to Camilla taking the children back to México, Julieta mentioned that there were changes in the relations with her three sons, daughters-in-law (including Camilla), and grandkids.

Julieta mentioned that before TB, her family used to love to come over to her house for dinner, and when she disclosed her diagnosis of TB, they stopped visiting her. Julieta said that one of the reasons might be the influence of the daughters-in-law over their husbands, because when her sons tried to visit her, the daughters-in-law would stay by the fence of her house and would not allow the grandchildren to say hi to their grandmother. Even though Julieta was wearing the mask, which prevented the risk of infection to the grandchildren, the daughters-in-law did not want their children near Julieta. Although her relationships with her sons have worsened, Julieta mentioned that they do call her often. She wishes for the family to return to

her house as they did in the past.

In addition to, or possibly because of, feeling stigmatized by her family, Julieta has stigmatized herself. The day of the interview Julieta was wearing a mask and did not want to get too close to me, because she expressed her feelings of being a threat to me, she said, “No me le acerco señorita porque me da miedo de contagiarla” (I don’t want to get close miss because I’m afraid of infecting you). Julieta’s stigma has been internalized as she sanctions herself from getting closer to me and to people around her as she feared passing TB. Julieta’s stigma was also internalized because she indicated feeling less as a person because of TB. During the interview, Julieta tried to move backward and kept covering her mouth even as she wore a mask.

When I asked her to explain what she felt while wearing the mask she said:

Pues se siente uno mal de que lo vea la gente, pues dirán ¿Qué tendrá esta mujer, o porque anda así? Si se siente uno mal de tener la mascarilla de estar junto a la gente más si son niños, y digo ¿hay Dios mío, y si estoy? Y si me hago para un lado, me volteo para otro lado, no hablo, nada. Si se siente uno mal... No sé, pues no es igual pues la gente teme agarrar el contagio...

You feel bad that people look at you and they might say “What does this woman have, or why is she wearing that?” You do feel bad to wear the mask, to be next to people, more if they are kids, and I say “Oh God, what if I am?” And I do move to the side, I move to the other side, I don’t speak, anything. You do feel bad... I don’t know, it’s not the same because people fear being infected...

Julieta wore the mask, which does not allow the bacteria to pass through it, but she still feared that she could infect others and she still felt bad. This is indicative of the stigma that she felt.

When Julieta was telling me how she felt, her phone rang; it was the children’s mother, Camilla, calling her from Ciudad Juárez. Camilla called to inform Julieta that her two-year old grandson, Alejandro, had a positive reaction to the TB skin test. This meant that Alejandro now had TB and that he was going to have treatment for latent TB over the next nine months. Julieta said that she felt sad because she knew she was the source of the TB in her family and that it was

her fault that her grandson had TB. She said that she felt more depressed now because there was increased uncertainty that she was not going to be able to see her grandchildren again.

Julieta completed her interview by telling me that during the time she has undergone treatment, she has not told many people how she felt. This demonstrates her isolation and the stigma that she was feeling. The only person who knew how she felt was the nurse who provided her medicine and now me. She said she was uncertain if she could have asked the doctor for help with the depression she was feeling, and if there was anyone available to help her. Julieta will complete her treatment in the fall of 2010, and hopes to see her grandchildren again. Perhaps her feelings of stigma will disappear once she re-integrates with her family and is cured. Julieta did not know if her family was going to be the same as before, nor did she know if her family was going to blame her for Alejandro's TB.

The narratives presented above illustrate some of the challenges participants living in El Paso faced while dealing with TB. However, some people with TB are influenced positively because of it. In the next section, I will describe the theme of positive changes while having TB, and I will incorporate three different narratives of how TB can change one's life in a positive aspect.

3.3 Positive Outcomes of TB

In this section I will explain positive personal and social changes that participants experienced during and after being diagnosed with TB. The pre-defined code for this section is "*Positive aspects of TB*", and it was sub-coded into three child nodes: "*positive changes in behavior because of TB*;" "*desire to give back to the community after completing TB treatment*;" and "*improved family relations because of TB*."

3.3.1 Positive changes in behavior because of TB

Positive changes in behavior because of TB was defined as beneficial personal changes the participant experienced after being diagnosed with TB. Ten out of 15 participants reported some of the following changes after being diagnosed with TB: taking a more active role in the care of their health, quitting smoking, following a healthy diet, having a more active lifestyle (e.g., exercising), withdrawing from illegal drug use, and changing illegal behavior because of TB.

To illustrate the theme of “*positive change of behavior because of TB*,” I will describe the story of Sebastián, a 24 year old man born in Ciudad Juárez, who has lived in El Paso as a legal resident for six years. Sebastián was chosen because he had experienced all of the behavioral changes mentioned above. In 2009, Sebastián began to experience a cough accompanied by phlegm, fatigue, and loss of appetite. Sebastián said that those symptoms were not surprising to him, given the stress of his job. Sebastián said that at that time he was recruiting people to smuggle illegal drugs from El Paso to different cities in the United States, including New York and Chicago. Sebastián said that being part of an illegal business demanded too much from his body. He said that he never slept enough or ate healthy foods, and that he used a variety of illegal drugs from marijuana to cocaine, and he frequently drank large quantities of alcohol.

In the winter of 2009, Sebastián was arrested at his home for illegally using marijuana. After being detained by police, Sebastián was transferred to a federal prison because he had previous charges for drugs and assault. Sebastián said that his case was handled by Immigration and Customs Enforcement (ICE) and he faced deportation to México. Sebastián said that while in prison, the medical staff performed a physical examination on him, and when they did an x-ray, they told him that something did not look right on his lungs. Sebastián said that in prison

they also performed sputum testing, and that was how they confirmed he had TB. In prison, Sebastián began his nine month treatment for TB, and then later in the spring of 2010, Sebastián was released from prison after winning his deportation case. Sebastián continued his treatment at the TB clinic.

Sebastián believed that TB was something that happens to *other* people. By this he meant people that used intravenous drugs, people of low social class, and those who had low levels of hygiene. He said that he could not believe he had TB, since he had no family history of TB, or any obvious reasons or places where he believed that he could have gotten infected. He said:

Yo pensaba que era inmune, eso es lo que me paso a mí, yo pensaba que en la vida a mí nunca me iba pasar algo así. Yo veía o escuchaba acerca de la TB, y me he dado cuenta que alrededor de una adicción es común de que se pueda contraer esa enfermedad, pero yo la asociaba con personas que se inyectan, con personas que están en un nivel de vida, por decirlo así bajo. Mi incógnita es saber porque me infecte de TB, si mi entorno, lo creía muy seguro, casi blindado de cualquier cosa. Pero hay que tener una mente abierta siempre y darte cuenta que entre todo, tu salud es primero y que en cualquier síntoma en verdad hay que ir a chequearse... porque yo muchas veces lo relacionaba con el frío... Decía es que me duele la espalda por el frío, y ándele es la TB. Pero la verdad hay que darle prioridad a la salud, no se puede dejar pasar la vida, porque en cualquier momento te dan esta noticia y no sabes cómo tomarlo... ¿No sabes que vas a hacer, no sabes si saldrás victorioso? Y te arrepientes de no haber hecho cosas a tiempo para haber podido prevenirlo...

I thought I was immune, that's what happened to me; I never thought that something like that was going to happen. I would hear or see something about TB, and I thought that these were common diseases of drug addicts, but I associated TB with people who do intravenous drugs, with people who have low social class. My question is why I became infected with TB? I considered my surroundings very safe, almost armored. But you need to have an open mind, always, and realize that your health is first, and that any symptom, seriously, you need to get checked... because many times I would relate it to the cold weather... I used to say, my back hurts because it was cold, and it was TB. But the truth is that you need to prioritize your health, you cannot let life pass by, because at any moment they will give you the news, and you don't know how to take it... You don't know what to do, or if you will come out victorious? And you regret not doing things at the right time to prevent it...

It is likely that these feelings of regret have influenced Sebastián to make positive changes in his life.

Sebastián has experienced several positive changes in his life because of TB. Prior to his diagnosis, Sebastián never went to see the doctor. He said that when he felt sick, he would postpone doctor visits because he always thought it was nothing serious. It was TB that has made Sebastián more aware of his health, and to begin to prioritize taking care of his body. TB changed the direction that Sebastián was heading in life, as he also faced addiction to alcohol and drugs that he has since overcome.

TB was a positive experience for Sebastián because it made his life change radically for the better. Sebastián said that for many years he has wanted to change his behavior, especially since he has a two-year old daughter. Although Sebastián had been accepted twice in rehabilitation centers for drug addiction in the past eight years, nothing had changed his behavior, until he was diagnosed with TB. He explained:

Yo creo que es algo bien positivo de que haya llegado a mí estos estudios y que me hayan dicho que era TB. Ha sido como un freno, un jalón de orejas. Fue algo bien impactante, porque yo creo que cuando te enteras de algo así, es como que casi te dijeran que es SIDA... Porque me doy cuenta de que la TB te puede matar, si no es detectada a tiempo. Yo muchas veces me quedaba pensando ¿Y que si no me hubieran arrestado? ¿Dónde estaría hiendo mi enfermedad? Y también estaba pensando de que hay gente que me necesita a mi alrededor y yo creo que las cosas la veo de un punto muy egoísta, por andar en algo más conveniente...

I thought it was something very positive that I got this testing, and that they told me it was TB. It has been like a sudden jolt, like crashing into a wall. It was very shocking... because I think that when you learn about something like that, it is like they told me that I had AIDS. Because I realized that TB could kill you if it is not detected on time. Many times I stop to think, what if I had never been arrested? Where would my illness be going? And I started thinking that there are people who need me, and I believe that I used to see things from a very selfish point of view...

After Sebastián was released from prison in April of 2010 he began to change several aspects of

his life. For example, Sebastián started eating healthier, exercising every day, and using his bicycle. Sebastián also wants to look for a different job and start going to college:

He cambiado mucho, porque ahora si le doy más valor a mi persona, y me empiezo a preocupar por mí mismo. De que no puedo darle tan duro a mi cuerpo, tengo que dejarlo descansar y sacar lo que no es bueno y que más que nada va a traer resultados positivos en mi vida. Va a llegar un momento en el que tanto hacer ejercicio me va a dar más seguridad personal.... Entonces, busco tener una alimentación completa y tener mis alimentos a horas... Porque algo que me decían era, ¿Si tú hubieras tenido las defensas altas? Ese virus no te había atacado. Yo siempre creí que el comer de la manera que yo lo hacía mantenía mis defensas bien... Ahora, yo quiero buscar un empleo digno, quiero aprovechar mi familia al máximo, quiero ver las cosas como deben de ser... ¿Si me entiendes? Porque a partir de que me paso esto, mi vida pudo estar colgando de un hilo; aunque si lo estuvo por mucho tiempo, por otras circunstancias, pero pues ya aquí hablando de salud, ahí son cosas que ya no están en tus manos. Eso me ha cambiado mucho, yo quiero estar cerca de todo... Yo creo que estoy logrando ese cambio que yo siempre estuve esperando en mi vida. Eso es lo más positivo, que batalle tanto para cambiar las perspectivas de las cosas y una enfermedad lo está logrando. Si lo estoy valorizando mucho....

I have changed a lot, because now I value myself more, and I worry about myself. I worry that I cannot treat my body the way I used to, that I need to let my body rest. I have to let bad things go because it is going to bring positive results in my life. It is going to get to a point that exercise is going to give me more personal confidence, so I try to look for a healthy diet, to eat at a certain time. Because they told me, "if you had a good immune system, the virus might not have attacked you". I thought that the way I was eating was keeping my immune system fine. And now, I want to find a dignifying job, I want to enjoy my family; I want to see things the way they should be. Do you understand? Because since that happened to me... my life could have been hanging by a thread; although it was, but there were different circumstances, but we are talking about my health, those are things that are not in your hands. That has changed me a lot; I want to be close to everything... I believe I am achieving this change that I have always wanted in my life. The most positive thing is that I struggled to change things and one illness is doing it... and I appreciate that...

Sebastián has not consumed illegal drugs or alcohol for more than six months (he quit after he was diagnosed) because he realized that he had many things to look forward in his life.

Sebastián also said that after being diagnosed with TB, he did not want to be involved in the business of smuggling illegal drugs anymore. In fact, after completing his treatment, he plans to work in his family business. That is because, as Sebastián said, his daughter is going to grow up

one day, and she wants to know who her father is. Sebastián wants to make his daughter feel proud of her father. Sebastián completed treatment in the fall of 2010.

3.3.2 Desire to give back to the community

Desire to give back to the community was defined as the willingness participants had for becoming active in organizations of general interest and those related to TB in their communities because of their experiences with TB. When asked directly, 14 out of 15 participants said that they would be willing to speak to other people who were undergoing treatment for TB at the clinic, so others could learn about their experiences and side effects of medications. Twelve participants mentioned that they would like to become part of an organization to help other people with TB in their communities. The last form of giving back to the community was speaking to educate people about TB, 12 participants said that they would be willing to inform *others*, that there is a clinic where people can get treated, and that TB is an illness that can be cured.

To illustrate the theme of “*desire to give back to the community*” I will draw on the case of Samuel, a 62-year old man who has lived in El Paso for 18 years. Samuel was selected because as a survivor of MDRTB (Multi-Drug Resistant Tuberculosis), he had the most desire to help other people learn about TB. In 2003, Samuel began to experience the symptoms of TB: night sweats, cough, phlegm, loss of appetite and shivers. He waited more than a month before he went to the doctor. As an El Paso resident, Samuel did not know that El Paso had a free TB clinic where people could get treatment and medications at a low cost.

Samuel was diagnosed with TB in Juárez after visiting a doctor that he knew for many years; Samuel also believed that by going to Juárez he was going to save some money on the

prescribed medications for TB. Samuel said that when he was diagnosed with TB, his doctor did not place him in isolation or quarantine. In fact, he continued working at a local factory that produced rustic furniture in El Paso. Samuel said that he would cross to Juárez when he needed another prescription to buy more medication and when the doctor asked him for another chest X-ray and smear test (in this test, the phlegm of the person is checked to see if TB bacteria is still active). Samuel was under treatment for six months. He remembers asking the doctor if he was completely cured.

Samuel said that his doctor told him that he was cured and that he could continue with a normal life. He said:

A lo último de los seis meses, después de que me dio de alta me dijo ¡No es necesario que regreses tu ya estás bien! Y dure bien años, fueron años que dure bien, ni tos, ni nada, absolutamente nada de eso. Y luego cuando me dio la tos esa vez, me llamo mucho a mi la atención porque yo casi nunca me enfermo de una gripe yo nunca tosía por decirlo así, es mas por decirlo así yo fui una persona muy sana. Y luego yo pensé, ¡si...esa tos no me gusta!... Si porque, mire, esta segunda vez que me dio yo no sentía las sudoraciones, yo no las tenía, no tenía sudoración, tenía tos y flema nada más, pero ya los estremecimientos tampoco tenían. Más bien lo que me empezó a dar fue tos y flema pero con eso me basto para pensar que me había vuelto la enfermedad.

At the end of the six months, after I was discharged, the doctor told me that it was not necessary for me to come back: “you are in good health now”! And I was in good health for years. It was years that I was in good health, no cough, nothing, absolutely nothing. And then when I got that cough, it caught my attention because I would never get the flu, I would never cough, to say it like that, I was a very healthy person. And then I thought, yes, I don’t like this cough!... Because this was the second time that I got TB, I had no night sweats, I didn’t have them, I had no shivers, all I had was cough and phlegm, but I did not have the shivers. What I had was cough and phlegm, but that was enough for me to think that the illness had returned.

The cough and phlegm returned in the early months of 2009, right after Samuel was fired from his job at the furniture factory because they were cutting down the personnel. He returned to his doctor in Juárez who confirmed that Samuel’s TB had returned. On this second occasion, Samuel did not have the economic means to seek treatment from his doctor in Juárez, due to the

fact that he was not working. Samuel was worried and desperate because he wanted to be healthy.

This is how Samuel tells his story of finding treatment this second time he got TB. He said:

Esta segunda vez que me volvió la enfermedad fui con el doctor allá en Juárez y el me dijo “ya te volvió a dar la enfermedad” Entonces yo en esos días no tenía trabajo, ya tenía como tres meses que no trabajaba, y en esa época mi hija era la que me estaba ayudando, tengo dos hijas que me ayudan económicamente. Entonces me dijeron papá, ya no vas poder estar yendo allá, porque es mucho gasto. Entonces me dice mi hija “¿Qué podemos hacer?” Y le digo pues no sé, le digo pero hay que hacer algo. Entonces ella dijo yo voy a buscar... Nunca platicamos como ella se entero de aquí, ella no más me dijo ¡papá, ya te conseguí un lugar, ya te están esperando ahí!, y ya vine y si, ya llene una hoja que me dieron e inmediatamente el Doctor Bohorquez me metió al hospital de Thomason, ahí pase un mes y una semana... Entonces el doctor Bohorquez me decía que estaban buscando la medicina buena que me hiciera efecto porque como era la segunda vez que me daba tuberculosis. Esta vez me dijo el Doctor Bohorquez como tú ya tuviste esa enfermedad, y te volvió, entonces ya es más resistente, ahorita estamos buscando la solución para darte la medicina que necesitas. Y si estuvieron buscando la medicina por dos semanas, pero me dijeron que andaban buscando la medicina que necesitaba para curarme. Así es, y desde el hospital, las últimas tres semanas ya estuve tomando la medicina, total que al mes, y una semana me dieron de alta de ahí.

This second time that I got the illness, I returned to the doctor in Juárez, and he said: “the illness has returned!” By then I didn’t have a job, I had been without work for three months. At that time it was my daughter who was helping me, because I have two daughters that help me financially. My daughter told me, “dad you can’t go there anymore, because it’s a lot of money”. So my daughter told me “what can we do?” I said, “I don’t know but we have to do something.” We never talked about how she found out about this place, she just told me, “Dad, I found a place for you, and they are waiting for you!” And then I came here, I filled out a form that they had given me, and immediately, Doctor Bohorquez transferred me to Thomason, where I spent a month and a week. Then Doctor Bohorquez told me that they were looking for good medicine that would work, because this was the second time that I had gotten TB. This time the doctor told me: “since you already had the illness, and it has returned, it is more resistant, now we are looking for a solution to give you and the medicine you need”. They looked for the medicine for two weeks, and they told me that they were looking for the medicine to cure me. I took medication in the hospital for three weeks, after five weeks I was discharged from the hospital.

Neither Samuel nor his daughters knew about the local clinic before this. As Samuel said, he felt blessed that they were able to help him at the TB clinic and that it was almost free of charge, because his daughters could help him with the \$5 dollar payment. To Samuel, having free treatment was amazing, because he did not feel entitled to it. He could not believe that TB medicine was free, and that it was delivered straight to his house.

It is this that makes Samuel feel that he has to give back to his community because he felt that he was already helped and now he needed to return the favor to those who might need help.

He explained:

No, se imagina usted, olvídese, no tengo palabras, no sabría como decirle, estoy súper agradecido con el doctor y las enfermeras como le digo, que me hayan ayudado, pues yo económicamente si me hubiera ido a un hospital yo no podría pagar. Yo recibí ayuda de todo a todo... me siento muy bien... Y lo que he pensado es trabajar para no sé, un lugar donde ayuden a gente con TB, ayuda como un medio tiempo, como dicen ayudar a la comunidad verdad, ya me ayudaron a mí con esto, yo quiero ayudar a los demás... como ser un voluntario....

You cannot imagine, I have no words, I don't know how to tell you. I am so grateful for the doctor and the nurses that have helped me; because I could not afford to go to the hospital. I received everything, all the help, and I feel very good. And what I have been thinking about is to work for a place where they help people with TB. Like they say to help the community, because they help me with this, now I want to help others, I'd like to be a volunteer.

The day of our interview, July 15, 2010, Samuel showed me his certificate of TB treatment completion. Samuel was very happy because after completing a year and a half of treatment for MDRTB, he felt ready to help others in his community. Unfortunately, the TB clinic does not have a person in charge of providing this type of information. Samuel did ask me if I knew of local agencies or community centers where they might need volunteers; I was able to refer Samuel to a couple of agencies and community centers close to his home (I have tried to reach Samuel several times over the phone to find out if he was able to volunteer in an organization,

but I have not been able to find out). Samuel said that his promise was to help others, and to give back to those in the TB community in need.

3.3.3 Improved family relations

Improved family relations were defined as those positive changes that individuals were having with their families because of TB. Some of the positive changes in relations were: improving closeness from one member to the other, talking more openly about the sources of TB with family members, providing more emotional and psychological support, and coming to realize that TB is a disease that can attack any person and that the person who is undergoing treatment does not need to feel that he or she is at fault because of passing TB to other family members. Eight participants mentioned having one or more of these positive changes in relations with their family members. To illustrate the theme of “*positive change of family relations*”, I will draw on the case of Beatriz and Ximena, who were previously introduced in the section of “*Delayed Diagnosis*”. Ximena, who is undergoing preventive treatment for TB after testing positive on the skin test, was selected because she had the most powerful change in relations with her mother Beatriz (the primary interviewee), who most likely infected Ximena with TB.

At the time in which Beatriz was finally correctly diagnosed with TB and in treatment (discussed earlier), Ximena and Beatriz did not have a very solid relationship. In fact it was TB and the challenges related to the illness that made their relationship more positive. Ximena indicated that one of the main reasons that they did not have a close relationship was that Beatriz did not have a place of her own to live as her mother has always lived with relatives after the death of her husband. In December of 2008, Beatriz, who at the time was living with her 90 year

old sister, fell and broke her leg. Beatriz was placed in a nursing home, because she needed someone who could take care of her, neither her sons nor Ximena were able to provide help.

After Beatriz was able to walk, she returned to live with her sister. Beatriz said that living with her sister was horrible because she would not allow Beatriz to turn on the air conditioner nor open the door or the windows of her house. This was because the sister suffered from pulmonary emphysema, which made her feel cold most of the time, even when it was quite warm out. Beatriz felt trapped at this house because her sister would not allow her to move freely in the house. Beatriz had to remain in her room most of the time and she could not make noise during the day, because her sister slept most of the day, and spent the night watching TV. Beatriz said that every time she would try to open the door or turn on the air, her sister would yell at her. Beatriz was further deterred from opening the windows because they were taped with dark paper and had curtains to make the house darker. Ximena felt that she could not help her mother because she could not afford a place or pay rent for Beatriz. Ximena was living in Juárez at the time and was facing financial problems after closing a small craft business in the Mercado (or market) in Juárez because of the narco-trafficking-related violence, and also because her husband, a former wage earner in El Paso, was deported to México after failing to show up for his appointments to legalize his immigration documents.

Even though Ximena could not provide financial help for her mother, she was able to help her mother emotionally and build a closer relationship with her through the process of coping with TB. Beatriz was very depressed since she was under treatment and lived in a place that was dark without sufficient ventilation. Although Beatriz and Ximena were facing housing and financial problems, Ximena was able to create a closer relationship with her mother, a relationship that has never been built before. She said:

En mi experiencia, a mi madre, yo siempre he visto a mi madre fuerte, positiva, luchona, porque mi madre siempre ha sido así. Pero ahora que ya tiene esa enfermedad, yo la vi frágil, yo la vi indefensa, aislada, entonces para mí, me sirvió mucho porque ahora que ella paso por esto, yo sé que mi madre me necesita, porque ella es una persona grande y con esta enfermedad siento que me unió mas a ella, y más cuando me dijeron que era cáncer, porque cuando me dijeron que era cáncer yo dije voy a perder a mi madre, como que desperté y pensé, ¿Se me va a morir mi madre? ¡Y que voy a hacer!.... Entonces para mí esta es una experiencia que me humanizo más con mi mamá...

In my experience, I always saw my mom as strong, positive, because my mother has always been like that. But now that my mom has this illness, I saw her as fragile, I saw her as brittle, isolated. This taught me that she needs me, because she is a good person, and I feel that this illness brought me closer to her. Even more when they told me it was cancer, because when they told me it was cancer, I thought I was going to lose my mother, and then I thought, my mom was going to die, and what I was going to do? For me this experience has humanized me more with my mother.

When Ximena realized that she could lose her mother, she began looking for possibilities to get employed with a home care agency in El Paso to be able to be her provider. As a provider, Ximena gets paid to care for her mother, to cook and clean for four hours a day from 8 am to 12pm, Monday through Friday. Since Ximena got this job, mother and daughter have been able to talk more, work through Beatriz's feelings of depression, and improve their relationship.

The day of our interview Ximena and Beatriz asked me if I could help them with housing, since they really wanted to get a place where Beatriz could live alone, and be free to do what she wanted. I was not able to provide the help, because when I tried calling the Housing Authority, they did not provide any type of information, because I am not a relative of Beatriz and Ximena. Since the clinic does not have a social worker, I shared the information about the need for a house (with the permission of Beatriz and Ximena) with the clinic's staff. A few days after our interview, I was informed at the clinic that one of Beatriz's sons had rented a small house for her and that Ximena was also able to move from Juárez to El Paso to live with her. Beatriz and Ximena are now closer and this demonstrates that there can be positive aspects of

having an illness like TB.

The narratives presented above illustrate some of the ways in which TB can change one's life in a positive aspect. In the next chapter I will provide a discussion of the significance of the "*Delayed Diagnoses*" section, the "*Challenges*" section, and the "*Positive aspects of TB*" section.

CHAPTER 4

DISCUSSION

Health narratives, the orienting method for data collection and the presentation of results, was an effective method to describe the impacts of TB on residents of El Paso, Texas undergoing treatment at the TB clinic. Their experiences with this illness were reflected in the stories told in the sections of Delayed Diagnosis, Challenges Faced by People with TB, and Positive Outcomes of TB. In the analysis, I sought to understand TB, not only in terms of how the sick person and members of the family saw TB, but in terms of how they lived with the illness, responded to symptoms of disability, and coped with the illness (these aims were described in Bell, 2000). As Bell (2000) suggested, the health narratives presented in this study contributes to the ability to highlight the fragmented griefs in delayed diagnosis of TB, the unresolved challenges of a person with TB, and the positive aspects that are born of an illness and its treatment.

While TB is not the most common illness studied from this perspective, McEwen (2003) investigated, through the use of narratives, the experiences of latent TB infection (LTBI) in infected immigrants (see also McEwen 2005). Another study based on the experiences of people with TB presented phenomenological reflections of daily routine care, impersonal treatment in health care settings, and the personal responsibilities of TB patients under treatment in Belém, Brazil (Araujo Paz & Moita Sa, 2009). Although TB has been studied from a narratives approach in these two studies, my study included people with active disease (unlike McEwen, 2003, 2005) and had a broader focus than explanatory models for TB (the focus of McEwen, 2003, 2005) and treatment delivery (the focus of Araujo Paz & Moita Sa 2009). Because little was known of how the experiences of people seeking treatment for TB especially in underserved border communities, these narratives were important to report.

Next, I will provide answers to the three research questions posed earlier in the thesis, including a discussion of how my findings relate to the literature. In relation to the first question, “Why do people experience delayed diagnosis of TB?” This analysis found that participants who sought frequent medical care were misdiagnosed with different illnesses, and TB was not considered by doctors to be a possible illness affecting participants. A second finding was that participants who sought care especially in emergency centers experienced poor quality of care and a lack of knowledge of TB on the part of the doctors. Doctors on both sides of the border (El Paso, and Ciudad Juárez) diagnosed participants with pneumonia, and provided antibiotics which could have promoted a TB more resistant to medications. This finding indicates that health care professionals need to be more aware of the symptoms and severity of TB. Another finding that account for the experience of delayed diagnosis was fear to seek care because of the presence of immigration officials at health centers (hospitals and clinics) which inhibited participants from seeking care in early stages of the illness leading to severe symptoms of TB. Lastly, having few economic resources was an important factor that delayed diagnosis for TB. Since most participants in this study were uninsured and did not have enough economic resources to seek care, delayed diagnosis occurred as a direct consequence of not having resources to afford medical services.

In terms of connections to the literature, the findings regarding the prevalence of delayed diagnosis among my participants reflects the reality of inadequate access to health care, structural barriers for care, and mal-practice that Farmer (1998, 2003, & 2004) highlights as occurring in more peripheral countries like Haiti. A study in the US-México border quantified the occurrence of delayed diagnosis for people with TB: in a sample of 167 Hispanic participants, the median duration of symptoms was four months prior to receiving a diagnosis

and that one-third of all patients had been symptomatic for six months or longer (Wells et al., 1999). This finding is similar to this study as 12 out of 15 participants also experienced symptoms lasting more than four months, even when seeking frequent care. In a case study of TB in El Paso (and Juárez), Moya & Lusk, (2009) provided a detailed example of delayed diagnosis using the case of one El Paso woman who was misdiagnosed over a period of four years. To Wells' et al. (1999) quantitative finding and Moya & Lusk's (2009) detailed account of one woman, my study adds the richness of the narratives of 11 people that struggled with a delayed diagnosis

Given that there has been limited research into the experiences of people with TB and their delayed diagnoses, I did not find coverage in the literature related to my specific themes: *misdiagnosis, lack of awareness of TB by doctors, fear of immigration authorities, and few economic resources for health care*. However, these themes are not surprising and have been addressed in-depth in the more general access literature (see Berk & Schur 2001; Derose, Escarse, & Lurie, 2007; and Heyman, Nunez, & Talavera 2009), but not related to TB specifically. These explored topics make this study an important contribution to the understanding of delayed diagnosis of TB in the border community.

In relation to the second research question, "What are the challenges faced by the individual affected by TB?" Findings from this study indicated that poverty, accessing social services, lack of knowledge about TB and stigma were all interrelated challenges affecting people with this illness. In relation to poverty, challenges that affected participants were few economic resources to seek medical care, resources to afford a healthy diet, transportation (e.g., not having a vehicle to come to the clinic, reliance on other family members for transportation, and usage of the bus, or bicycle in order to come to the clinic for appointments), and better

opportunities for employment because of TB. In relation to accessing social services, participant's challenges included not being eligible for Medicare/Medicaid, unemployment compensation, housing, and/or food stamps, because of legal status, number of years of legal residency in the US, or fear of abusing the system and lack of assistance to referred them to non-profit organizations in which participants could have access assistance. Another challenge participants faced was knowledge about TB. In this challenge participants did not know sources of transmission, different types of TB, clinics where people could get tested and treated for TB, and TB myths or traditional beliefs about the illness. A more personal challenge affecting people undergoing treatment was stigma. Examples of this challenge include discrimination participants felt from family members, spouses and friends because of TB, feeling less of a person because they had to wear the mask during active TB, and depression. Since depression was the main factor affecting participants undergoing treatment, this indicated that participants' social and psychological needs required prompt attention from health care providers at the clinic.

In relation to how my findings relate to the literature, the experiences of El Paso residents with TB connect to the realities of forced and voluntary migration, lack of education, poverty, and stigma that Farmer (1998, 2003 & 2004) has addressed in his narratives of TB in poor nations. This study provides support that TB is associated with poverty (Farmer, 1998) and that poverty continues to be a factor that affects people's ability to seek health care, receive treatment, access medications for TB, and access social services to help them manage financial difficulties. Few economic resources is not the only challenge people with TB faced, the lack of preventive information about TB was another challenge, which was highlighted by Asch, et al., (1998), Wolfe et al., (1995), Fanning, (2000), Alinger, Lasus, & Dear, (2003) and Moya & Lusk (2009).

In addition, Araujo Paz & Moita Sa (2009) found that TB needed to be addressed not only as a biomedical illness; it was also important to address the personal and social needs of those undergoing treatment. The findings from my study underscore that point. My participants received satisfactory treatment for TB, but their personal, social, and financial needs were not being equally addressed as participants faced many challenges aside from having an illness. Specific to stigma, De Heer et al. (2009), Moya & Lusk (2009), and Moya (2010) found that TB continues to be a stigmatized health issue. My study also provides evidence that individuals with TB are discriminated against due to the illness, present in the lack of understanding and knowledge from family members and the community.

Considering the third research question, “What positive impacts can come from being a person with TB?” I found that some El Paso residents made TB into a positive life event, which was a mechanism by which they could adapt to TB. By overcoming the forms of stigma (Shih, 2004), the process of making TB a positive aspect in life was an everyday learning process that, for some participants, was reflected in a positive change in their behavior. Other participants made this positive adaptation by helping others and becoming active members of an organization and advocates for TB literacy. The last form of positive impacts from the experiences of these participants was changes in the relationships between family members that created closeness and a source of trust to understand and cope with TB.

This study demonstrates that the experiences of El Paso residents overcoming stigma connects to the empowerment model of Shih (2004). Shih (2004) argues that individuals who successfully manage their stigma tend to adopt an empowerment model, which allows them to avoid being a passive target of prejudice, and enables an understanding of their social world, compensating for their stigma by developing skills to help the individual achieve goals,

overcome disadvantages, and actively participate in society. I was able to see this mechanism of empowerment, although it was difficult for participants to identify positive outcomes of having TB. Throughout their narratives, participants expressed their feelings of changing some of the negative aspects of their lives after having TB, for example, changing their behaviors (e.g., more exercise, stop use of illegal drugs, etc.), volunteering in the community, and improving relations with family members.

4.1 Structural Violence

Structural violence can serve as a conceptual framework for highlighting the social injustices caused by social structures, poverty, and social inequality (Galtung 1969, & Farmer 2004) in the experiences of El Paso residents with TB. In the following section I will highlight examples of structural violence which contribute to the understanding of human suffering, and social injustices that took place among participants of this study based on Farmer's (1996, 2003) analytic frame of social axes of: ethnicity [race], immigration status, and socioeconomic status (e.g., health insurance). These axes cross-cut the three themes already discussed, and sustain the justifications for social inequalities, the constraints of human agency and the suffering; all forms of structural violence that these participants with TB experienced.

4.1.2 Ethnicity [Race]

Ethnic or racial classification has been used to deprive many groups of basic rights and is an important cause of inequality and suffering (Farmer, 1996, 2003). Hispanics in the border region have lower income status, have higher rates of poverty, are disproportionately uninsured, have low educational attainment, and lack adequate health care (United States-México Border

Health Commission, 2010). The experiences of the participants in El Paso with TB demonstrate how being Hispanic, specifically when the person has limited English proficiency, and is uninsured, (e.g., is undocumented, does not qualify for health insurance such as Medicare or Medicaid, or health insurance is not provided by employer) limit the agency of those with little knowledge to receive basic services.

Samuel, a survivor of multi-drug resistant tuberculosis (MDRTB) who was previously introduced in the analysis chapter can serve as an example of why being Hispanic can structure, in an unjust way, the possibility of acquiring TB. Samuel's case illustrates how a lack of English proficiency and health insurance constrained his agency for the right to health care. Samuel, whose annual income was less than \$5,000 dollars a year, sought care in Juárez as a result of not having health insurance through his employer, not being able to afford medical services in El Paso, and not having information where he could have sought care at a low cost. In addition, Samuel said that since he did not speak English, he saw seeking care in the US as more of an obstacle than a possibility, which created a stressful situation because he could not communicate his symptoms. This was evident when Samuel was diagnosed with MDRTB. Samuel said that during the time he was hospitalized he often had to have someone translate for him because he could not communicate with the doctors, especially when they were informing him about the specific medications that they needed to treat his MDRTB.

Samuel's case illustrates how providing health insurance, and making US medical settings more accessible to persons who are not proficient in the English language can play an important role in increasing the possibilities of persons acquiring treatment promptly; more importantly, decreasing the risk that someone would acquire drug resistant TB like Samuel did. In addition, political, social, and economic policies placed by government officials to address the

needs of poor Hispanics in relation to health care continue to be insufficient. The border region offers ideal circumstances for Hispanics to develop TB, to suffer, to be victims of social injustices, as no other border in the world shows such inequalities in power, and social and human conditions (Alvarez, 1995).

4.1.3 Gender

Gender inequality helps explain why women's suffering around the world is more commonplace than that of men (Farmer, 1996, 2003). In my study context, gender intersects with Hispanic ethnicity of poor women to shape unequal risk. The experiences of the women in this study: Marcela, Dianna, Esperanza, Beatriz, Ximena, Alexandra, and Julieta were shaped by sexism and social injustices both before they contracted TB and during their treatment. I will use additional details about Marcela's life before she contracted TB to illustrate how gender inequality shapes life chances and risks for acquiring infectious diseases like TB. In the case of Marcela, her afflictions (TB and HIV) were not "accidents," they were structured, and the result of direct and indirect human agency related to gender inequality. During our interview, Marcela said that as a little girl she was never given the opportunity to study in the US (even as a US citizen), on the contrary she was forced by her mother to move, against her will, to Ciudad Juárez to live with her grandparents. Marcela said that at age 16 she married a man who was chosen for her by her grandparents.

During her first marriage, Marcela suffered domestic violence, and was not allowed, by her husband, to return to the US, except to give birth to her second child. After her husband abandoned her, she did not have the economic means to support her children. In Ciudad Juárez, she could not find a place where she could get support and financial assistance to help her with

her family. As a result, she sought a second relationship, and had three more children, one who was also born in the US. In this relationship, she also suffered domestic and psychological abuse. This partner provided only limited financial support because he did not hold a permanent job, Marcela used to sell her children's clothing or do laundry for other people to provide meals for her children. Marcela said that one day her partner left to Tijuana because he had found a job, after a couple of months her partner told her that the whole family needed to move to Tijuana, because he had the economic means to provide for them.

When Marcela arrived in Tijuana with her five children, she saw that her husband did not have a decent place to live. In fact, Marcela made it clear that her partner did not have a bed in which her children could sleep, or food to feed them. Upon her arrival Marcela said that her partner was in company of a man, and that they were partners selling illegal drugs. When Marcela realized that she did not have food or money to support her children, her partner's friend offered her \$20 to feed her children, but in return she needed to join an illegal business. Because of the desperation of not having money to feed the children, the pressure of her partner, and not having many possibilities to bring her children to the US because of immigration laws, Marcela started smuggling people illegally from México to the US until she was arrested.

In the case of Marcela, both of her ex-husbands constrained her agency and she did things that she did not want to, and traditional gender roles kept her from standing up to them. Her lack of education and poverty coupled with her gender shaped her prelude into an illegal business because she saw that there was no way to escape a forced reality. If she had the education, employment opportunities, health care, and immigration assistance to bring her children, who were born in México, into the US she might have had a different story. She may have never gotten TB or HIV. While Marcela's case provides a dramatic example, she is not the only

woman with a story like this. Gender inequality affects many women who suffer, often in silence, as victims of sexism and structural violence.

4.1.4 Immigration status

Any social or biological characteristic can serve as a pretext for discrimination and thus a cause of suffering for the poor and the powerless (Farmer 1996, 2003). One such characteristic particularly relevant in my study area is immigration status. The case of Jorge (who was introduced in the analysis section) demonstrates how the immigration system enacts structural violence against the undocumented. Because of his “lack” of legal status, Jorge could not see the doctor after his brother was killed or seek psychological assistance as result of this terrible incident. In the US most undocumented people delay care, mainly because of legal status and the fear of immigration authorities in hospitals, clinics, and health centers (Asch et al., 1998). Jorge waited for several months to seek care, until he could not tolerate the pain from his back wound.

In addition to this physical pain, he suffered the emotion pain of losing his brother, and may have needed mental health care after witnessing the murder of his sibling. After the murder, Jorge returned to El Paso, and found refuge in intravenous drugs, because he believed that there was nothing or anyone else that could have helped him, making this another example of structural violence (because there was no more formalized help for him). Once Jorge was diagnosed with TB, his fear of immigration authorities being present at the hospital and the TB clinic made Jorge powerless, he knew that if he was to get caught, he would face deportation.

At the same time his agency was constrained, because as an undocumented immigrant his job opportunities were limited. Jorge could only do jobs for which undocumented people are

hired, usually in construction and other physically demanding jobs. Unfortunately, since suffering from his injury and TB, Jorge's back was not the same, and he was unable to engage those types of jobs, severely limiting his possibilities for employment. In addition, Jorge could not return to México, because he fears being re-attacked, and since the violence in Ciudad Juárez continues to worsen, it constrains his agency to move with his wife and two children (all US citizens) to these violent conditions. Immigration laws are structurally violent because they prohibit undocumented immigrants like Jorge the right to health care, employment, access to social services, education, and freedom from want.

4.1.5 Socioeconomic status

Disparate access to health care is an important tool to understand structural violence and its impact of disease distribution, diagnosis and effective care (Farmer, 2006). The experiences of the participants in this thesis reflect the realities of occupying the bottom rung of the social ladder in an inequalitarian society like the US as the majority lived in poverty and did not have health insurance and waited for months before seeking medical attention, instead of freely accessing care. In the case of Dianna, who was previously introduced in the analysis chapter, her lack to health insurance, tied to her low socio-economic-status, was related to her experiences with TB. Dianna could not afford to buy health insurance, and she struggled to pay the \$5 visit fee at the TB clinic. Farmer (2008) says that, in situations like this, health becomes a commodity that is bought and sold by those who can afford it. In the case of Dianna, neither she, nor her little daughter, could afford to pay for health insurance.

Dianna's narrative is an example of how structural violence denies the poor and the powerless the opportunity to claim the dignity of health. Dianna is a victim of structural

violence because social policies of health care come together to constrain her agency. Specifically, she became eligible for Medicaid while pregnant, but lost her coverage after giving birth to her child. At that point, she was not eligible to any health care plan, forcing her to rely on emergency rooms as the only source of care. This delayed her TB diagnosis and kept her infectious for a longer period of time. The inability to access health insurance not only constrains options for treatment, but perpetuates TB by keeping people in active disease longer. This will continue as long as this right (i.e., health) is seen as a commodity that only those with enough money can afford.

4.1.6 Other Sources of Oppression

During the two months that I conducted my interviews at the TB clinic, I observed several instances of structural violence not yet mentioned. These relate to the way in which services are structured at the TB clinic. First, the TB clinic does not promote its free services for undocumented immigrants because of the political concerns and consequences of doing so. The impact of not promoting free services for undocumented immigrants causes delays in care as people do not know about the clinic or how to access it. Secondly, the TB clinic concentrates mainly on providing medical treatment for those affected by TB. The social, psychological, and emotional needs of the persons who are treated there seem to be invisible to the staff.

Beatriz, who was introduced in the analysis chapter, demonstrates how the TB clinic leaves causes of structural violence unresolved. When Beatriz told me that she was living in harsh conditions with her sister, I asked Beatriz if she would grant me permission to share the information with the TB clinic manager. Once Beatriz agreed, I informed someone at the clinic about Beatriz's situation. The response from this person was that they were aware of the

conditions that Beatriz lived in, but that they were unable to help her because they did not provide social assistance. I contacted my thesis chair, and the third member of this thesis committee, because I needed guidance on how to refer Beatriz to an agency that could help her. Unfortunately, contacting social agencies is not an easy job because they do not provide personal information to third parties, in this case, me. When I returned to the clinic, they informed me that Beatriz's son was able to rent a place for his mother, and she was to move to her new place soon.

The case of Beatriz demonstrates that although she was receiving excellent medical attention, her basic rights, such as a safe place to live, were not being met. They were being ignored by the clinic staff that has the education and the resources to reach out to other social agencies. Cases like Beatriz's were not unique, several participants had additional needs apart from the TB medications, such as psychological help for Julieta since she showed signs of depression; food stamps and housing for Dianna as she was struggling to meet basic needs for her daughter; unemployment compensation in the case of Esperanza; referrals to non-profit immigration organizations for Jorge, Dianna, Marcela, and Ximena; and referrals to organizations where participants could learn English, volunteer, or receive primary medical care in the cases of Jorge, Iván, Samuel, Sebastián, Dianna, Marcela, and Ximena.

The specific experiences of the participants presented in this thesis convey the afflictions, the suffering, the constraint on human agency, and the powerlessness that affect people with TB in El Paso, Texas. Nonetheless, people manage to cope. Alexandra mentioned at the end of our interview that “Dios no pone cargas en brazos débiles” or “God does not lay heavy burdens in weak arms”. The poor and those lacking power are the people affected by TB. The majority of these participants in this study do carry a heavy burden, a heavy burden that must be addressed

and changed politically, socially, and economically. As long as the silence and the apathy that accompanies the structural violences outlined here is not broken, people will continue to suffer from TB.

4.2 Limitations

This study has several limitations. First, the findings apply most closely to people that are in the final stages of their treatment. This is because most of the participants in this study were finishing treatment when I met them. Future work should include people in the first stages of treatment. Secondly, this study only pertains to El Paso residents, when TB is, in fact, a more serious problem in El Paso's sister city, Ciudad Juárez. However, the current narco-related violence influenced my decision to not include a sample of residents seeking treatment in Ciudad Juárez. Having a sample from both cities would be ideal because it could offer an understanding of how TB is experienced on both sides of the border, and because TB is a transnational epidemic affecting both the United States and México. Thirdly, I offer only the narratives of patients undergoing treatment when having the narratives of staff would complement these findings. Future studies should include both perspectives. An intervention study to measure the impact that offering social work services at the TB clinic would have on patient outcomes is also needed.

In addition to those mentioned, additional topics for future research stemming from my findings include: studying the identity and self of a person with TB, the experiences of prison inmates with TB that are facing deportation, the process of re-integration into the family and society after being treated for TB and experiencing stigma, depression and TB, how social and cultural capital impact the management of TB, health narratives of people with MDRTB in the

US-México border, and information about the general knowledge about TB that is present in the general population.

CHAPTER 5

CONCLUSION

Tuberculosis is a chronic illness affecting people in El Paso, Texas. TB continues to be a disease of great concern along the US-México border. The number of new TB cases in 2008 and 2009 for El Paso were 40 and 67 cases and in Ciudad Juárez, they were 311 and 306 cases (Moya, 2010). This study relied on interviews with fifteen people undergoing treatment for TB (and three of their children) using a health narratives approach. Important themes from the narratives included delayed diagnosis, challenges in dealing with TB, and positive aspects that came out of recovering from the disease. In terms of explaining why people were delayed in diagnosis, reasons ranged from several misdiagnoses in a row, lack of awareness of TB by doctors fear of immigration authorities, and fewer economic resources for health care. Once receiving a diagnosis, participants faced additional challenges including poverty and difficulties accessing social services (e.g., finding employment because of TB, and eligibility to qualify for social assistance such as unemployment compensation, food stamps or housing). Other challenges participants faced while undergoing treatment include a lack of knowledge about TB (e.g., sources of infection, treatments, and clinics where people can get tested) and stigma. At the end of treatment, some participants reported positive outcomes from being a person with TB, they were illustrated in positive changes in behaviors (e.g., consuming healthier foods, stopping illegal drug use and exercising); a desire to give back to their community (e.g., volunteering); and positive changes in family relations (e.g., closer relationships). This study contributes to the understanding of the experiences of people with TB in communities with a relatively high burden of disease. In the next section, I will provide policy recommendations related to each of these three themes, and related to structural violence (previously discussed).

5. Policy Recommendations

5.1 Delayed diagnosis

Control of TB in the US-México border region has relied primarily on the identification and treatment of active TB cases. Findings from this study suggest that prompt diagnosis of TB could be achieved if medical personnel (doctors, nurses, and specialists) had a higher index of suspicion and recognition of symptoms. This would keep people affected by TB from being misdiagnosed with other illness like pneumonia. A possible way to achieve TB emphasis in medical curricula (e.g., at the local Texas Tech Medical School in El Paso, the University of Texas at El Paso and El Paso Community College nursing schools) could better prepare medical personnel because they can possibly avoid misdiagnosis. Another way to achieve TB emphasis will be through advocacy groups, such as the Border Health Association (through the Voices and Images of TB Guidance Committee), as these groups can target medical students, professors, and graduate medical professionals to become more aware of the possibilities in mis-diagnosing TB. This can be achieved by presenting the narratives of delayed diagnosis in this thesis. The results in this study also have implications for public health policies that will aim to control TB by encouraging increased access to health care regardless of legal status or socioeconomic status, especially for vulnerable people without health insurance or economic resources who usually seek care at the emergency room. Health policy change must occur in order to defeat these barriers of fear of deportation and the high monetary costs related to medical care that delays diagnosis of TB.

5.2 Challenges faced by people with TB

Related to the challenges faced by people with TB while undergoing treatment, one of my recommendations is to expand the social services available to help persons affected by TB by extending public services of unemployment compensation, food stamps, and housing, if necessary, to allow the person to completely recover until he/she is able return to normal activities. For those who are undocumented, this is a challenge given the way that legal status currently determines one's access to governmental social services, but it can be addressed by non-profit organizations throughout the community already extending similar services to persons facing economic challenges. Another recommendation is to provide a social work practicum at the TB clinic for UTEP's Department of Social Work graduate students (MSW). Since budget at the TB clinic is limited, this practicum would better serve the needs of people undergoing treatment for TB while recognizing financial limitations of the clinic.

Given that a lack of information and stigma were challenges for my participants, another way to help people with TB is through education. The need for expanded health and stigma education for TB is evident from my findings. Education should not be limited to vulnerable populations and high risk groups; it should be available to everyone. The best way to achieve health and stigma education about TB is through education at public schools, churches, community centers, clinics, hospitals, social service agencies, and non-profit organizations, because anyone - regardless of socioeconomic status - can develop TB. Accurate information is the key to treat and cure TB, and none should be discriminated against because of TB.

5.3 Positive outcomes of TB

The stories of positive outcomes of TB illustrate that people who experienced TB-related challenges and overcame them successfully can be an empowering resource for those persons who are recently diagnosed with TB and/or are undergoing treatment. One of my recommendations is to encourage people who complete their treatment and experience positive outcomes to give public presentations in schools, churches, and community centers. This could be facilitated through community organizations such as the Border Health Association. To fully take advantage of the experiences of those with positive outcomes, additional support is required. For example, information is needed at the TB clinic to refer persons to organizations to volunteer.

5.4 Structural Violence

Structural violence is often a determinant of both the distribution and outcome of chronic illness (Farmer, 2006). In order to promote change for those affected by TB, the task at hand is to break the silence, to change the social forces that continue making substantial rights (like health) into commodities, and to identify those structures that promote suffering that are embedded in the social axes of: ethnicity [race], gender, and socioeconomic status. In relation to ethnicity, there should be more attention to the needs of Hispanics in the border region from local, state, and national governments, in order to increase education, income status, and access to health insurance. Gender inequality must also be addressed, as women need equal opportunities for education, employment, and child care. Immigration and health policies must also be reconsidered. Fair immigration laws and universal health insurance will be important factors in reducing the spread of TB. Based on these general recommendations I will provide more specific information at three interconnected structural levels in order to promote change for

people who continue being affected by TB: the TB clinic, the municipal level (El Paso and Ciudad Juárez), and national level.

5.4.1 TB Clinic

The TB clinic, whose main role is to provide medical services for people affected by TB, also enacts structural violence as it does not recognize the social and psychological needs of the persons who seek treatment there. One of my recommendations is to provide a full time social worker to the TB clinic. The service of a social worker at the clinic will improve the circumstances of those affected by TB by providing counseling to the person and their families, assistance with employment and education, and referrals to programs where the person can receive help for addictions. In nearly every one of my interviews, I saw examples of how the need for social services would have significantly helped the people during their treatment for TB.

Secondly, information about the TB clinic and its services for legal and undocumented people should be promoted throughout the city of El Paso and adjacent communities. Little is known about this clinic and its services. Thirdly, to effectively prevent new infections, the TB clinic must take a more active role in the community and offer free TB testing throughout the city instead of relying on contact tracking (i.e., the method used to locate and test the people closest to a person had been diagnosed with TB) because it can only have a limited effect in identifying active TB; since most patients seek care as a result of symptoms. This will reduce the chances of people getting mis-diagnosed or diagnosed late when properly referred to medical services.

Increased focus on patient education should be a priority at the clinic because participants who were undergoing treatment did not remember how TB was spread, and people continued to have incorrect information about the illness even after completing their treatment. In addition, treatment should be free since not everyone can afford to pay TB related expenses, as it was illustrated in the case of Dianna. Lastly, it is important to acknowledge that the TB clinics budget is currently limited and it cannot do all without the financial support from the county, as the county is facing severe financial and budget cuts (El Paso Times, 2010). But TB control and awareness is something that needs to be prioritized, even during financially difficult times.

5.4.2 El Paso Texas and Ciudad Juárez

Laws and policies at the city-level enact structural violence and contribute to the risk of people in the border region to acquire TB. In order to promote change, the local governments of El Paso Texas and Ciudad Juárez should facilitate and work to promote health education about TB and raise awareness of the low cost services available to people with this illness. Although participants in El Paso have to pay a nominal fee for TB treatment, the city government should also take an active role in informing people, regardless of legal status, residing in this city about the clinic. The city's needs to inform people that there is an affordable TB clinic, and that they can use this clinic instead of going to Juárez, or seeking costly care elsewhere, as some participants did, resulting in a delayed diagnosis of TB.

On the other hand, while TB treatment is free in Ciudad Juárez, little is known about these sites/programs as was illustrated by Marcela's case (which was previously introduced in the analysis section). Unfortunately, residents like Marcela and her children, did not know about

these places where she could have received adequate treatment for TB and/or HIV that she was entitled to as a poor resident in this city. TB education and information about clinics and organizations that provide help to these people should be a priority as it can provide awareness and change for an illness that does not know borders.

5.4.3 United States of America

Lastly, all residents of the United States of America should be aware of the importance of TB and demand a comprehensive immigration and health reform that will allow for a universal health care plan that is affordable for all US residents including undocumented residents, because access to health care is a basic human right that will make an impact on TB. Participation from all citizens is required, because basic rights like health cannot be commodities that only people with economic resources can afford. Both the United States and Mexican governments need to acknowledge TB as a transnational epidemic. Funding aimed at TB control, education, poverty reduction, immigration policies, and public services can help break the silence, the silence of an illness that continues to disproportionately affect Hispanics.

REFERENCES

- Asch, S., Leake, B., Anderson, R., & Gelberg, L. (1998.) Why Do Symptomatic Patients Delay Obtaining Care for Tuberculosis? *American Journal of Respiratory and Critical Care Medicine*. 157,1244-1248.
- Ailinger, R. L., Laus, Howard., Dear, M. (2003.) American's Knowledge and Perceived Risk of Tuberculosis. *Public Health Nursing*. 20(3), 211-215.
- Araujo, Paz E.P., & Moita, Sa A.M. (2009.) The Daily Routine of Patients In Tuberculosis Treatment In Basic Health Care Units: A Phenomenological Approach. *Latino-am Enfermagem*. 17(2)180-6.
- Bearison, D. (1991.) *"They Never Want to Tell You."Children Talk About Cancer*. Cambridge: Harvard.
- Bell, S. E. (2000.) Experiencing Illness In/And Narrative. In C. Bird, P. Conrad, and A. Fremont, *Handbook of Medical Sociology* (pp. 184-189). Upper Saddle River, NJ: Prentice Hall.
- Berk, M., Schur, C. (2001) The effect of fear on access to care among undocumented Latino immigrants. *Journal of Immigrant Health*. 3,151-156.
- Cantwell, M.F., McKenna, M.T., McCray, E. & Onorato, I.M. (1998.) Tuberculosis and Race/Ethnicity in the United States, Impact of Socioeconomic Status. *American Journal of Respiratory Critical Care Medicine*. 157,1016-1020.
- California Health and Human Services Agency. (2010.) *Report on tuberculosis in 2009*. http://www.cdph.ca.gov/data/statistics/Documents/TBCB_Report_2009.pdf.
- Centers for Disease Control and Prevention. (2008.) *Tuberculosis elimination and general information. Safer healthier people*. www.cdc.gov/tb.
- Cervera Gómez, L.E., Monárrez Fragoso, J., Montero Mendoza, M.T., Burgués Rodríguez, A., Rubio Salas, R., Coronado Ramírez, J.L., Cruz Piñeiro, R., Cital Beltrán, P. (2005). Diagnóstico geo-socioeconómico de Ciudad Juárez y su Sociedad. El Colegio de la Frontera Norte Instituto Nacional de las Mujeres. pp. 1-355.
- Conrad, P., & Bury, M. 1997. "Anselm Strauss and the Sociological Study of Chronic Illness: A Reflection and Appreciation." *Sociology of Health & Illness* 19(3) 373-76.
- Deiss, R., Garfein, R.S., Lozada, R., Burgos, J.L., Brouwer, K.C., Moser, K.S., Zuniga, M.L.,

- Rodwell TC., Ojeda, VD., Strathdee SA. (2009). Influences of cross-border mobility on tuberculosis diagnoses and treatment interruption among injection drug users in Tijuana, México. *American Journal of Public Health*. 99 (8) 1491-1495.
- De Heer, H., Moya, EM., Lacson, R., Sheldin, MG. (2009). Voices and images. Tuberculosis photovoice in a binational setting. *Cases in Public Health Communication and Marketing*. 2, 55-86.
- Derosé, K.P., Escarse, J.J., & Lurie, N. (2007.) Immigrant and Health Care: Sources of Vulnerability. *Health Affairs* 26(5),1258-1268.
- Drieger, S.M., Crooks, V., & Bennett, D. (2004). Engaging in the disablement process over space and time: narratives of persons with multiple sclerosis in Ottawa, Canada. *The Canadian Geographer*, 48(2), 119-136.
- Eun Jeong Hwang, Young Hae Kim, Seong Sook Jun. (2004). Lives experience of Korean women suffering from rheumatoid arthritis: a phenomenological approach. *International Journal of Nursing Studies*, 41 (3), 239-246.
- Fanning, A. (2000) The importance of education, training, and supervision in global TB control. *International Journal of Tuberculosis and Lung Disease*, 4 (12), 5208-5214.
- Farmer, P. (2004). An Anthropology of Structural Violence: Sidney W. Mintz Lecture for 2001. *Current Anthropology*, 45(3),305-325.
- Farmer, P. (1998). *Infectious and Inequalities*. Berkeley: University of California Press.
- Farmer, P. (2008.) *Landmine Boy and Stupid Deaths. A Paul Farmer Reader*. Berkeley and Los Angeles, CA: University of California Press.
- Farmer, P. (2003) *Pathologies of Power*. Berkeley: University of California Press.
- Farmer, P. (2010) *Partner to the Poor. A Paul Farmer Reader*. Berkeley and Los Angeles, CA: University of California Press.
- Farmer, P. (1993, 2006.) *On Suffering and Structural Violence. Social and Economic Rights in the Global Era. A Paul Farmer Reader*. Berkeley and Los Angeles, CA: University of California Press.
- Galtung, J. (1969). Violence, Peace, and Peace Research. *Journal of Peace Research*, 6(3),167-191.
- Gaviria, M.B., Henao, H.M., Martinez, T., & Bernal, E. (2010). Papel del Personal de Salud en el Diagnostico Tardío de la Tuberculosis Pulmonar en Adultos de Medellín, Colombia. *Revista Panamericana de la Salud Publica*, 27(2),.83-92.

- Goffman, E. (1959). Symbolic interactionism and dramaturgy. Appelrouth, S., & Edles, L. (2007). *Twentieth-Century Sociological Traditions*. Pp. 474-536. Thousand Oaks, California: Pine Forge Press.
- Goffman, E. (1959). Symbolic Interactionism. Ritzer, G. (2008). *Sociological Theory*: McGraw Hill Higher Education. New York, NY.
- Goffman, E. (1963). Stigma. Notes on the Management of Spoiled Identity. Prentice-Hall, Inc. Englewood Cliffs, NJ.
- Good, B., & Jo Del Vecchio Good, M. (1994). "In the Subjunctive Mode: Epilepsy Narratives in Turkey." In collaboration with Isenbike Togan, Zafer Ilbars, A. Guvener, and Ilker Gelisen. *Social Science and Medicine*, 38(6)835-42.
- Heyman, J.M., Nunez, G.G. and Talavera, V. 2009. Healthcare Access and Barriers for Unauthorized Immigrants in El Paso County, Texas. *Family and Community Health*, 32(1), 4-21.
- Holtgrave, D.R., & Crosby, R.A. (2004.) Social Determinants of Tuberculosis Case Rates in the United States. *American Journal of Preventive Medicine*, 26(2),159-162.
- Kleiman, A., Wen-Hil, W., Shi-Chou, L, Xueming, C., Xiu-Ying, D., Kun-Tun, L, & Kleiman,J. (1995). "The Social Course of Epilepsy: Chronic Illness as Social Experience in Interior China. *Social Science and Medicine*, 40(10), 1319-30.
- Marinac, J.S., Willsie, S.K., McBride, D., Hamburger, S.C. (1998.) Knowledge of tuberculosis in high-risk populations: survey of inner city minorities. *International Journal of Tuberculosis and Lung Disease*, 2(10), 804-810.
- McEwen, MM. (2003). Mexican immigrants understanding and experience of tuberculosis infection. University of Arizona. Thesis Dissertation, pp.1-274.
- McEwen, MM. (2005). Mexican immigrants; explanatory model of latent tuberculosis infection. *Journal of Transcultural Nursing*, 16(4), 347-355.
- Moya, E.M., & Lusk, M. (2009). Tuberculosis and Stigma: Two Case Studies in El Paso, Texas and Ciudad Juárez , México. Professional Development, *The International Journal & Continuing Social Work Education*, 12,(3) 48-58.
- Moya, E.M. (2010). Tuberculosis and stigma: impacts on health-seeking behaviors and access in Ciudad Juárez, México, and El Paso, Texas. Thesis Dissertation. University of Texas at El Paso.
- Pan American Health Organization. (2007). Frontera De Estados Unidos Y México. Salud En Las Americas, Volumen II – Paises.

- Quitugua, TN., Seaworth, BJ., Weis, SE., Taylor, JP., Gillette, JS., Rosas, II., Jost, KC., Magee, DM. (2002). Transmission of drug-resistant tuberculosis in Texas and México. *Journal of Clinical Microbiology*, 40(8) 2716-2724.
- Rivera J O, Ortiz M, and Cardenas V. 2009. Cross-Border Purchase of Medications and Health Care in a Sample of Residents of El Paso, Texas, and Ciudad Juárez , México. *Journal of the National Medical Association*, 101,167-173.
- Schladen, M. (2010, September 21) County approves tax hike, officials trim courts budgets and union agrees to concessions. *El Paso Times*. http://www.elpasotimes.com/news/ci_16129165?IADID=Search-www.elpasotimes.com-www.elpasotimes.com
- Shih, M. (2004). Positive stigma: examining resilience and empowerment in overcoming stigma. *Annals of the American Academy of Political and Social Science*, 591, 175-185.
- Somma, D., Thomas, B.E., Karim, F., Kemp, J., Arias, N., Auer, C., Gosoniu, G.D., Abouihia, A., & Weiss, M.G. (2008). Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *International Journal of Tuberculosis and Lung Disease*, 12(7), 856-866.
- The City of El Paso, Texas. Department of Public Health, Tuberculosis Control Clinic. <http://www.ci.el-paso.tx.us/health/tb.asp>
- Tsai, T.C., Hung, M.S., Chen, I.C., Chew, G., & Lee, W.H. (2008.) Delayed Diagnosis of Active Pulmonary Tuberculosis in Emergency Department. *American Journal of Emergency Medicine*, 26, 888-892.
- United States–México Border Health Commission. (2009). Tuberculosis along the United States–México Border.
- US Bureau Of The Census (2008) Quick Facts about El Paso County. Washington DC.
- Wallace, R.M., Kammerer, J.S, Iademarco, M.F., Althomsons, S.P., Winston, C.A., & Navin, T.R. (2009.) Increasing Proportions of Advanced Pulmonary Tuberculosis Reported in the United States. Are Delays in Diagnosis in the Rise? *American Journal of Respiratory and Critical Care Medicine*, 180, 1016-1022.
- Wells CD., Ocana, M., Moser, K., Bergmire-Sweat, D., Mohle-Boetani, JC., Binkin, NJ. (1999). A study of tuberculosis among foreign-born Hispanic persons in the U.S. states bordering México. *American Journal Respiratory and Critical Care Medicine*, 159, 834-837.
- Wolfe, H., Marmor, M., Maslansky, R., Nichols, S., Simberkoff, M., Jarlais, D.D., Moss, A. (1995.) Tuberculosis knowledge among New York ity injection drug users. *American Journal of Public Health*, 85(7), 985-988.

World Health Organization. (2007). Global tuberculosis control surveillance, planning, and financing. WHO Report. (WHO/HTM/TB/2007.306).

APPENDIX

Calendario de Entrevista

Fecha de la entrevista: ____ / ____ / ____

ID: _____

Your story with TB

1. When did you find out you had TB?
 - a. What were some of the initial symptoms?
 - b. When did you start experiencing these symptoms?
 - c. How long did you wait before seeking health care?
 - d. Why do you think you got infected?
 - e. Why do you think you got TB as opposed as someone else?
 - f. How do you make sense of what is happening to you?
2. How was the process of being diagnosed with TB? What happened?
 - a. How long did it take you to receive a diagnosis?
 - b. Where did you receive the diagnosis?
 - c. Did you start treatment right after being diagnosed? If yes, where, and if not, why not?
 - d. Were you diagnosed in the U.S or Mexico? Why did your diagnosis happen there?
 - e. Did you receive treatment in the U.S., Mexico or both (specify)? If both, how does that work?
3. Do you know if you have infected anyone else? What happened?
4. Do you have any other illness besides TB, like diabetes or HIV?
 - a. If you have any other health conditions, how has having TB impacted them?
 - b. Does one condition aggravate the other? How?
 - c. How would you compare the medical care you get for the other disease with the care you get from TB?
 - d. How do the medications make you feel? How do you feel about your medications? Has this changed throughout treatment?
 - e. What are some of the side-effects from medications?
5. How did you hear about the TB clinic?
 - a. Tell me your experience of receiving treatment at the TB clinic.
 - b. How does the treatment process work? Does someone ever come to your home? If so, what happens?
 - c. Has the clinic influenced your thoughts about TB?
6. What are some of the resources the TB clinic offers you? For example, can you call 24/7 in case you have questions regarding medication?
 - a. Do you receive treatments at home, and how does this process happens?
 - b. Have you met with a social worker to learn about how to receive social assistance from the government or non-profit organizations to help you with housing, food,

transportation, medications, etc? If yes, please tell me how this happens?

Su Historia Con La TB

1. ¿Cuándo se enteró que tenía TB?
 - a. ¿Cuáles fueron algunos de los síntomas iniciales?
 - b. ¿Cuándo comenzó a sentir estos síntomas?
 - c. ¿Cuánto tiempo espero antes de buscar atención médica?
 - d. ¿Por qué cree que se infectó?
 - e. ¿Por qué cree usted que tiene TB en vez de otra persona?
 - f. ¿Cómo da sentido a lo que le está pasando?
2. ¿Cómo fue el proceso de ser diagnosticado con TB? ¿Qué pasó?
 - a. ¿Cuánto tiempo le tomo para recibir un diagnóstico?
 - b. ¿En dónde recibió el diagnóstico?
 - c. ¿Comenzó el tratamiento después de ser diagnosticado? En caso afirmativo, dónde, y si no, ¿por qué no?
 - d. ¿Le diagnosticaron en los EE.UU. o México? ¿Por qué su diagnóstico ocurrió allí?
 - e. ¿Ha recibido tratamiento en los EE.UU., México o ambos (especifique)? Si ambos, ¿cómo funciona ese proceso?
3. ¿Sabe usted si ha infectado a alguien más? ¿Qué paso?
4. ¿Tiene usted alguna otra enfermedad aparte de la TB, como la diabetes o el VIH?
 - a. Si usted tiene alguna otra condición de salud, ¿Cómo la TB afecta esa otra condición?
 - b. ¿Hay una condición que agrave la otra? ¿Cómo?
 - c. ¿Cómo se compara la atención médica que recibe de la otra enfermedad con la atención que recibe de la TB?
 - d. ¿Cómo lo hacen sentir los medicamentos? ¿Cómo se siente acerca de sus medicamentos? ¿Ha cambiado esto durante todo el tratamiento?
 - f. ¿Cuáles son algunos de los efectos secundarios de los medicamentos?
5. ¿Cómo escucho de la clínica de la TB?
 - a. ¿Dígame cuál es su experiencia de recibir tratamiento en la clínica de la TB?
 - b. ¿Cómo funciona el proceso de tratamiento? ¿Viene alguna persona de la clínica a su casa? Si es así, ¿Cómo pasa?
 - c. ¿Ha influenciado la clínica sus pensamientos acerca de la TB?
6. ¿Cuáles son algunos de los recursos que la clínica de la TB, le ofrece? Por ejemplo, ¿puede llamar durante las 24 horas del día en caso de tener preguntas sobre medicamentos?
 - a. ¿Recibe usted tratamiento en la casa, y cómo ocurre este proceso?
 - b. ¿Se ha reunido con un trabajador social para aprender acerca de cómo recibir asistencia social del gobierno o de organizaciones sin fines de lucro que le ayude con vivienda, comida, transporte, medicamentos, etc.? En caso afirmativo, por favor

dígame cómo sucede esto?

Personal Changes

1. What are some of the changes you noticed in yourself that have happened ever since you found out you had TB? (How different are you?)
 - a. How has your self-esteem changed? How was it before? What about now?
 - b. Why do you think it changed (if it did) and why do you think it did not (if it did not)? If it lowered, are there ways you have tried to raise it?
2. What are some of the emotional effects of being a person with TB?
 - a. Have you feel depressed because of TB? How would you describe how you felt?
 - b. Have you received treatment for depression?
3. Are you a religious person? How does religion or faith play a role for someone with TB?
 - a. What are some of the spiritual changes of being a person with TB?
 - b. Has your relationship with God changed, and how do you explain that?
 - c. Do you attend church more often, or have you separated yourself from religion because of TB?
 - d. How does religion help you cope with TB?

Cambios personales

1. ¿Cuáles son algunos de los cambios que ha notado en usted desde que se enteró de que tenía TB? (¿Qué tan diferente es usted?)
 - a. ¿Cómo ha cambiado su autoestima? ¿Cómo era antes? ¿Y cómo es ahora?
 - b. ¿Por qué cree que su autoestima ha cambiado (si lo ha hecho) y por qué cree que no ha cambiado (si, no)? Si su autoestima a bajado, en qué manera ha tratado de subirla?
2. ¿Cuáles son algunos de los efectos emocionales de ser una persona con TB?
 - a. ¿Se siente deprimido a causa de la TB? ¿Cómo describiría usted cómo se siente?
 - b. ¿Ha recibido tratamiento para la depresión?
3. ¿Es usted una persona religiosa? ¿Cómo la religión o la fe para una persona con TB?
 - a. ¿Cuáles son algunos de los cambios espirituales de ser una persona con TB?
 - b. ¿Ha cambiado su relación con Dios, y cómo se explica eso?
 - c. ¿Va a la iglesia con más frecuencia, o se ha separado de la religión a causa de la TB?
 - d. ¿Cómo la religión le ayuda con la TB?

Social Interactions

1. How has your daily activities changed since you got TB?
 - a. How was your life before TB?
 - b. How had your life changed since you were diagnosed?
 - c. How has TB changed your expectations about life?

- d. Employment?
- e. Education?
- f. Family?

1. Does anyone else know that you have TB? If so, how did you tell them?
 - a. How about family?
 - b. Friends, co-workers? How did they react?
2. How have your interactions with others change comparing the time when you first had symptoms and now that you are in treatment?
 - a. How were your interactions with others when you had active TB?
 - b. How did your interactions change once you got diagnosed and started treatment?
 - c. Did interactions change when you no longer had active disease? What about now?
3. What are your sources of social support?
 - a. Is there anyone in particular that has been really helpful or supportive as you have faced TB? How have they supported you?

Interacciones Sociales

1. ¿Cómo ha cambiado sus actividades diarias desde que usted tiene TB?
 - a. ¿Cómo era su vida antes de la TB?
 - b. ¿Cómo ha cambiado su vida desde que usted fue diagnosticado?
 - c. ¿Cómo ha cambiado la TB sus expectativas acerca de la vida?
 - d. ¿Del empleo?
 - e. ¿Educación?
 - f. ¿Familia?
2. ¿Alguien más sabe que tiene TB? Si es así, ¿cómo les dijo?
 - a. ¿Qué sobre su familia?
 - b. ¿Amigos, compañeros de trabajo? ¿Cómo reaccionaron?
3. ¿Cómo han cambiado sus relaciones con otras personas desde que tenían síntomas y, ahora que usted está en tratamiento?
 - a. ¿Cómo fueron sus interacciones con otras personas cuando tenía TB activa?
 - b. ¿Cómo cambiaron sus interacciones una vez que lo diagnosticaron y comenzó el tratamiento?
 - c. ¿Cómo cambiaron sus interacciones con otras personas cuando ya no tenían la enfermedad activa? ¿Y cómo es ahora?
4. ¿Cuáles son sus fuentes de apoyo social?
 - a. ¿Hay alguien en particular que ha sido de gran ayuda o de apoyo a medida que se ha enfrentado a la TB? ¿Cómo le han apoyado?

Your Home

1. What is it like where you live (including your home and your neighborhood)?
 - a. How many rooms does your house have?

- b. How many people live in your home? Tell me about these people.
- c. Have you had to make any changes in your home or daily routine because of TB? If so, what were these?

Su Casa

- 1. ¿Cómo es donde vive (incluyendo su casa y su vecindario)?
 - a. ¿Cuántas habitaciones tiene su casa?
 - b. ¿Cuántas personas viven en su casa? Hábleme de estas personas.
 - c. ¿Ha tenido que realizar algún cambio en su hogar o rutina diaria a causa de la TB?
En caso afirmativo, ¿cuáles son esos cambios?

Diet

- 1. What is your diet like? Does your condition require you to eat certain types of foods? If so which ones?
 - a. Do you usually have enough money to buy healthy groceries?
 - b. If not, do you receive any type of assistance to help you paid for food? If yes, which program? If not, what do you do?

Dieta

- 1. ¿En qué consiste su dieta? ¿Le exige su condición comer cierto tipo de alimentos? En caso afirmativo ¿Qué tipo de alimentos?
 - a. ¿Suele tener suficiente dinero para comprar alimentos saludables?
 - b. Si no, ¿recibe algún tipo de asistencia para ayudar a que usted pueda pagar por la comida? En caso afirmativo, ¿qué programa? Si no, ¿qué hace?

Transportation

- 1. Do you own a vehicle? If not, what source of transportation do you use to receive treatment at the clinic?
 - a. If you do own a car, describe the process of getting to the clinic.
 - b. How long does it take you to get to the clinic?
 - c. If you don't have your own car, what are some of the difficulties related to this?
 - d. Does anyone offers to bring you to the clinic? If so, who?

Transporte

- 1. ¿Es dueño de vehículo/automóvil? Si no, ¿qué medio de transporte utiliza para recibir tratamiento en la clínica?
 - a. ¿Si usted tiene un automóvil, describa el proceso de llegar a la clínica?
 - b. ¿Cuánto tiempo le toma para llegar a la clínica?
 - c. Si no dispone de vehículo propio, ¿cuáles son algunas de las dificultades relacionadas con no tener transporte?
 - d. ¿Se ofrece alguien a traerlo a la clínica? Si es así, ¿quién?

Employment

1. Do you work outside the home? If so, in what job?
 - a. Has TB impacted your employment? Are you the primary source of income in your family?
 - b. Who else in the household provides financial support?

Empleo

1. ¿Trabaja fuera del hogar? En caso afirmativo, ¿en qué trabaja?
 - a. ¿Ha afectado la TB su empleo? ¿Es usted es la fuente principal de ingresos en su familia?
 - b. ¿Quién más en el hogar ofrece ayuda financiera?

Challenges

1. Has the violence impacted your treatment or care for TB in anyway?
 - a. Has the violence in Juárez impacted your life in any way? Have you changed the way you used to cross the border? How?
 - b. Where do you currently live? Is this related because the situation in Juárez?
 - c. Has the violence affected you in the purchase of medications (for TB or other health conditions), and how do you manage that?
2. How important is to speak English as someone getting treatment for TB at this clinic?
 - a. If you don't know English, has not knowing English influenced the way you cope with TB?
 - b. How about taking medications that have labels in English, or interactions with doctors and nurses)?
3. How does poverty affects you and your situation?
 - a. What sorts of extra expenses do you have b/c of TB?
 - b. How do you deal with the extra expenses?
 - c buying additional medications
 - dpaying for doctors visits?
 - e. ...paying for transportation?
 - f. ...paying for house bills, etc?
 - g. ...accessing social services?
4. How well has the health care system met your needs? Before you got TB? Once you got your diagnosis until now?
 - a. Have you ever sought health care across the border? What was it like? (to receive proper care in Ciudad Juárez, Mexico vs. El Paso, Texas)
 - b. If you receive any social services, what are some of the difficulties in receiving them?

Retos

1. ¿Ha afectado la violencia de alguna forma su tratamiento o atención para la TB?
 - a. ¿Ha impactado su vida la violencia en Juárez de alguna manera? ¿Ha cambiado la

- forma en cruzar la frontera? ¿Cómo?
- b. ¿Dónde vive usted actualmente? ¿Está relacionado por la situación en Juárez?
 - c. ¿Le ha afectado la violencia en la compra de medicamentos (para la TB u otras condiciones de salud), ¿y cómo es eso?
2. ¿Qué tan importante es hablar Inglés como alguien que recibe tratamiento para la TB en esta clínica?
 - a. Si no sabe Inglés, ha influido no saber Inglés la forma en que hace frente a la TB?
 - c. ¿Qué pasa cuando toma medicamentos que tengan etiquetas en Inglés, o interacciones con los médicos y enfermeras)?
 3. ¿Cómo la pobreza lo afecta a usted y a su situación?
 - a. ¿Qué tipo de gastos extras tienes a causa de la TB?
 - b. ¿Cómo enfrenta esos gastos extra?
 - c. ... ¿La compra de medicamentos adicionales
 - d. ... ¿El pago por visitas al médico?
 - e. ... ¿El pago del transporte?
 - f. ... ¿El pago de facturas (biles) de la casa, etc.?
 - g. ... ¿Acceso a los servicios sociales?
 4. ¿Qué tan bien a cumplido el sistema de salud sus necesidades? Antes de que tuviera TB? Y na vez que lo diagnosticaron hasta ahora?
 - a. ¿Alguna vez ha solicitado servicios de salud en la frontera? ¿Cómo fue? (Para recibir atención adecuada en Ciudad Juárez, México vs El Paso, Texas)
 - b. Si recibe cualquiera de los servicios sociales, ¿cuáles son algunas de las dificultades para recibirlos?

Discrimination

1. Did you ever try to hide your diagnosis from others? If so, why? How do you do this? If no, why not?
2. Do you think people see you as less because you have TB? Why?
3. How does having TB affect what others think of your family?
4. How do you manage TB-related complications or problems with your partner or children if you have any?
5. Have you ever experienced any form of discrimination because of TB? What happened?
6. Do you think you are discriminated because you are an immigrant (if applicable)?
7. Can you compare and contrast the discrimination experienced as someone with TB between the U.S. and Mexico? If so, describe it?
8. What could be done to better help people with TB? Do you need information regarding: health care, social programs, transportation, etc?)

Discriminación

1. ¿Ha alguna vez tratado de ocultar su diagnóstico a otras personas? Si es así, ¿por qué? ¿Cómo hace esto? En caso negativo, ¿por qué no?
2. ¿Cree usted que la gente lo ve como menos porque usted tiene TB? ¿Por qué?

3. ¿Cómo le afecta lo que otros piensen de su familia por que usted tiene TB?
4. ¿Cómo controla las complicaciones/problemas relacionados con la TB con su pareja o hijos, si tiene?
5. ¿Alguna vez has experimentado cualquier forma de discriminación a causa de la TB?
¿Qué pasó?
6. ¿Cree que es discriminado porque usted es un inmigrante (si lo es)?
7. ¿Se puede comparar y contrastar la discriminación que sufre como alguien con TB entre los EE.UU. y México? Si es así, lo describiría?
8. ¿Qué podría hacerse para ayudar mejor a las personas con TB? ¿Necesita información sobre: salud, programas sociales, transporte, etc.?)

Positive outcomes of TB

1. Do you think there is anything positive that can come out of having TB? What might those things be?
2. In your experience as someone with TB, do you think there are positive ways in which stigma and discrimination can be overcome?
3. Have you ever thought about educating others about TB, and serving as a role model of your community? Why or why not?
4. Is there anything else that I should know about people with TB?

Resultados positivos de la TB

1. ¿Cree que hay algo positivo que puede salir de tener TB? ¿Cuáles podrían ser esas cosas?
2. En su experiencia como una persona con TB, ¿cree que hay maneras positivas en que la discriminación y el estigma se puedan superar ?
3. ¿Alguna vez has pensado en educar a otros acerca de la TB, y servir como un modelo a seguir para su comunidad? ¿Por qué o por qué no?
4. ¿Hay algo más que debería saber acerca de las personas con TB?

(Survey questions, next page)

(Preguntas de la encuesta en la página siguiente)

Preguntas de la encuesta:

ID: _____

Preguntas de la encuesta: Su participación en esta encuesta es voluntaria, y puede pasar cualquier pregunta que no quiera contestar.

Por favor llene las siguientes preguntas.

1. ¿Cuál es su sexo?

Hombre ☐

Mujer ☐

2. ¿Cuántos años tiene? _____

3. ¿Cuál es su estado civil?

Soltero ☐

Unión Libre ☐

Casado/a ☐

Viudo /a ☐

Divorciado /a Separado/a ☐

4. ¿Cuántas personas viven en su casa? _____

5. ¿Cuántos niños (menores de 18) viven en su casa: _____

6. ¿Cuál fue su país de nacimiento?

EE.UU. ☐

México ☐

Otro ☐

Por favor describa: _____

¿Cuánto tiempo lleva viviendo en El Paso? _____

1. ¿Qué tipo de vivienda mejor describe su casa?

Casa

☐

Apartamento

☐

Casa Mobile/Tráiler

☐

Dúplex

☐

Otro

☐

Por favor describa: _____

2. ¿Habla usted Ingles?

Si

☐

No

☐

3. ¿Habla usted Español?

Si

☐

No

☐

4. ¿Tiene seguro medico? ¿Si es afirmativo, que tipo?

Ninguno

☐

Medicaid

☐

Medicare

☐

Seguro privado de empleador

☐

Seguro Social

☐

Seguro Popular

☐

Otro

☐

Especifique: _____

5. ¿Tiene usted carro o alguien en su familia tiene carro?

Si

☐

No

☐

6. ¿Cuál es su tipo de transporte?

Mi propio vehículo

☐

El vehículo de un familiar

☐

El vehículo de un amigo/a

☐

Bus

☐

Taxi

☐

Otro, especifique: _____

7. ¿Marque la casilla junto a la cantidad que está más cerca de los ingresos anuales de su hogar?

Menos de \$5,000

☐

\$5,000 - \$10,000

☐

\$10,000- 14,999

☐

\$15,000- 19,999

☐

\$20,000- 39,999

☐

\$40,000- \$59,999

☐

\$60,000-\$79,000	<input type="checkbox"/>
\$80,000-\$99,999	<input type="checkbox"/>
\$100,000-\$149,999	<input type="checkbox"/>
\$150,000 o más	<input type="checkbox"/>

8. ¿Marque las casillas de todos los niveles de educación que usted ha alcanzado, y en qué país completo cada nivel?

	<u>U.S.</u>	<u>México</u>
Escuela Primaria	<input type="checkbox"/>	<input type="checkbox"/>
Parte de escuela secundaria	<input type="checkbox"/>	<input type="checkbox"/>
Título de escuela secundaria	<input type="checkbox"/>	<input type="checkbox"/>
Algo de colegio	<input type="checkbox"/>	<input type="checkbox"/>
Parte del Colegio Asociados Grado (2años o una formación especializada)	<input type="checkbox"/>	<input type="checkbox"/>
Más de Asociados	<input type="checkbox"/>	<input type="checkbox"/>
Título universitario de licenciatura	<input type="checkbox"/>	<input type="checkbox"/>
Más de Maestría/Medicina/Derecho/Doctorado	<input type="checkbox"/>	<input type="checkbox"/>

No sabe, especifique: _____

9. ¿Usted se describe a sí mismo como... (Marque todo lo que corresponda)?

Hispano/a, Latino/a Mexicano o México-Americano/a	<input type="checkbox"/>
Blanco o anglosajón	<input type="checkbox"/>
Negro o afro-americano	<input type="checkbox"/>
Asiático o de las islas del Pacífico	<input type="checkbox"/>

Americano nativo o indio norteamericano ☐

Otro

Por favor escriba: _____

10. ¿ Trabaja usted fuera de la casa?

Si

☐

¿Cuál es su ocupación?:

No

☐

11. Ha tenido algún miembro de su familia TB en el pasado?

Si

☐

En caso afirmativo, quien:

No

☐

12. ¿Cuántas veces cruza la frontera?

Todos los días

☐

Una vez a la semana

☐

Tres veces o más a la semana

☐

Una vez al mes

☐

Nunca

☐

13. ¿Cuántas veces cruzaba la frontera antes del incremento de violencia en Juárez?

Todos los días

☐

Una vez a la semana

☐

Tres veces o más a la semana

☐

Una vez al mes

☐

Nunca

☐

14. ¿Antes de que iniciara el tratamiento en esta clínica, donde buscaba por lo general atención de salud (incluyendo, si vivía en México o EE.UU.)?

	México	U.S.
Doctores o clínicas publicas	<input type="checkbox"/>	<input type="checkbox"/>
Doctores o clínicas privados	<input type="checkbox"/>	<input type="checkbox"/>
Servicios de salud religiosos u homeopáticos	<input type="checkbox"/>	<input type="checkbox"/>
Ningún servicio	<input type="checkbox"/>	<input type="checkbox"/>

Otro, por favor especifique: _____

15. ¿Cómo escuchó de los servicios de esta clínica?

Familia	<input type="checkbox"/>
Amigo	<input type="checkbox"/>
Compañero de trabajo	<input type="checkbox"/>
Proveedor de salud	<input type="checkbox"/>
Trabajador/a social	<input type="checkbox"/>
Otro	<input type="checkbox"/>

Especifique: _____

16. ¿Le gustaría recibir un resumen de los resultados de este proyecto de investigación sobre la TB?

YES ☐ NO ☐

Survey Questions:

ID: _____

Your participation in this survey is voluntarily, and you can skip any question you do not want to answer.

Please fill out the following questions.

1. What is your sex?

Male ☐

Female ☐

2. How old are you? ____

3. What is your marital status?

Single ☐

Unmarried (common-law) ☐

Married ☐

Divorced ☐

Widowed/widower ☐

Separated ☐

4. How many persons live in your household? _____

5. How many are children (under age 18): _____

6. What was your country of birth?

US ☐

Mexico ☐

Other ☐

If you live in the US, but were not born in the US, how long have you lived in the US?

Please list: _____

7. How long have you lived in El Paso? _____

8. What type of dwelling best describes your home?

House

☐

Apartment

☐

Mobile home

☐

Duplex

☐

Other

☐

Please describe: _____

9. Are you an English speaker?

Yes ☐

No ☐

10. Are you a Spanish speaker?

Yes ☐

No ☐

11. Do you currently have health insurance? If so, what type?

None

☐

Medicaid

☐

Medicare

☐

Private insurance or from job

☐

Seguro Social

☐

Seguro Popular

☐

Other

☐

Specify: _____

12. Do you or anyone in your household own a car?

Yes ☐

No ☐

13. What is your usual source of transportation?

My own vehicle ☐

A relative's vehicle ☐

A friend's/neighbor vehicle ☐

Bus ☐

Taxi ☐

Other, specify: _____

14. Check the box next to the amount that is closest to the annual income of your household.

Under \$5,000 ☐

\$5,000- \$10,000 ☐

\$10,000- 14,999 ☐

\$15,000- 19,999 ☐

\$20,000- 39,999 ☐

\$40,000- \$59,999 ☐

\$60,000-\$79,000 ☐

\$80,000-\$99,999 ☐

\$100,000-\$149,999 ☐

\$150,000 or higher ☐

15. Check the boxes for all levels of education that you have achieved, and in which country you completed each level?.

	<u>Mexico</u>	<u>U.S.</u>
Elementary School	<input type="checkbox"/>	<input type="checkbox"/>
Some High School	<input type="checkbox"/>	<input type="checkbox"/>
High School Degree	<input type="checkbox"/>	<input type="checkbox"/>
Part of College	<input type="checkbox"/>	<input type="checkbox"/>
Associates Degree (2-year or specialized training)	<input type="checkbox"/>	<input type="checkbox"/>
More than Associates Degree	<input type="checkbox"/>	<input type="checkbox"/>
College Graduate	<input type="checkbox"/>	<input type="checkbox"/>
More than Bachelor's Degree (Master's, Medical, Law, PhD)	<input type="checkbox"/>	<input type="checkbox"/>

Don't know, Specify:

16. Would you describe yourself as... (Check all that apply)

Hispanic, Latino/a Mexican or Mexican-American	<input type="checkbox"/>
White or Anglo	<input type="checkbox"/>
Black or African-American	<input type="checkbox"/>
Asian or Pacific Islander	<input type="checkbox"/>
Native American/ American Indian	<input type="checkbox"/>
Other	<input type="checkbox"/>

Please list: _____

17. Do you work outside the home?

Yes

☐

What is your occupation?

No

☐

18. Have any members of your family ever had TB in the past?

Yes

☐

If yes, who:

No

☐

19. How often do you cross the border now?

Every day

☐

Once a week

☐

Three or more times a week

☐

Once a month

☐

Never

☐

20. How often did you cross the border before the violence spike in Juárez?

Every day

☐

Once a week

☐

Three or more times a week

☐

Once a month

☐

Never

☐

21. Before you began treatment at this clinic, where did you usually seek health care (including if it was in Mexico or the U.S)?

Mexico

U.S.

Public doctors or clinics

☐☐

Private doctors or clinics	<input type="checkbox"/>	<input type="checkbox"/>
Religious or homeopathic health services	<input type="checkbox"/>	<input type="checkbox"/>
No services	<input type="checkbox"/>	<input type="checkbox"/>

Other (Please, specify:_____)

22. How did you hear about the services in this clinic?

Family	<input type="checkbox"/>
Friend	<input type="checkbox"/>
Co-worker	<input type="checkbox"/>
Health provider	<input type="checkbox"/>
Social service provider	<input type="checkbox"/>
Other	<input type="checkbox"/>

Specify: _____

23. Would you like to receive a summary of the results of this research project on tuberculosis? YES NO

VITA

Angelica Forero-Quintana was born in Bogotá, Colombia. Angelica has resided in the United States of America for seven years. Angelica has a Bachelor of Arts degree in Sociology from the University of Texas at El Paso. Angelica serves on the Border Health Association Committee, which is an organization that raises awareness about tuberculosis on the US-México border.

Permanent address: 298 Webb Rd
Clint, Texas 79836

This thesis was typed by Angelica Forero-Quintana.