



**Two Case Studies in El Paso, Texas, and Ciudad Juárez, Mexico**

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# Tuberculosis and Stigma: Two Case Studies in El Paso, Texas, and Ciudad Juárez, México

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Eva M. Moya and Mark Lusk

## Tuberculosis in the Context of the United States and Mexico

Tuberculosis (TB) continues to be a major cause of morbidity, mortality, and disability globally. Until 50 years ago, there were no medicines known to cure TB. Fortunately, there *are* efficacious bio-medical treatment options available today, though some strains of TB have become resistant to anti-TB medication and may require more expensive and more extensive treatment options (e.g., chemotherapy, “second-line” drugs). Each year, nearly nine million people around the world become sick with TB. There are approximately two million TB-related deaths world-wide every year, and TB is the leading killer of people who are HIV-infected (WHO, 2007). Despite pharmaceutical advancements, however, tuberculosis is still one of the world’s deadliest infections. In 2007, there were 14,424,343 people living with tuberculosis globally (Kaiser Family Foundation, 2008). One third of the world’s population is infected with the bacilli.

In Mexico, every day there are 54 new tuberculosis cases, and every six hours a person dies from tuberculosis (Plataforma Unica: Modulo de Tuberculosis SSA, 2007). Tuberculosis continues to disproportionately affect those communities and individuals that are most vulnerable (e.g., poor, underserved, malnourished, HIV/AIDS, diabetics). The national TB rate for Mexico in 2007 was 21 per 100,000 (Kaiser Family Foundation, 2008), which is over five times the rate in the United States. Each of the six Mexico states that border the United States has higher TB rates than the national TB rate, and combined they represented 31% of the total cases for the country in 2007, with the border municipalities of the states of Baja California, Tamaulipas, and Chihuahua having the largest concentration of tuberculosis cases.

According to the Centers for Disease Control and Prevention (CDC), in 2007 in the United States a total of 13,293 tuberculosis cases were reported, and the TB rate declined 4.2% from 2006 to 4.4 cases per 100,000 (CDC MMWR, 2008). The national TB incidence rate in 2007 was the lowest since national reporting began in 1953. Despite this improvement, foreign-born persons and racial and ethnic minorities continue to bear a disproportionate burden of the disease in the United States. TB rates among Hispanics, primarily Mexican-origin individuals, blacks and Asians were 7.8, 8.3 and 22.9 times higher than among non-Hispanic whites respectively in 2007 (CDC MMWR, 2008).

## La Frontera - Border Region

The United States-Mexico Border region has been thought to be a high risk environment for tuberculosis and other health risks due, among other factors, to socioeconomic stress, rapid and dynamic population growth, the interrelationship of cultures (Finch, Hummer, Kolody, and Vega, 2001), and a young population (Harrison and Kennedy, 1994; USMBHC, 2003). Studies of public health in the U.S.-Mexico Border region (Maxwell, 2006; Firestone Cruz et al., 2006; and Ramos et al., 2007) point to serious health disparities, for example, access to health care, low insurance coverage, socioeconomic disadvantages, and high rates of tuberculosis, HIV, and chronic diseases. Thus the U.S.-Mexico Border area represents a natural learning laboratory for other areas of the country and the world experiencing high rates of Mexican-origin immigrants as well as other countries experiencing rapid economic and social change on their borders.

El Paso, Texas, and Ciudad Juarez, Mexico, is a metropolitan community of about 2.5 million

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residents. This border and bi-national community is situated at the midpoint of the 2000-mile U.S.-Mexico Border, a dynamic, growing, and on the Mexican side of the border highly militarized region. This area is characterized by specific socioeconomic and environmental characteristics that complicate the ability to address public and environmental health problems like tuberculosis. Ciudad Juarez is the fifth largest city in Mexico, according to the 2006-2007 Ciudad Juarez Strategic Plan, and is one of the most densely populated and highly industrialized cities in Mexico (De Heer, Moya, and Lacon, 2008). It is also one of the most (if not *the* most) militarized cities in Mexico given the most recent wave of organized crime. In El Paso, Texas, almost half of the Hispanics reported not having health insurance (De Heer, et al., 2008). In El Paso the unemployment rates are twice the state and national average and per capita income is two times lower than the national average, further complicating TB detection and treatment.

### **Tuberculosis Related Stigma**

Stigma associated with tuberculosis has been identified as a major barrier to health care and quality of life in tuberculosis management (Deacon, 2006; Macq, 2007; ACMS Stop TB Partnership, 2007; Jaramillo, 2002; Van Rie et al., 2008; Weiss & Ramakrishna, 2001; Karim et al., 2007; Heijnders et al., 2006; Somma et al., 2008; Macq et al., 2006; Westaway, 1989; Barnhoorn & Adriaanse 1992). A generally accepted theory on stigma (Goffman 1963) defines it as a “deeply discrediting” attribute that is applied by society and borne or possessed by groups and individuals. At present, there is no comprehensive theory applied to health-related stigma -- one that starts with a logical definition of stigma that embraces both the complex intervention of individual and social dimensions of this phenomenon (Deacon, 2006). Also research on the positive impacts of stigma is very scarce (Shih, 2004).

Several studies (Kelly 1999, Van Rie et al. 2008; Armijos et al. 2008) indicate that individuals diagnosed with tuberculosis who undergo a traditional medical model were frequently perceived as disease vectors, and after the diagnosis nearly all

patients felt that their family and friends avoided and stigmatized them.

Understanding how individuals affected by tuberculosis and stigma are influenced by what family, friends, and other member of their social networks tell them about the disease and its treatment is important. Understanding these influences can provide vital insights into how tuberculosis is experienced.

Studies in stigma indicate that it deters people from seeking diagnosis and care, and that women bear the highest burden of stigma-avoiding behaviors (ACMS Framework for Action 2006-2015, 2007; Heijnders & Van der Meij, 2006).

Stigma and discrimination are drawn by multiple forces, including lack of understanding of the disease, myths about how tuberculosis is transmitted, prejudice, lack of access to services, irresponsible media reporting, and the link between HIV/AIDS and TB, as well as fear of relating the illness to disability and death (Parker & Aggleton, 2003; Link & Phelan, 2001; Kidd & Clay, 2003).

Tuberculosis fits the profile that carries a high level of stigmatization (Herek, 1999; Macq, 2007). People infected with tuberculosis are often blamed for their condition (Stop TB Partnership, 2004; Macq, 2007; Kelly, 1999; Armijos et al., 2008). Although TB is treatable and curable it is nevertheless progressive. TB transmission is poorly understood by the general public. Although the asymptomatic nature of TB means that it can often be concealed, but the symptoms of TB illness cannot. Symptoms may be considered disruptive to social interactions, repulsive, and ugly (Herek, 1999). If the person with tuberculosis is living with HIV/AIDS, or is a substance user and a member of a minority, then the level of stigmatization is even more significant (Herek, 1999; ACMS Stop TB Partnership, 2007).

Stigma is harmful to the individuals, creating feelings of shame, isolation, and guilt. In addition, negative thoughts can lead individuals to do things or omit to do things that harm or discredit others infected with tuberculosis or even deny services to (i.e., discriminate against) them (Alvarez-Gordillo et al., 2003; Lawn, 2000).

Research on the causes and sustainability of stigma is needed to guide public health interven-

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tions to reduce its effects. A working definition of stigma is also needed that identifies the nature of stigma in specific health conditions in order to guide intervention programs.

The following two cases are part of a doctoral qualitative exploratory study conducted by Moya on ten adult individuals that were affected by tuberculosis and who TB Photovoice<sup>1</sup> (Wang, 1997 & 2004; De Heer, Moya and Lacson, 2008) participants in 2006-2007. Participants were interviewed to elicit their perceptions on tuberculosis, TB-related stigma, positive and negative impacts of stigma, and the impacts of the Photovoice method on the individuals. The interviews elicited the subject's experiences, representations, and perceptions of tuberculosis and TB-related stigma.

Interviewees agreed to voluntarily participate, and interviews were conducted in either English or Spanish. The interviews took place at either a health clinic or TB program office. A gift card of \$25.00 dollars or the equivalent in Mexican pesos was presented as an incentive to interviewees who participated in the in-depth interviews. A bilingual semi-structured guide with both closed and open-ended questions was used for the interview. An informed consent was completed prior to the interview.

### **Case Study: Patient Zero**

Rita (not her real name) is a 41-year-old, single Mexican American with no children who has never been married. As is not uncommon in the border region, she lives with her parents and other members of her extended family. She is a college graduate and is a school teacher. Her home is in the lower valley region of greater El Paso, an area that is primarily low income and predominantly Mexican American. This small town, located 20 miles east of downtown El Paso, has a median age of 22.1 years, well below the Texas median age of 32.3 years (U.S. Census, 2009). The average annual household income in her community is \$24,473, while U.S. median household income is \$50,233. Her town is 99.5% Hispanic; 42% of its residents were born in Mexico (U.S. Census Bureau, 2009).

Rita was born in Ciudad Juarez, Mexico, across the Rio Grande from El Paso, and moved with her

parents to the *Segundo Barrio* (Second Ward) district of south El Paso at the age of four. Her family moved to the United States to improve their economic situation and was eventually able to obtain legal status. Shortly after moving to the *Segundo Barrio* their rental unit was condemned and so they moved to a *colonia*<sup>2</sup> in the lower valley where her father built a modest home. Rita has always lived with her parents in their home.

Seven years ago, after feeling ill for some time, Rita was diagnosed with Type II diabetes. Uninsured, she sought medical care in local free clinics and went to doctor's offices in Mexico during her frequent trips over the border.

Yes, Type II, and then I went through a lot of ups and downs with medications so I was going to the clinic very often and finally they hit upon a pretty good dosage and I was managing it well, then I started getting the coughing and wheezing and started the weight loss which to my doctors was good, "you're following the regimen, you're getting your act together, you're realizing that you need to lose weight" (for diabetes) so losing weight was good, but they first thought it was my allergies that were aggravated, then they diagnosed me with a lot of other things like infections. I had laryngitis. In the beginning of the fall I would get really bad sore throat which they thought might be strep and then laryngitis when the winter set in and then after the second winter I had that, things would get alleviated when the spring came around. But after the second winter, I had these symptoms and they thought it was asthma so they started me on asthma medication and it helped a little bit with the coughing and the sore throat, but I still felt really bad breathing.

Rita visited community clinics on an average of once every two months for four years where she was variously diagnosed with asthma, respiratory infections, sore throats, acid reflux disease (because of night-time coughing) and other misdiagnoses. Rita had informed her doctors that she had relatives who had been treated for tuberculo-

sis, yet only after four years did a physician order a chest x-ray. Her x-ray technician told her it looked “pretty bad.” She relayed to him that she had all of the major symptoms of TB for years yet none of her physicians had tested her for TB until she herself suggested it. Three physicians examined the x-ray films and told her she might have non-tubercular micro-bacteria or a fungal infection of the lungs. Finally, a sputum test confirmed a diagnosis that had gone undetected for years. In the meantime, Rita had been administered multiple short courses of antibiotics, including an antibiotic for drug resistant TB, thereby precisely endangering her to a drug resistant TB, which fortunately, she did not develop.

Once properly diagnosed, Rita visited a clinic that treats TB. She met a compassionate nurse who encouraged her, saying that she would be disease free in six months if she followed their treatment plan. In a warm and positive interaction this nurse explained that her immediate relatives would need to be tested. She then waited in the lobby. What happened next is quite striking:

And then I hear from the back of the office, somebody real loud saying, “Where’s this person, where’s this patient?” And I looked around and I was the only one in the lobby, and I said “Oh God, I hope she doesn’t mean me.” I hope not, because she was very upset, very loud, and mad. And she said, “You can’t leave this patient in here without a face mask! She’s supposed to cover up. We just got the positive diagnosis. She’s got to have a face mask on!” The other nurse said “I don’t believe you know which patient you’re talking about, but please let’s go in the back and talk about it.” So she closed the door to her office and I could hear raised voices. I couldn’t make out everything that was being said, but again, something about a face mask and you can’t have her interacting with people without a face mask. I found out it was the manager of the TB clinic. And then my angel of a nurse came to me and said, “Rita, would you please come to the back part of the clinic” and my heart fell ‘cause I thought “It is me who they’re talking about.” It was me, the manager was talking about, and that was my

first moment where I felt discriminated against, where **I felt like a thing rather than a person**, because I was being treated as something that couldn’t and shouldn’t be with the rest of the people.

Rita goes on to explain:

And so my nurse took me back and she said, “Please have a seat here and don’t worry about anything. Any patient that’s been confirmed with a diagnosis of TB has to wear the face mask. So please don’t feel bad. Don’t worry because it’s not only for our protection but for yours as well.” She stayed a while until I calmed down because by then I was very teary eyed. I didn’t say anything, the tears kept flowing. She gave me a big hug and said, “I’ll be right back with a face mask.” I stayed there for a while. I don’t know if she was getting yelled at.... And in the meantime I looked around and there were boxes of things -- old furniture and **I said, “This is probably the storage room. It’s probably where the undesirable ones...** (weeps)...and so that was a really hard day.”

Initially, Rita did not tell her family that she had TB, but finally, when she had the courage, she told them and said that they would also have to be tested. Her mother replied, “No, no *mija*, (*daughter*) it can’t be TB. No, I know people with TB. They’re real thin and they’re coughing up blood and oh, it can’t be TB. They got it wrong.” In their minds, this was a disease of the slums, and a professional teacher could not possibly have it. Her relatives were tested; six of them were positive for tuberculosis, leading to treatment. Her guilt over this was enormous.

I started feeling guilty about my family then and it multiplied when I got a lot of kids that I came in contact with (at school) for two years by that time and I did give them a lot of information as to which schools and what classrooms I subbed more often and which if any of them were very closed spaces. I said, ‘how many of those kids that they will be testing will come back positive? And I asked them and of course they would not tell me, but I found out later that at least two

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were put on medication from one of the schools where I taught, yes.

Rita's little niece was among the ones who were required to take treatment for latent TB. The little girl had also had two surgeries on her feet for recurring cysts. Scheduled to go in yet again for surgery, Rita asked her physicians to culture the cyst for TB.

The surgeon that was going to perform the operation, she just looked at us as if we were crazy. TB is in the lungs. TB has nothing to do with her foot. They went ahead with the surgery and did a culture and it came out positive for TB.

Rita goes on to explain:

I was dealing with my family and seeing how hard it was for everybody and then they started talking to me about other possible contacts and I just kept thinking, the school children. It's really hard because they don't understand what's going on, they hate medication no matter how sugary you might make it, and seeing my niece kick and scream every day so that I could give her a little syringe and medication, I just kept thinking, "God I hope those students first of all, never find out where they got it. . . . I felt so guilty." And then I hope they don't have any bad side effects. . . . I kept praying for them. And that goes to a lot of the stigma that I was feeling. And I remember the first time I went to the TB Voices and Images orientation (A Photovoice Project). I feel like **patient zero**. At the center this epidemic, I've caused so much, I've complicated people's lives so much.

Rita underwent TB treatment for the next nine months. For the first three months, she wore a mask and was under house and clinic quarantine, an experience she remembers as isolating and stigmatizing. Her own relatives, hearing of her illness, stopped visiting. She said she experienced avoidance and rejection from those closest to her. Her mother told her to hide her illness from everyone. Even though there had been others in her family who had been ill with TB, she was admonished to be quiet. This led to a "culture of silence."

Once she recovered and was able to return to work as a teacher she learned that her co-workers

had been tested for TB. Rita's clinician told her not to inform her co-workers as they "were very negative about having to be tested." In her school and at the local community center, numerous individuals had to be tested for latent or active TB. Some who tested positive for latent TB refused to be treated.

There was very negative reaction, especially from older people. They wanted to know why they were being targeted, because they were Hispanic. "You think we're dirty, you think since we're immigrants and that's why you want to point us out as having TB."

That was the community sentiment. And when they were tested they were adamant. "Okay so who's got it? Why do we need to do this? Isn't TB something of the past? Only this type of people, we don't hang around drug users. We don't hang around with these types of people. So who has it and who doesn't?"

Under such circumstances, Rita chose not to disclose that she had been the person with tuberculosis.

Rita joined a group of people who had lived with and recovered from tuberculosis. The group, called Voices and Images of TB, used the Photovoice method. Group participants received an orientation and training on the use of a camera. Participants affected by tuberculosis took photographs of how they view their lives and their condition. They participated in facilitated discussions. These discussions helped participants understand and reflect on the subjective aspects of the disease and how it had affected their lives.<sup>3</sup> In 2008, the first article on the El Paso-Ciudad Juarez Bi-national TB Photovoice Project was published (De Heer, Moya, and Lacson). It was in this group setting that Rita came to understand her experience in greater depth. It was difficult for her at first, "I had never thought of capturing my TB experience as something worthwhile. Why invite somebody into this horrible ordeal?"

As a novice in the group and still under quarantine, Rita wore a face mask, which to her was a symbol of otherness and what she described as "worthlessness" – like "*caca en la esquina*" (sh\*t on the street corner). It was difficult under such

circumstances to open up.

Sharing my feelings...because like I said, I didn't feel I had anything useful to say because I was feeling so guilty about infecting people. That's the way I felt, infecting so many people in my immediate family. I felt, because I was in such a low mood, that **I was afraid of infecting people with my depression too**. I felt, God, if I let all of this out, people, I'm just going to get people down or bring them back..... most people that have gone through the TB experience don't want to talk about it because it's like they did their time in prison.

With time, Rita came to grips with the illness and its sequel – the depression, stigma, rejection, and guilt of having infected others. She accomplished this through the Photovoice group, which she saw as a form of therapy. After becoming symptom-free, she began to work as a community activist on behalf of people with TB, and worked to educate the public about the disease and the unnecessary stigma that accompanies it.

Qualitative analysis of her case reveals several important themes in understanding serious infectious disease that ranged from the personal history with tuberculosis, social norms and values, and the emotional aspects of the disease.

#### Emerging Themes:

- **Guilt** - over possibly infecting her students and guilt over complicating other people's lives – “*I am patient zero in my own epidemic.*”<sup>4</sup>
- **Avoidance** – her own relatives stopped visiting.
- **Outcast** - to the storage room with other undesirable objects, masked like an outcast. **Culture of Silence** – her mother told her to hide the illness even though many of her relatives had had active TB.
- **Rejection** – her clinician told her not to inform her co-workers as they were very negative about having had to be tested. Some co-workers suggested that they were being tested because of racism toward Mexican Americans who might have this “dirty disease.”
- **Disbelief** - by doctors at the suggestion that the

MD test a cyst on her niece's foot for TB, when in fact that is what it proved to be.

- **Stigma** - wearing the mask is like being “*caca en la esquina*” (sh\*t on the street corner).
- **Isolation** - when invited into a Photo Voice support group, she asked “Why would I invite someone inside of this horrible ordeal?” “Most people who have had TB don't want to talk about it because they have already served their time in prison and don't want to relive it.”
- **Misdiagnoses** – she was misdiagnosed multiple times and treated for various conditions, which delayed the diagnoses for tuberculosis.
- **Fear** - Patient Zero – “*I was also afraid of infecting others with my depression.*”
- **Co-infection** – “TB does not live alone.” It co-occurs with diabetes, HIV/AIDS, alcoholism, and depression.

#### Case Study – Down and Out in Ciudad Juárez, Mexico

Laura (not her real name) is a 42-year-old Mexican citizen who resides in Ciudad Juarez, a city of 1.5 million inhabitants on the U.S. border with El Paso. She is married and has three children, one boy and two girls. Two of her children are grown up. They continue to live with her. Both have children of their own and they also live with Laura. Her youngest daughter is in 5<sup>th</sup> grade. They live in a modest three-room home which she inherited from her deceased parent. Her children work and they help her financially to cover the primary household expenses. She does on and off housekeeping jobs to supplement the income. Her husband has diabetes and was recently hospitalized for a severe episode of hypertension and kidney failure. He was treated in El Paso and recovered. He is in his early 50's and lives in Brownsville, Texas, where he is temporarily employed doing housekeeping and maintenance work. They are separated. Laura plans to move to Brownsville and live with him as soon as he is able to send financial resources to travel, and she plans to take her youngest child with her. Laura has never resided in the United States, but she crosses over a few times a month. She has completed sixth grade

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and is a homemaker who presently has no outside employment. Laura began to have symptoms of tuberculosis sixteen years ago. She was working two jobs at the time: during the daytime she was a seamstress and her second job was as in a twin plant or maquiladora, which she describes as a big *galeron* or warehouse. The *galeron* had neither heat nor windows. She began to suffer from a serious cough during the winter months. Since she worked all day and into the evening, it was difficult for her to see a doctor. When she got up in the morning, she had severe coughing fits. She endured this cough for over six months without medical attention. When her coughing became constant, she went to see a physician at the *Seguro Social clinic*.

Porque ya pues era imposible vivir así, en cuanto me levantaba, en la noche caía rendida porque me cansaba mucho, entonces en cuanto ponía un pie que me levantaba de la cama empezaba la tos y la tos y la tos. (Because, well, it was impossible to live like that, insofar as when I got up, and when I laid down exhausted, when I tried to get up from bed, I just coughed and coughed and coughed).

Laura continued to go to work while very sick. “I arrived at work in a bad mood and tired. I never felt feverish, but I always felt so tired.”

When she was seen by a physician at one of the *Seguro Social clinics*, she tested positive for TB and began a six-month course of treatment. Interestingly, the medical staff did not ask about her work or her surroundings at home – whether she was potentially infecting co-workers or family. The doctor who diagnosed her said, “You have tuberculosis, thank me because I just saved your life.” She thanked him. He went on to say, “You are going to have to get treatment. I am not going to give it to you.... You need to go to *Medicina Preventiva* (Preventive Medicine Department). I can’t touch you now; down there they will take care of all of that.” She said she was shamed by this remark. She understood nothing about the disease and was told nothing. She did not know if she got it because she was undernourished, because she worked so hard, or perhaps because her mother

had had it. She was not told how to take precautions.

After six months of coming in to get her medicine, she was symptom free. She felt pleased that she had regained some weight and was no longer coughing. She indicated that she was ashamed to have TB. For the six months of treatment, she stayed away from people and stayed at home as much as possible. She indicated that she did not feel so much rejected by others as she was rejected by herself. For example, she was at the hospital and had her chest x-rays in her hands and she saw someone she knew who asked her if they were her x-rays. She said, “No, they are my mother’s.” Laura said she did so from shame and fear. She was afraid not only of rejection, or how her friend might react, but was also wary that the gossip would get back to co-workers.

She stayed at home with her kids and relatives. Her mother helped with the children because Laura was irritable with her cough. She was in close proximity to her children, aged five and three at the time, and had never been told by health workers not to be in such close contact while her illness was active and contagious. Her relatives who visited, unaware of her disease, treated her as usual. She, herself, was unaware of the risks she posed to them. Later, when she came to learn more about the disease, she was mortified at her situation. Incredibly, the health care workers, upon learning of her diagnosis, did not test her children or immediate family. They did not teach Laura about the disease from which she suffered. There was no medical intervention or education beyond her individual anti-bacterial treatment; instead, she was furloughed from work for six months.

Laura’s mother, father, and niece had also had TB, but she was unsure how she had become sick, “perhaps because we were so poorly nourished.” She remembered her mother coughing up blood and remembered being told not to get too close to her mother, but she understood nothing about the disease. Her mother was sick when Laura was 14. Her father became ill when Laura was 26. More recently, her niece had contracted TB. Initially, her niece refused treatment and said she was going to go ahead and die from the disease.

Laura urged her to take the injections and to swallow all the pills that her niece protested, saying that your family is worrying about you and depending on you to take your medication. All of them eventually underwent treatment and recovered, yet none of them was counseled on how to avoid spreading the illness.

Upon completion of her treatment and at the end of her furlough, Laura decided not to return to work. She said she felt shame and was afraid that her employer would learn about her former illness and would not allow her to work there. Fearful of rejection, she did not seek work elsewhere. She describes stigma as: "*Que no se dice, que no se habla, se tiene como en secreto.*" (That which remains unspoken, about which nothing is said, and which is held in secret.)

*Por eso también cuando a uno le dicen que tiene esta enfermedad uno piensa que es muy fea, que es de lo peor, que, que yo si pensaba que me iba a morir, y así me lo dijo, así me dijo mi sobrina cuando se lo diagnosticaron.* (And also when they tell you that you have this disease, one thinks that it is very ugly, and I thought that I was going to die. That is what my little cousin said when she was diagnosed.)

*Que ya para que, que si ya se iba a morir, (llora...) de la gente, y ya ve que uno a veces pos hace, hace bromas y pos uno si las toma muy a pecho, cualquier cosa que, que le dicen a uno y ella, me decía mi hermana que ya no quería que nadie se arrimara con ella porque ella tenía el virus, y que tiene un sobrinito chiquito y no quería ni agarrar al sobrino ni o sea que y se la pasaba llorando, me hablo mi hermana llorando para decirme eso.* (And for what, if she was going to have to die (weeps) ...the people who at times, well, make fun of you and you take it to heart, whatever things they say about you. My sister said she did not want to get close to her and hold her (her daughter) because she had the sickness and that she has a little nephew and she did not want to hold him or what not and she cried about it, my sister cried when she told me

this).

Laura felt that upon being diagnosed with TB, she had been "banished." To reduce her sense of being cast out, she kept her diagnosis a strict secret known only to immediate family and health-care workers. In time, she became aware of the Voices and Images of TB Project and there was able to meet with other individuals affected by TB. Her sense of isolation and shame declined.

*Pues aprendí a que... que no tenemos por qué avergonzarnos, avergonzarnos de eso, porque pues a cualquier persona le puede pasar ya sea rico o pobres, sucio o limpio, eso no es por... por falta de higiene o por falta de dinero, porque pos ta' uno... vive uno humildemente, tal vez yo pienso que por el rico lo puede tener por exceso de trabajo, porque él lo que quiere es tener más dinero, el pobre por falta de comida porque pos a veces no nos alcanza para... para darnos una alimentación sana, y pues nada a todos nos puede suceder."* (Well I learned that we did not have to be ashamed, ashamed about it because anybody can get it, rich or poor, clean or dirty, it's not a lack of hygiene or a lack of money, because, well...one lives humbly, I think that perhaps the rich get it because they might work to excess because they want more money, but the poor perhaps for lack of food because at times, it's out of reach...to eat healthily, but then anyone can get it.)

After Laura joined the TB Photovoice Project, she learned for the first time about tuberculosis as a disease and as a social process. At last, she more or less understood how the disease is transmitted, treated, and controlled. She was able to talk about her experience with other people who had been through TB. With a renewed outlook, she was able to reconnect with her estranged spouse and will soon be moving to the United States to join him.

Qualitative analysis of her case reveals several important themes in understanding this disease and its social sequel.

## Tuberculosis and Stigma

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### Emerging themes:

- **Secrecy** – She was unable to tell anyone about her illness for fear of rejection and retaliation.
- **Banishment** – Not only did she feel like an exile, she acted like one, choosing to close herself off from society, work, and friends.
- **Shame** – Her view was that this was a dirty disease caused by poor sanitation, poverty, and malnutrition.
- **Rejection** – Her physician condescendingly told her to thank him for saving her life, and then sent her to Preventative Treatment saying, “I can’t touch you anymore.”
- **Death** – Her niece, who also got TB, said she would rather die than take all those pills and shots and be faced with this dirty disease.
- **Malpractice** – Her health care providers did not test her family members or co-workers and did not teach her how the disease is transmitted.
- **Isolation** – She lived without any social support beyond her immediate family, was unemployed, separated from her spouse, and cut off from friends and daily social discourse.
- **Poverty** – Unable and unwilling to work because of her disease, she fell deep into poverty. Without an income she relied on her family and scraped by -- cold, malnourished, and profoundly ill.

### Conclusion

These two cases illustrate the social implications of tuberculosis in a low-income border region. Like dozens of other people we have interviewed, these two women have paid an enormous personal price for having encountered this infection. It has led to job loss, isolation, rejection, and the burning sting of stigma. The stories also illustrate the positive impacts that the TB Photovoice project had on them personally. However, most persons with TB are rejected by society, and unfortunately tuberculosis continues to be associated with lack of hygiene. It reminds one of biblical tales of leprosy.

It is not enough to eliminate the tuberculosis

bacteria that cause the disease to cure tuberculosis. When addressing TB, health and human service professionals and workers need to deal with the special challenges the disease presents, such as diabetes, HIV/AIDS, and the needs of mobile and migrant populations. The involvement of people with TB -- families and communities -- can potentially increase the social ownership and provide a stronger basis for advocacy for improved TB services on both sides of the U.S.-Mexico Border. In addition the involvement of people with TB and communities should complement high quality services. Raising awareness and educating community members about tuberculosis are fundamental for changing behavior. Stigma is often a problem; therefore, effective communication that starts with personal communication between the health workers and the people with TB, their families, and local communities helps build a supportive environment for people who feel ill and may have tuberculosis. Communication and education interventions to mitigate stigma and discrimination among people at risk for TB can play a major role in the battle against tuberculosis.

The experience of these women and their participation in the TB Photovoice Project provide evidence for the effectiveness of communication and education strategies that put a “human face and voice to a health problem.” The empowering experiences of these women are inspirational. More research is needed that focuses on identifying those factors which contribute to the harmful effects that stigma has on the lives of TB sufferers, as well as on the factors that individuals use to overcome the harmful consequences of stigmatization. We need to study and adopt new approaches to gain a fuller understanding of the experiences of being stigmatized. We must help heal the wounded souls of those who have faced the disastrous social and psychological consequences of this disease.

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#### Footnotes

1. Photovoice is a participatory research, arts, and social action strategy in which participants use the photographic medium as a way to find greater meaning of their experience of a personal and community challenge (e.g., as a person with TB, homeless, refugee, etc.). It facilitates dialogue and can be an important mechanism for informing policy makers.
2. Colonias are unincorporated border communities that do not have adequate water and sewer systems and other infrastructure.
3. In epidemiology, *patient zero* is the individual who is believed to be the first person in an epidemic to be infected. In her case, she is using it as a metaphor.
4. *Seguro Social* (Social Security) is the public Mexican health care and retirement system for workers.

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