

End of Year Project Report

# Trans-border Research on Stigma and Treatment Adherence in Tuberculosis

Tuberculosis is lurking around.- Miguel, Photovoice Participant

Por un mundo  
sin tuberculosis



For our voice.- Hilda, Photovoice Participant

If you have tuberculosis, Don't stop your treatment.- Lore, Photovoice Participant

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**Nuestra Casa Project: A Three Dimensional Exhibit on Tuberculosis  
The University of Texas at El Paso  
October 2009**

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## 2. Executive Summary

This end of year report presents the implementation and accomplishments of the first border binational Pilot Study on Tuberculosis (TB) and HIV/AIDS Stigma in Ciudad Juárez, México and El Paso, Texas, funded by the Programa de Investigación en Migración y Salud in January 21, 2009 to the University of Texas at El Paso (UTEP) College of Health Sciences.

This project conducted a study of tuberculosis and TB-related stigma in Ciudad Juárez, México, and El Paso, Texas and examined the experiences and perspectives on TB from the vantage point of the Persons Affected by Tuberculosis (PATB). Research on the causes and impacts of stigma will be useful to guide programs, social interventions, research and policy that reduce its effects. Of significance is the focus on the behavioral, psychological as well as in the social context and dimensions of TB-related stigma in a border binational region. TB is a stigmatized disease that causes discrimination against the person who suffers from what affects the disease's development, but has not yet been studied sufficiently (Moya, 2010). This study helps to close a gap in the literature.

The project reports on the triangulation of data from three different and complementary studies using corresponding methods of data collection and is organized into three distinct sections: (1) In-depth interviews with Persons Affected by TB and in treatment for TB using a bilingual semi-structured interview guide, (2) Focus groups with family members of Persons Affected with TB, and (3) Implementation of the Photovoice method.

**In depth interviews** were conducted to study TB-related stigma and the impact on access and health-seeking behaviors for TB in 30 Mexican-origin adults (18 years and older) in Ciudad Juárez, México, and El Paso, Texas undergoing TB treatment at a health center. The interviews

gathered first-hand experiences and perspectives on the impact of TB and TB-related stigma.

Two focus **groups were conducted** - one with parents and one with family members of Persons Affected with TB. The first group consisted of eight participants. The second group consisted of six participants and partners of persons affected by tuberculosis. The focus groups gathered information from the perspectives of relatives and caregivers on the impact of TB. **Photovoice method** (referred in this document as Voices and Images of TB) is a method research, in which photographs are used to

encourage individuals to talk about and reflect upon their everyday health and life realities. The 'Voices and Images' method consists of empowering persons affected with TB to present their stories, securing public commitments from decision makers that will contribute to TB awareness and eradication, securing funding for existing prevention and control programs, and disseminating the findings.

The studies reported: (1) traditional beliefs and myths about tuberculosis TB symptoms, (2) issues of stigma associated with tuberculosis and HIV/AIDS, (3) reliable and popular sources of health information, and (4) views

regarding the barriers and facilitators to TB care.

The project concludes that TB continues in many respects to be a social illness that creates socioeconomic differentials and inequalities in the US, Mexico Border are strongly associated with its burden.

Study findings have implications for: (1) informing health services and decision makers about how persons of Mexican-origin affected with TB in the US, México border interpret their illness and stigma, (2) research on health related stigma and interventions, and (3) expanding and informing health-related theory on TB stigma and individual structural stigma reduction interventions. The findings provide the basis for the future development of individual and structural stigma reduction interventions among populations of Mexican-origin groups in order to ensure that persons affected by tuberculosis receive crucial preventive, diagnostic and treatment services that are free of stigma and discrimination beyond the border region.



"What are you doing to fight against tuberculosis I never thought I would be a victim of tuberculosis"

-Miguel

Careful! You Could Be Next- Miguel Photovoice Participant

### 3. Background

#### a.PIMSA funding

UTEP received the first PIMSA award in the 2008-cycle. The grant amount awarded was \$39,910.00. The awarded was made to the University of Texas El Paso and Universidad Autónoma de Ciudad Juárez. The project received technical support from Programa Compañeros A.C. in Ciudad Juárez, México and the Alliance of Border Collaboratives (ABC), formerly the U.S.-México Border Health Association in El Paso, Texas.

The Project received Institutional Review Board (IRB) approval from UTEP in January 2009. With the PIMSA funding, the project (1) hired bi-national and bilingual staff; (2) trained three interviewers; (3) conducted qualitative research and collected data in two locations; (4) transcribed all interview and focus groups findings; (5) translated project findings and informational materials; (6) formed two Photovoice groups and one binational advisory committee; (7) produced two TB Photovoice galleries; (8) published an article in a peer-reviewed journal on the perspectives of PATB in the border region; (9) presented the project findings to policy and decision makers at local, regional, national and international forums; and (10) institutionalized the use of the Photovoice method in the Health Jurisdiction of Ciudad Juárez, México and the El Paso Department of Public Health TB Program.

#### b.Collaborators

The University of Texas El Paso is a state university, and part of the University of Texas System. It is located on the northern bank of the Rio Grande in El Paso, Texas. UTEP is the largest university in the U.S. with a majority Mexican-American student population (about 75%). It is the only such university to be classified as "Research University with High Research Activity (RU/H) by the Carnegie Foundation.

The Autonomous University of Ciudad Juárez (Universidad Autónoma de Ciudad Juárez) is a public institution. The UACJ mission is to create, share, extend and disseminate knowledge; preserve and consolidate the values that strengthen the country's cultural identity, and the preservation of the environment. UACJ is recognized as Research Mexican Center by the National Council for Science and Technology.

The U.S.-México Border Health Association (now the Alliance of Border Collaboratives) was created under the direction of the Pan American Health Organization as a U.S. based non-profit corporation over 60 years ago. In January 2010, the USMBHA Board of directors decided to reorganize and close its operations. The Alliance of Border Collaboratives was thus created and incorporated to continue to provide training and technical assistance to community-based initiatives and networks.

Programa Compañeros A.C. is a nonprofit organization located in Ciudad Juárez, México with more than 20 years working with the people, it is a community based organization with the mission of participate and contribute in the movement toward a more equitable society that responds to the vulnerable population needs and promotes the participation of key social actors.

### 4.Introduction

Traditionally, tuberculosis is described as a disease process resulting from infection by bacterium (*Mycobacterium tuberculosis*). TB is also understood as a social illness that causes great suffering, a disease of "at-risk populations," and a sign of poverty and as a global pandemic. Tuberculosis is a medical and social condition that involves profound emotional experiences, narratives of illness, alienation from family members, isolation and stigmatization. Tuberculosis ravages interpersonal connections as much as a person's body. The subjective and interpersonal experience of tuberculosis illustrates that an infectious disease entails more than treatment involving medications, microbes, and risk categories (Kim, 2010). TB is responsible for the highest number of deaths in human populations produced by a single microbial pathogen (Barnes, 1995; WHO, 2005; PAHO, 2004). Worldwide, tuberculosis continues to be a major cause of morbidity, mortality, and disability.



I Thought It Was Impossible-Miguel, Photovoice Participant

"I thought was impossible to recover from tuberculosis. I felt I had to jump over an enormous obstacle like this wall. I did it thanks God and the medication. Today I am recovering."

-Miguel

Although México is not one of that 22 countries that account for 80% of cases of tuberculosis, and TB is not considered an epidemic in México, there are 17,000 new cases of the disease and 2000 deaths annually. The U.S-México Border states have double the TB incidence than the national average.

The border bi-national region of Ciudad Juárez, México, and El Paso, Texas is a large metropolitan area of 2.5 million in population. Ciudad Juárez and El Paso are closely linked by family ties, social and economic issues. That is why what happens in one of the cities affects the other and vice versa. Ciudad Juarez and El Paso have experienced rapid population growth, higher than the national average. The border is a region that attracts mobility and migration and in which there are insufficient infrastructure and public services. There has been an endemic lack of local capital resources to raise the competitiveness of enterprises and to improve living conditions.

From a public health perspective, the US-México Border region should be considered as one epidemiological unit. Ciudad Juárez, México has higher incidence than the national average of deaths from external causes, like violence. There is also a higher incidence of chronic degenerative diseases, a high risk for behavioral and emotional illness and limited psychological and social services. Ciudad Juárez ranks second among metropolitan areas of the country in drug use, with an increasing trend in the consumption of "hard drugs".

**Comparative Rates  
New Cases and Risk Factor for TB  
in Ciudad Juárez, México and El Paso, Texas**

El Paso, Texas-Ciudad Juárez, México TB rate (2008 & 2009)	
El Paso, Texas: <sup>2</sup> 5.4 and 8.9 per 100,000	Ciudad Juárez, México: <sup>1</sup> 13.5 and 13.3 per 100,000
New TB cases (2008 & 2009)	
El Paso <sup>2</sup> 40 and 67	Ciudad Juárez <sup>1</sup> 311 and 306t
Percentage of TB cases with risk factors, ages 18 years > (2009)	
El Paso: <sup>2</sup> foreign born 76.2%, alcohol use 35.5%, diabetes 15.2%, HIV/AIDS 11.8%, IVDU <sup>3</sup> 5% weight < 10%, 67.8%, NIDU <sup>4</sup> 20%	Ciudad Juárez: <sup>1</sup> diabetes 17%, alcohol use 5% HIV/AIDS 7%, malnutrition 11%, IVDU <sup>3</sup> 5%,

Note: patients can have multiple risk factors. <sup>1</sup>Plataforma única de tuberculosis, SSA. 10 de Enero de 2010  
<sup>2</sup> <http://www.dshs.state.tx.us/idcu/disease/tb/statistics/cunty.pdf> retrieved on April 10, 2010. <sup>3</sup> Intravenous Drug Use  
<sup>4</sup> Non- Intravenous Drug Use



Not to discrimination and Yes to support!  
-Ahinoam, Photovoice Participant

**5. Objectives**

**Primary objectives**

- To study the knowledge, attitudes and practices in TB among PATB in order to improve adherence to treatment of TB among mobile and trans border populations from El Paso, Texas, and Ciudad Juárez, México.
- To identify factors that enable and/or hinder care adherence.
- To implement the Voices and Images of TB methodology.
- To engage persons affected with TB in advocacy efforts to increase awareness and influence decision makers.

**Secondary objectives**

To conduct a trans-border bi-national study using three different participatory methodologies (1) To understand: the concepts of tuberculosis in the community; (2) the experiences and perspectives of PATB; (3) well as the stigma and discrimination that affect health outcomes in trans-border populations of Ciudad Juárez, México and El Paso, Texas.



Labyrinth-Ahinoman, Photovoice Participant

"This photograph reflects how I felt when I was sick with tuberculosis. It was like being in an alley with no way out. That's how I saw the illness. It terrified me to see the end. I couldn't find a door out. There were exits, but I didn't knock on any doors to ask for help. Now I feel capable of knocking on door and moving forward!"  
-Ahinoam

## 6. Methods

This is an exploratory pilot study. The study samples included Mexican-origin adults that cross the border between Ciudad Juárez, México and El Paso, Texas, and are affected with Tuberculosis and in treatment for TB or that completed TB treatment in the past six months. Three sub-studies were conducted:

- a) In-depth interviews using a semi-structured guide with PATB.
- b) Focus Groups with parents and relatives of PATB.
- c) Two Photovoice groups, one in Ciudad Juárez, and one in El Paso, Texas.

The study explored stigma-related to TB and factors affecting access and health-seeking behaviors for TB in El Paso and Ciudad Juarez. The value of these interviews and the Photovoice groups relies in their ability to demonstrate that some of the representations of TB need to be revised because they no longer apply, even though the ideas behind them are still present in how society views people with TB. The old labels are described in every interview conducted and are cited as the source of the stigma and discrimination.

“Even though tuberculosis is a curable disease, there are people that tend to say: Get away! This situation exist because we are not well informed about the disease and feel insecure.”  
-Miguel and Micaela



Rejection-Miguel and Micaela, Photovoice Participant

### a. In-depth interviews with PATB

This investigation used an exploratory qualitative design (in-depth interviews) to study TB-related stigma and the impact on access and health-seeking behaviors for TB in a criterion-sample of 30 Mexican-origin adults (18 years and older).

### Inclusion criteria

The inclusion criteria for participants consisted of individuals 18 years old or older, male or female, from Ciudad Juárez, México, and El Paso, Texas, of Mexican-origin in treatment for TB or who completed TB treatment in the two cities.

### Instrument

English and Spanish semi-structured guides were developed by the bi-national project research team and field tested at the project sites. The guides consisted of three sections. The first section explored general and socio-demographic characteristics. A second section focused on the knowledge, attitudes and practices associated with TB. The final section consisted of the administration of the TB and HIV/AIDS Subscales (Moya et al., 2010). Most questions elicited open-ended responses. The analysis is descriptive and qualitative.

### Interview locations

Interviews were conducted at either the El Paso TB Program Clinic or at Programa Compañeros, in Ciudad Juárez. One interview took place at the participant's home. The interviews ranged from 60 to 90 min. A single interview was done with each subject. All interviews were conducted in Spanish with the exception of one. Questions raised during the interpretative process were noted, described, discussed and transcribed.

### Data analysis

Descriptive analysis of study variables was conducted. Data analysis continued with searching for patterns in the data. Credibility of findings was attained through engagement and data triangulation. Prior to conducting the investigation, prolonged engagement and participation with the community and culture in El Paso, Texas, and Ciudad Juárez, México was done to minimize threats to the true value and contributed to accurate representation of the investigation findings within the cultural context.

Data was triangulated from the following sources: demographic data, participant interview and field notes. Interview transcripts were read multiple times by the investigator/PI's with experience in qualitative research.



We need health promoters-Jesús, Photovoice Participant

"I give my community information on tuberculosis: How to prevent it, how it can spread, and how to cure it."

-Jesús

## b. Focus groups

Focus group methodology is one of several tools that can use to generate valid information. This investigation used focus groups to examine feelings, knowledge, attitudes and perceptions of TB and TB-related stigma in persons that provide support to PATB.

## Inclusion criteria

The inclusion criteria consisted of individuals (e.g. parents, siblings and close relatives of PATB) 18 years old or older, male or female, from Ciudad Juárez, México, and El Paso, Texas, of Mexican-origin who provided support to the PATB. The first focus group consisted of parents and partners of persons affected by tuberculosis (n=8). The second group, consisted of relatives and supporting individuals of persons affected (n=6).

## Instrument

A discussion guide was developed by the project research team and field tested in Ciudad Juárez for each of the groups. The guides consisted of 15 questions organized in six topic clusters. The focus groups focused on the life experiences in accompanying a family member suffering with tuberculosis (TB).

The guide consisted of these themes:

- Feelings toward the PATB.
- Knowledge regarding TB.
- Attitudes associated with TB and PATB
- Perceptions on TB and TB-related stigma and discrimination
- Life experiences in accompanying a PATB
- Needs of PATB



Dawn-Jesús, Photovoice Participant

"A new day of hope. One more day to give thanks to God. I think in a positive way to go on with my life.

When I was sick, I felt in the dark.

Now, I see the light, and I am beating tuberculosis."

-Jesús

## Interview locations

The focus groups took place in Ciudad Juárez at the Centros Ambulatorios de Prevención y Atención en SIDA e Infecciones de Transmisión Sexual (CAPASITS). The focus groups ranged from 60 to 90 min. The discussions were digitally taped and later transcribed. The facilitator explained the methodology of the focus group and emphasizing the importance of the group's participation. The first group consisted of eight participants, six females and two males (ages 28-64). The second group consisted of five females and one male (ages 18-29).

## Data analysis

Data analysis started with searching for patterns in data. Focus groups transcripts were read multiple times by the investigators to capture the major elements and themes of the family member's understanding and perceptions of their experience with TB and a PATB. The results of the study are presented later in this document.

### c. Voices and Images of the TB Photovoice method

Photovoice is a technique where photographs are used to encourage individuals to talk about their everyday health, life, and work realities. Photovoice is meant to be a tool of empowerment enabling those with little money, power, or status to communicate to decision- and policy-makers. The technique is based on the understanding that if policies and decisions affecting the community are derived from the integration of local knowledge, skills, and resources within affected populations, the policies will

be more effective. The objective was to develop an understanding of the subjective experience of the participants of the TB Photovoice Project.

The first border TB Photovoice project was launched in 2006 in Ciudad Juárez, México, and El Paso, Texas with support from the Amaya-Lacson TB Photovoice Project. The findings from this project helped to inform the basis for the PIMSA Project proposal. The strategy aims to mobilize and empower participants, with the purpose of reaching

those in power to affect social change within the community.

Photovoice objectives are to: (1) empower persons affected by tuberculosis to present their stories, (2) secure public commitments from decision-makers that will contribute to TB awareness and eradication, (3) secure funding for existing TB prevention and control programs, and (4) disseminate participant messages about TB.



Alliance-Micaela, Photovoice Participant

"There are people that provide treatment and are concerned with the well being of the person with tuberculosis. They help us and encourage us to go on. As people affected by tuberculosis, we also have to do our part to heal ourselves."

-Micaela



Winter nights-Ahinoam, Photovoice Participant

"When I was going with my friend to work, I saw the plastic air figure that falls and stands up. That's how I felt when I had tuberculosis. When it was cold, the illness got worse, and I would end up in bed. I would take vitamins and antibiotics and I would get up again. But it wasn't enough, because I would end up falling once more."

-Ahinoam

#### Inclusion criteria

The project recruited nine individuals (18 years and older) affected with TB (in treatment for TB or that completed TB treatment in the past six months) in El Paso, Texas, and Ciudad Juárez, México.

#### Instrument

A bilingual TB Photovoice recruitment protocol was developed and field tested. The training was modeled after the TB Amaya-Lacson TB Photovoice Training curriculum. Photovoice consists of small group discussions of 6-8 individuals that meet the inclusion criteria. An average of seven sessions was facilitated with each group.

#### Interview locations

The primary area for conducting the Photovoice sessions were in the TB Program Clinic in El Paso, Texas or at Programa Compañeros, AC in Ciudad Juárez, México. An orientation on ethics was conducted with project participants. Informed consents were signed. Project participant took photos on a weekly basis. Weekly or bi-weekly meetings with participants were facilitated by an experienced professional to discuss the photographs and develop the stories. Selection of themes by participants followed. Two photographic galleries were developed and presented in various local and bi-national forums.

#### Data analysis

Analysis was conducted by reviewing the transcriptions of the group discussions and identifying patterns in the data. In addition, the participants selected the photographs that most accurately reflect their concerns and perspectives in TB and their communities. This was followed by contextualizing or telling stories about what the photographs meant to them. Issues and themes that emerged were identified. Participants finally grouped photographs and accompanying stories into categories. A copy of the Ciudad Juárez, México and El Paso, Texas Voices and Images galleries can be found in the report DVD.

The voices and images of TB themes were:

- Tuberculosis diagnosis
- TB-related stigma
- Discrimination
- Respect, love, and support for a Person Affected by Tuberculosis
- Dignity and determination
- Mitigating the negative impacts of tuberculosis



Voices and Images Advisory Committee Members

## Guidance committee

The establishment of an advisory or guidance committee is an essential step in the Photovoice process. This project recruited twelve decision makers and key stakeholders from the study locations. Members of the committee served as an ad hoc advisory board. The committee met on monthly bases and received a formal orientation of the project goals and a presentation of expected outcomes.

The committee members acted as 'gatekeepers' for the project, providing access to influential individuals and organizations. A work plan was developed and the committee members met 12 times and alternated meeting locations between Ciudad Juárez, México, and El Paso. The meetings were conducted in both Spanish and English to assure that everyone could participate in the discussions. The advisory committee decided

that they would meet in El Paso instead of Ciudad Juárez due to restrictions by the University of Texas System for travel to México due to the insecurity associated with organized crime and violence. Despite these challenges, the committee met on a regular base and advanced planning and implementation through virtual and telephone modes when necessary.

## 7. Results

### a. In-depth Interviews

#### Socio- demographics

Fifteen of the participants (50%) were living in Ciudad Juarez, Mexico at the time of the interview and the other half in El Paso, Texas. More than half (56%) were male and 44% females. The mean age was 40 years old; participants completed up to six years of formal education; and 43% were employed.

The majority of the participants identified barriers to accessing health care services when they needed medical care for their TB condition. One of the barriers was not having the financial means to pay for medical care and the lack of health insurance coverage. In El Paso, seven participants had some type of health insurance (e.g. Medicaid or Medicare). In Juárez, five participants had Seguro Popular - a publicly-funded health insurance program in Mexico - the other half of the respondents was uninsured.

### Tuberculosis diagnosis: Severe symptoms prompted treatment

More than half of the participants perceived their health status to be good (24) or fair (4). Participants described the problems and difficulties associated with tuberculosis prior to treatment as multiple and difficult. Interviewees referenced a myriad of TB symptoms like: productive cough, cough with phlegm, cough with blood, fever, weight loss, muscle aches, difficulty breathing, weakness and fatigue, and general aches and pains.

Courtesy of PAHO-WHO



Voices and Images of TB Gallery Exhibit at Mexican Consulate

Most of the participants reported that they experienced symptoms associated with TB for months (6-24 months) from the onset of the condition (TB) before they received treatment. Two respondents abandoned the initial TB treatment and developed multi-drug resistance TB (MDR).

Ten of the participants had or have a relative (in some cases more than one) with tuberculosis. In some cases, their relatives had

died from tuberculosis. All participants reported delays in seeking treatment for several months (up to 24 months) between the onset of the symptoms and the initiation of tuberculosis treatment in both study locations.

Most of the participants received some type of support during their treatment. Most received an explanation on how the TB treatment medications work. About half of

the respondents indicated that they received an explanation on the side effects of the TB medications and the other half did not. The majority of participants knew about the importance of adhering to treatment in order to cure the disease.

They also described their relationship with the TB health care workers as very good or excellent.

### Curability, adherence and severity of tuberculosis

Participants knew that tuberculosis was curable and cited taking medication (for TB) as prescribed by a physician and completing the treatment as the two requirements for cure. Two participants in Ciudad Juárez abandoned their first TB treatment. One received treatment without supervision through a public facility and another individual stopped the treatment when feeling better, which appears to be associated with the limited understanding of how the medication works and the length of treatment. In addition, two individuals developed MDR TB, which might be an indication of incorrect treatment or misdiagnosis.

Cost was identified as a factor in why some do not access health services when needed. Participants in Ciudad Juárez indicated that TB treatment was free of charge at the *Centros de Salud*. Participants in El Paso indicated that the TB treatment was free, however X-rays were not.

Some participants indicated that they heard their parents or grandparents talk about the severity of tuberculosis when they were growing up. Participants mentioned a couple of the Spanish terms used to refer to persons affected by TB as *"tuberculoso or*

*tisico"* and referred to isolation and fear of infection. These comments were not very different from those expressed by the participants now. Some of these comments included: avoid contact with a TB patient, children should not have contact with a

Person Affected with TB, do not share utensils or eat meals with persons with TB. Other participants had not heard about TB until they were diagnosed with the condition.

### Knowledge about tuberculosis

A majority of participants had heard 'something' about TB before being diagnosed, but were not aware of the magnitude of the condition until they began treatment. Ten of the participants had a family member (parent, sibling or other relative) who was treated for tuberculosis. Participants cited mass media (television) as the primary source of health information, followed by brochures



Get informed! - Humberto, Photovoice Participant

### Vulnerabilities and tuberculosis

The perceptions were mixed on how vulnerable and susceptible people were to get TB. Responses on who could get TB included: anyone (18), only drug users and alcohol drinkers (11), persons with other health conditions like diabetes or malnourishment (14), persons living with HIV/AIDS (4), children and seniors. The perception of risk of getting infected with TB before their diagnosis was low.



Childhood-Raúl, Photovoice Participant

### Reactions when diagnosed with tuberculosis

Reactions people had when diagnosed ranged with tuberculosis range from depression, sadness (over what would happen to them); doubt (about getting cured), anger (over how they were infected), and fear of rejection (spouse, family, peers and losing job). Some participants tried to hide the TB diagnosis from other persons (not their family). Some participants felt hurt when they were asked to sleep separately from their family during the illness. Others could not hold, hug or kiss their children. Some participants' lost earnings during their treatment and two lost their jobs. They were told they could no longer work because of their condition and the risk of infecting others.

## Attitudes about stigma

Attitudes about stigma and discrimination were explored by posing a series of open-ended questions followed by the administration of two validated sub scales consisting of 23 items (MOYA. ETAL, 2010). The participants answered questions in regard to the way that a person with tuberculosis is treated. Questions related to the way people with HIV/AIDS were treated were also included, since HIV/AIDS, as well as other conditions, are related to stigma and discrimination.

A majority of the subjects indicated that a person with TB experiences rejection and is feared as a source of infection. Respondents indicated that the social environment reacts negatively, especially when others fear that they could get infected. A selection of statements is included to elucidate how the participants responded to the open-ended questions. The majority of the participants (22) agreed that a person with tuberculosis is often treated by others differently, only a few of the interviewees (8) indicated that the society treats them normally or without stigmatization. The differences in treatment include: perceived rejection by family and/or society members (22) and fear of getting infected with TB (9). A number of participants indicated that a TB diagnosis carries social stigma. This triggers distress and can contribute to delays in access to treatment.



Phobias-Humberto, Photovoice Participant

## Experiences associated with stigma and discrimination

The stigmatization of TB seemed to continue to be associated with beliefs that TB is linked primarily with poverty, homeless, and addiction. The correlation of having TB with being dirty or filthy and the belief that TB is transmitted through casual and physical contact were cited as reasons why stigma continue to be so real. The majority of the participants (28) perceived experiences with stigmatization related to TB. Stigmatization was described in terms of discrimination from family (distancing), peers (afraid of visiting for fear of contagion), and work (losing job or feeling discriminated against); isolation

from loved ones (especially children and spouse); rejection by family members; perception that a person with TB is filthy or disgusting; and by the fear of infecting others.

Most participants indicated that a person with TB was treated differently and negatively by others. According to the participants, a diagnosis of TB carried negative connotations. More than half of the respondents indicated that they experienced rejection by others founded on lack of understanding of the nature of the disease or felt

isolated during treatment. More than half of the participants reported feeling useless. They also indicated that as a result of having tuberculosis, they felt rejection or lack of understanding or empathy from others. Some participants indicated that they became sad, depressed, humiliated or angry. Some participants indicated that during the time they were isolated or in quarantine, they felt lonely. They had few or no visitors, and the special measures taken to avoid contamination were difficult to live with, especially when they were asked to wear a

face mask. Terms used in Spanish to describe the face mask include "the mask" (la mascara), "muzzle" (el bozal), and "that thing" (esa cosa).

A number of participants indicated that stigmatization toward persons with TB also takes place through discrimination or rejection (primarily by family members), by labeling the person (referring to the person as disgusting, filthy) or through fear (of infection or getting infected or infecting others).

## Negative impacts of stigma

Respondents identified the following negative impacts of stigma related to tuberculosis: (1) low self-esteem and morale, (2) depression and sadness, (3) fear of casual transmission, (4) shame and guilt, and 5) negative emotions and feelings toward a person affected with TB.

The dimension of disclosure was important. Several of the participants were cautious about whom they disclosed their condition to for fear of being rejected or judged. Disclosure of condition was primarily done with immediate family members or very close friends. Participants indicated that lack of information leads to prejudice and fear and that it was not uncommon for uninformed persons to make quick judgments and display prejudices against people affected with TB. Near unanimously, interviewees stressed the importance of informing and educating the general public and their families in order to dispel myths and fears.

## Positive impacts of stigma related to tuberculosis

Most said that a disease like tuberculosis hurts both physically and emotionally, however, overcoming the disease and the social stigma could help the persons affected to think positively about life and how to care for one's health. It had not been easy for any of the participants to live with tuberculosis; however, several of the respondents indicated that they became "stronger" emotionally as a result of having recovered from TB. Paradoxically, the use of the words "stronger" and "more positive" were cited by participants when asked about the helpful impacts of their condition. Some of the participants indicated that they are more appreciative of their health and their families as a result of the condition.

Several of the participants indicated that the family members grew closer to each other while with others this was the opposite. Five participants indicated that there is nothing positive about the experience of having tuberculosis or feeling stigmatized.



Nuestra Casa Exhibit at UTEP

## Mitigating stigma and discrimination toward persons affected with tuberculosis

To mitigate stigma and discrimination associated with TB, we asked participants what could be done. The following situations were identified as discriminatory and unfair by the participants: being treated unjustly at work, losing one's job, being rejected by family, being pointed out in school or not receiving services as a result of the health condition primarily based on fear of infection.

### Health service providers

There was consensus that the primary responsibility that health care workers have was to treat the PATB with dignity and to offer concise information on causes, treatment, adverse effects of medication, and the dangers of interrupting treatment, transmission, and prevention of tuberculosis. In addition, providing emotional and psychological support or services was identified as important strategies overcome the negativity, rejection and isolation associated with the condition. Ensuring privacy and confidentiality when delivering medical care was identified as an important concern. Treating persons with respect and dignity regardless of who they are and whether they have the means or not to pay for services was alluded to in several occasions as important in mitigating both stigma and discrimination.

The provision of confidential services, accurate information and orientation to patients and families about the disease, was noted as one of the most important actions that health care workers can take to mitigate discrimination. Participants indicated that no person should be treated unfairly. Participants felt that once a person was discriminated by health personnel, there was nothing that could be done.



President Dr S. Bertel Squire, International Union Against TB and Lung Disease With Mexican Delegation

### Family members

The single most important thing that families could do was to be informed about tuberculosis, its forms of transmission, prevention, treatment and cure. Participants indicated that family members should be accepting of the persons with TB and avoid isolating them or making them feel guilty. Family members need to be informed about the disease and provide moral and emotional support or be referred to receive these services if needed.

### General population

The single most important thing that families could do was to be informed about tuberculosis, its forms of transmission, prevention, treatment and cure.

## Persons affected with tuberculosis

The three most important actions that persons affected by tuberculosis could do to eliminate stigma and discrimination were to take and adhere to treatment, get cured, and avoid exposing others to the disease. In addition, seeking emotional support when needed was frequently mentioned. A small number of participants indicated that there was nothing that could be done to eliminate discrimination.

Participants were unable to verbalize the change they would like, and their feelings of “guilt” led them to conclude that maybe they deserved being stigmatized, and some were even clear on having internalized stigma. While personal responsibility was emphasized in present day society that is highly individualistic, this approach has come at a loss of any answers related to combating stigma.

### b. Focus groups

Parents in the focus group discussed the primary feelings associated with the experience of living with a PATB as: sadness, rage, frustration; impotence and desperation that resulted from witnessing discrimination by members of the society and health care workers.

A common theme in both groups was the economic distress that individuals are experiencing because of the economic recession and high unemployment in Ciudad Juárez. This finding is consistent with other research that links TB with lower socio-economic status and distress.

Participants expressed great concern regarding the present economic situation, how difficult it is - especially for the heads of households to be ill and unemployed with no source of income. Participants mentioned examples of separation, distress and difficulties in proving the basic needs (e.g. food, shelter, child care) for their loved one affected with TB.

Myths associated with how TB is transmitted (e.g. saliva, sexual intercourse, shaking

hands) were mentioned by participants. There is knowledge about the signs and symptoms associated with TB in both groups. Participants mentioned that they had heard vaguely about TB before having a loved one diagnosed with the condition.

Attitudes of stigma and discrimination toward PATB are evident and are mentioned by participants in both groups. Participants mentioned the importance of support services for PATB and the family members. Examples included: food pantry, support with transportation or tokens for the local transit bus to get to the clinic.

Family members discussed their experiences in accompanying a family member with TB. Participants expressed feelings of frustration with the family member (difficulties in adhering to treatment, medication side effects) and the importance of offering emotional support. Participants also expressed great sadness when seeing the impact of TB on their loved one.

All participants knew that TB is a curable disease. The participants spoke about the

importance of treatment adherence. For some participants, TB was a painful experience. Stigma and discrimination associated with TB (and other co-morbidities) were cited by the participants as situations that their loved one had encountered in community and health care settings. Participants emphasized the seriousness of lack of general knowledge about TB in the general community. They attributed the stigma and discrimination to ignorance about the disease (lack of information).

Participants concluded that medications intended to cure TB have side effects and can cause other health problems and that more information on how the TB treatment works needs to be given to family members to help the PATB manage the side effects.

They also identified informational needs about TB and other health topics like HIV/AIDS. The topic of adherence to TB treatment was brought up several times. A participant asked if the PATB could stop the TB treatment once he/she feels better information.

### c. Voices and images of tuberculosis groups

The themes from the El Paso, Texas Voices and Images of TB group were:

- Tuberculosis related-stigma
- Tuberculosis does not discriminate
- Respect, love, and support for a Person Affected by Tuberculosis
- Dignity and determination
- Need for a border TB free community

The Ciudad Juárez, México group themes were:

- Feelings and emotions associated with living with TB
- Discrimination
- Vital support for a Person Affected by Tuberculosis
- Actions to mitigate the effects of tuberculosis

The participants described the TB Photovoice Project as valuable in their recovery and personal growth. Photovoice helped them to identify their feelings about TB and the stigma attached. Most importantly, their status as human beings deserving the rights as people and as patients was reinforced. The recovery is described as both physical and emotional by the Photovoice participants and expressed as the results of sharing with others in a similar situation and identifying themselves as part of a group. Discovering a common experience is seen by participants as an important element.

Photovoice gave participants the opportunity to communicate their inner thoughts and feelings to others within an emotionally safe workshop setting. They did it through dialogues, selecting photographs that most accurately reflected their concerns and perspectives on TB, and their communities for discussion. They contextualized and told stories and then identified the issues and themes that emerged. Participants shared their reflections with the group and defined the meaning of their images using the SHOWeD technique (Wallerstein, 1994).

Participants describe the SHOWeD technique as difficult because they realize that they have to reveal some of the most intimate feelings and thoughts, but in all cases they also described the experiences of the exercise to be of great value in allowing them to communicate without

Courtesy of PAHO-WHO



World TB Voices and Images TB Exhibit

words. Individuals identified additional experiences related to their participation in the Photovoice Project. Experiences ranged from the need for psychological and counseling services to the need for both the United States and the Mexican government to work together in a bi-national manner to fund, treat and cure tuberculosis.

The study illustrates that valuable changes occurred in terms of awareness, empowerment and social action by individuals affected by TB in El Paso, Texas, and Ciudad Juárez, México. The findings provide support for the premise that TB is a stigmatized state of being and that, social and border conditions and services were identified as essential themes and issues to participants living with TB. Participants identify the need

to conduct ongoing TB prevention and education with populations at risk for TB and HIV, persons affected with diabetes, and migrant and mobile communities. Additionally, participants agreed that once an individual is properly diagnosed, timely and person-centered services are needed on both sides of the border. The Photovoice intervention provides confirmation that Photovoice can be successful as an advo-

cacy, communication and empowerment strategy for marginalized populations. The project offers findings on the important contributions for both augmenting the conceptual understanding of the impact of tuberculosis on participants suggesting tools for policy change and improved delivery of health and human services in a region that is as challenging and dynamic as the U.S.-México Border region.

The findings of the study provide a glimpse of how individuals affected by TB perceived their community. The research demonstrate how these perspectives can be used by PATB and empower them to 'bridge the gap' between those affected by a disease and those in power to change policy related to the disease.

## 8. Additional accomplishments

### The Project had a series of additional accomplishments

- Participation of a delegation of ten PATB from the U.S.-México Border and The Voices and Images of TB Project in the 40th Union World Conference on Tuberculosis and Lung Health in Cancún, México. In addition, the PIMSA Voices and Images of TB galleries were exhibited in Mundo Latino with more than 2000 clinicians, health workers, decision makers and researchers from all over the world in attendance.
- First presentation of the “Nuestra Casa – Our House”, a TB Touring exhibition at the University of Texas at El Paso. The president of the University, Mexican Consul, Director of the Inter-American Foundation, the heads of various student associations and PIMSA project participants unveil the exhibit. Project participants presented their testimonies of how TB impacted their lives to an audience of students, faculty and decision-makers from Ciudad Juárez, Mexico, and El Paso, Texas. The Nuestra Casa exhibit aims to reach to the general public and decision makers to raise awareness on TB and HIV, in order to have leverage political support for education, care and research in TB, as well as to humanize the experience of living with TB in the border.

- Institutionalization of the Voices and Images of TB Gallery in the Jurisdicción Sanitaria II in Ciudad Juárez and in the El Paso Department of Health TB Program, of El Paso. The galleries are on permanent exhibit at these health care facilities.
- Institutionalization of the Voices and Images of TB Galleries in the UACJ campus to create awareness about TB through the Universidad Saludable initiative. This exhibition will reinforce the importance of mitigating stigma associated with TB and HIV/AIDS.
- The *‘Ventanilla de Salud’* (Health Station) of the El Paso Mexican Consulate incorporated tuberculosis education and referrals as a core component of their services. Distribution of printed materials on TB, presentation of TB messages for TV and radio as well as referrals for TB screenings on both sides of the border is under way.
- The University of Texas at El Paso is presently exhibiting the Voices and Images of TB Galleries and the Call to Action at the College of Health Sciences and School of Nursing Campus.
- The Soccer 2010 *“Stop TB Campaign”* will take place on September 2010. The target population is children (6 to 12 years) in El Paso, Texas and Ciudad Juárez, Mexico. The TB soccer ball was adapted from the original TB South African campaign and is now bilingual in Spanish. The campaign will raise TB awareness, lung health and healthy life styles in children and families.
- A Dissertation titled *“Tuberculosis and Stigma: Impacts on Health Seeking Behaviors, and Access in Ciudad Juárez, México, and El Paso, Texas”* was published by the PIMSA Project Co-Pi (Moya). The publication highlights the PIMSA Project and core findings from the 30 semi-structured interviews.
- The results of the project were presented at: (1) 40th Union World Conference on Tuberculosis and Lung Health *“Poverty and Respiratory Diseases”* in Cancún, Mexico, (2) 6th International Congress on Social Work and Health in Dublin, Ireland, (3) Bi-National Research Forum at the University of Texas at El Paso in El Paso, Texas, and (4) Doctoral Research Forum at New Mexico State University in Las Cruces.
- A manuscript by Lusk and Moya on Tuberculosis and perspectives of Persons Affected by TB in El Paso, Texas and Ciudad Juárez, México was published in the International Journal of Continuing Education in Social Work, August 2008.

## 9. Implications, conclusions and recommendations

- Stigma and discrimination against PATB can occur in many settings: at the workplace, in health care facilities, or within the community. Beyond the economic consequences, TB and TB-related stigma has a social and psychological impact. Such attitudes obstruct delivering effective treatment.
- The project findings can serve as the basis for future stigma measurement research with Mexican-origin populations in other countries to facilitate design of reduction interventions involving similar populations on other geographical contexts.
- The results provide data to make evident the potential impact of advocacy, communication and social mobilization activities.
- Findings reiterate the importance conducting research on the social and economic factors in which stigmatized individuals live.
- Old representations of tuberculosis no longer apply, even though the ideas behind them are still present in how society views people with tuberculosis. The previous labels are described in every interview conducted and were cited as the source of the stigma and discrimination associated with the disease.
- Further research is needed to examine how the stigma affect populations and may serve to improve our understanding of TB and HIV related stigma.

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Courtesy of PAHO-WHO

## Implications

The study findings will help scholars and programs to move from understanding stigma and its discourse to implementing reduction strategies and interventions. Study findings have implications for: (1) informing health services and decision-makers on how persons affected with tuberculosis in the United States-Mexico Border interpret their illness and stigma, (2)



World TB Day Formal open ceremony

research on health related stigma and interventions, (3) expanding and informing health-related theory on tuberculosis stigma and individual and structural stigma reduction interventions.

New approaches are needed to investigate ways of understanding disease related taking into account the social, cultural, political and economic determinants. Novel interventions and programs are necessary that respond to TB and HIV/AIDS related stigma and which engage communities and societies and those directly stigmatized and discriminated.

Also necessary is the further development of conceptual frameworks that build on exploratory and hypothesis generating studies (e.g. studies on the environmental or structural factors, social determinants) to inform research studies (e.g. local social processes and processes that cut across cultures) and research to inform policy and strategy (e.g. priorities for intervention) and policy oriented studies to inform program implementation.



Voices and Images of TB Gallery at International TB Conference

## Recommendations

- An interdisciplinary approach to tuberculosis care is essential, one which combines strengths of medical sciences and social and behavioral sciences and that looks at structural causes of health inequalities.
- Innovative programs and interventions to mitigate stigma related to TB and HIV/AIDS need to engage the persons affected by TB as well as the community at large
- The findings can also help advance the understanding of the factors that influence access and health seeking behaviors and help to design and implement stigma reduction and elimination interventions.
- It is essential to have an understanding of how individuals affected by TB and stigma are influenced by what family, friends and other members of their social networks tell them about the disease and its treatment or how they perceive or internalize stigma. Understanding these influences can provide vital insights into how TB is experienced, as well as an understanding of its diagnosis, treatment, and cure.
- These findings can also help programs and health care providers to use person-centered approaches instead of disease-centered care.