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

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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 Matthew Quintana, who has been my inspiration, and my source of strength in this thesis. To all, Thank You.

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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.

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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 Calemete-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.,