

BORDER TUBERCULOSIS PHOTOVOICES

Border TB Photovoice: Voices and Images

Goal: Increase awareness of the global burden of TB and assist in the eradication of TB.

Global Project Sites funded by Amaya-Lacson TB Photovoice:

- Rio de Janeiro, Brazil
- Chiang Mai, Thailand
- El Paso, Texas and Ciudad Juárez, Mexico

El Paso-Juárez Community Groups

- **Recruitment partners:** El Paso City-County Health and Environmental District-Tuberculosis Program, Juntos Project, Compañeros Program, Health Jurisdiction No. 2, and the State Health Services of Chihuahua
- **Participants:** Patients and people affected by Tuberculosis
- **Site:** El Paso TB Program, U.S.-Mexico Border Health Commission-Ciudad Juárez Regional Office and Compañeros
- **Number of participants:** 16 (ten females and six males)
- **Juarez Mexico:** Leticia, Lino, Alfredo, Hilda, Manuel, Alicia, Mother and son
- **El Paso, Texas:** Dix, Diana, Brenda and Joshua, Teresta, Rachel, Efran, Adriana
- **Age range:** 1.5 to 58 years



"Stop the Stigma, Discrimination and Negligence"

"We need to put an end to stigma, discrimination, negligence and indifference. We have the science, the medication and everything that it takes to stop Tuberculosis. What is keeping us from doing this?"
-Brenda

Abstract: Eva Moya, TB Division Director, United States-Mexico Border Health Association, Marie Villa, RN, Tuberculosis Program Manager, El Paso City-County Health and Environmental District, 8 Participants in El Paso; 8 Participants in Juárez, Mexico.

Introduction: Photovoice involves community people taking pictures of on their own health realities followed by group conclusion-raising discussions and presentations to policymakers. The Photovoice method was initially developed by Dr. Caroline Wang and Dr. Mary Ann Burris. In 2006, The Amaya-Lacson TB Photovoice Project awarded the U.S.-Mexico Border Health Association resources to implement the Border TB Photovoice Project in the El Paso/Ciudad Juárez region. TB Photovoice is about taking actions. It enables people to record and reflect upon their personal and community strengths and challenges. TB Photovoice promotes critical dialogue and knowledge about personal and community issues through group discussions of photographs. Reaching policymakers to create positive change in partnerships with communities is an important goal.

Rationale: The purpose of this project was to increase awareness of the global burden of Tuberculosis and Tuberculosis issues along the U.S.-Mexico border and to assist in the eradication of TB and TB Meningitis.

The objectives of this project are:

- To support and motivate TB patients to address policy decision makers.
- To conduct formative research that can inform communication strategies and program development.
- To disseminate formative research rooted in local people's perspectives.
- To develop better communication strategies and priorities for program development.

Methods: 18 participants, 8 in US, 10 in Mexico were recruited to take pictures of their reality concerning Tuberculosis Disease. Meetings were held, pictures were taken reviewed by the group and consensus was about the most important issues and themes were developed.

Results: Common themes identified by all participants fell into 4 broad categories:

- Medical misdiagnosis and delay of care
- Shame and stigma, including isolation
- Family support
- Economic issues

In Mexico, economical impact appeared more frequently than in US.

Conclusions: People affected by TB appear to have many similar reactions to the diagnosis. The stigma and shame, the lack of knowledge and the need for support and education are the same on both sides of the international border and across all ethnicities and social-economic levels.

About Tuberculosis



"My Duty and Responsibility"
"Taking medications is not easy. They taste bad and they make my stomach upset. After I take them, I don't like anyone to talk to me. It takes a while before I feel better. I know it is my obligation and responsibility, but how much longer must I take them?"
-Participant



"Discrimination and Isolation"
"This is the house of one the TB patients. His family put him in this place because they feared he could infect them. These people are being discriminated and abandoned by their families, communities, and the authorities because of ignorance."
-Lisa



"The Wheel of Tuberculosis"
"The Ferris Wheel is like our life. Sometimes we're on top, sometimes we're at the bottom. We have good and bad moments. When you have Tuberculosis, we spend more time at the bottom."
-Lisa

Social & Emotional Aspects



"The Two Goodwives"
"The picture represents the support Lapita needs. She is fighting to move on. She still can't forget the hardships of her past. It draws my attention that doctors have reached the most rural and indigenous areas. I feel sadness but a lot of faith. The 'Virgo of Goodwives' that dark-skinned ones gives her joy and strength."
-Afrida



"The Ladder"
"When you have HIV/TB, you want to go up step by step and it is not easy. You would like to go to the top, but it doesn't work like that. You have to adhere to the treatments and eat the example to help others. With perseverance, discipline, and will, you can get to the top."
-Lisa



"Tuberculosis is Not about Pigs"
"We tend to associate Tuberculosis with lack of hygiene. It has nothing to do with that."
-Evelina

Actions as Individuals



"Freedom"
"Wearing this mask was very important to me. I wore it for several months and it was very painful. My peers didn't know what my face really looked like. When I burned the mask, it was like getting rid of the stigma. Life free."
-Rachel



"Unity"
"Unity goes with strength. This picture represents the importance of creating borders and working together. As a border community, we need to unite against Tuberculosis."
-Diana



"The Gift of Health"
"This picture is the counter part to the one titled 'The torture.' Now, I look at it differently. Taking the medication is a gift of life I'm giving to myself. My attitude is much more positive."
-Rachel

Social Actions/Advocacy & Training



"No More Wires And Borders."
"We need to put an end to ignorance and educate the public about the disease. We need to stop building more fences and walls. Remember that the disease does not recognize borders and it goes back and forth."
-Brenda



"Wanted: Adequate Investments in Tuberculosis"
"More resources are needed for Tuberculosis on both sides of the border. Monetary investment is not enough. Resources, personnel, support groups, and increased access to health care are needed."
-Diana

We call on our governments, leaders, decision/policymakers and communities to:

- Invest now in TB by improving national, state and local financial contributions to TB control and research;
- Support the community involvement in the response to TB, empower people with TB and community and support advocacy efforts;
- Protect communities from the threat of extensively drug-resistant TB and HIV related TB and XDR-TB;
- Pursue high quality diagnoses, Direct Observed Treatment Short Course (DOTS) expansion and enhancement and patient center treatment based in dignity and respect;
- Commit to protect the poor and vulnerable populations from TB, TB/HIV and MDR-TB;
- Reach out, educate and engage all care providers;
- Think about TB, because TB is here, TB is everywhere, and
- Act now!

Common Themes Identified by Participants