National Association of Social Workers
Texas Chapter, Annual Meeting 2010
“Tuberculosis: Voices and Images of TB from the U.S.-Mexico Border.”

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Orientation Objectives

By the end of the workshop, you will be able to:

✓ Describe the goals of Photovoice
✓ Explain the methodology of TB Photovoice Project
✓ Explore the integration of the TB Photovoice project findings to Social Work practice with clients and students
✓ In summary, Photovoice is about:

  SHARING PICTURES,
  TELLING STORIES,
  EMPOWERING PEOPLE
  AND CHANGING COMMUNITIES

Revised on 7/2010
Introductions through photographs

- Name

- Role with regard to social work, social justice and health

- Select a photograph, describe what you see and what might be happening and how that relates (or not) to you
The Border - La Frontera

Quality of Life in the U.S.-Mexico Border

Photos by D. Schumman – Nuestra Casa Project, 2009
Economic Conditions

- Three-of-ten poorest counties in the U.S. are located in the U.S.-Mexico Border (El Paso is 3rd 28.1%)
- 21 counties are designated as economically distressed
- 20-30% of US border families live at or below poverty level (National average is 12.4%)
- In Texas and New Mexico, approximately 432,000 people live in 1200 colonias

(Deptartment of State Health Services, Office of Border Health, 2004)
If the U.S.-Mexico Border was Made the 51st State, the Border Region would:

- Rank last in access to health care;
- Second in death rates due to hepatitis;
- Third in deaths related to diabetes;
- Last in per capita income;
- First in the numbers of school children living in poverty; and
- First in the numbers of children who are uninsured;
- Last in primary health care professionals per capita;
- Second youngest state with almost 29 percent of pop. under age of 18; and
- Fifth in unemployment.

Sources: Bordering the Future Comptroller Report. 1998
PHOTOVOICE
GLOSSARY OF TERMS
Photovoice Defined

- Photovoice is a Participatory Action Research (PAR) method that employs photography and group dialogue as a means for marginalized individuals to deepen their understanding of a community issue or concern.

- Photovoice involves community people taking pictures of their own health realities followed by small group conscious-raising discussions and presentations to decision makers.

- Photovoice was initially developed by Drs. Caroline Wang and Mary Ann Burris in 1994 in China.
Photovoice Foundations

- Images trigger community self-reflection and discussion to examine root causes of community conditions.

- Participatory approach recognizes and honors community members’ subjective experience as researchers, advocates, and participants.

- Photographs and stories have been used for decades as a mechanism for social reform.
Photovoice: Theory

Education for critical consciousness
Participants consider and seek to act upon the historical, institutional, social, and political conditions that contribute to personal and community problems (Freire, 1974)

Feminist theory
Everyone has a specific story, a particular experience of the configuration of class, race, gender, sexuality, family, country, displacement, alliance…. Those stories are mediated by the forms of representation available in the culture (Wang, 1999)

Documentary photography
Examples of Photovoice Projects

**Language of Light Project.** Homeless women and men living in a shelter in Ann Arbor, MI (Wang, Cash, & Powers, 2000).

**The Voices of Students at Risk: A social validity study of Photovoice with at-risk students in Midwestern city** (Kroeger, 2003).

**Giving local health departments a new perspective on community health issues, Contra Costa, CA** (Spears, 1996; Pies & Parthasarathy, 2005).
Photovoice is designed to enable people to:

• Produce and discuss photographs as a means of catalyzing personal and community change.
• Document persons reality of their lives.
• Use the power of visual images to communicate their experiences and perceptions.
• Through critical reflection, discuss individual change, community quality of life and policy issues (Wallerstein, 1987).
• Creates evidence and promotes vivid participatory means of sharing experiences and knowledge through the immediacy of the visual image.
Participatory Action Research (PAR)

A method of collaborative research that involves increased understanding of an issue of concern and efforts aimed at improving social conditions through individual and group action.

Photovoice is a form of PAR!!
Photovoice Project

Photovoice

Research
- Data collection
- Data analysis
- Report writing
- Galleries
- CBR project design
- Resource development

Practice & Action
- Assessment tool
- Need identification
- Asset mapping
- Empowerment
- Political commitment
- Making changes

Note: Participatory Action Research (PAR)
Photovoice Facilitator

An individual that has a range of skills necessary to facilitate the form of participatory action research called Photovoice. The Photovoice facilitator requires knowledge of the investigative research process, ethical guidelines and the Photovoice method. The facilitator assumes the role of co-researcher and works closely with community members.
Photovoice Participant

An individual community member representing a marginalized group who agrees to take part in photo voice. A photo voice participant fulfills several roles in order to achieve the goals of the photo voice project.

Persons affected by TB (marginalized individuals) who take photos and describe through stories in small group meetings!!!
Roles and Responsibilities of Photovoice Participants

- Linkage with the community
- Gain trust with co-researchers
- Taking photography, selection and sorting of photos
- Explain stories in the meetings, help in data collection
- Risk management, reduction of barriers
- Community meetings, photo exhibition
- Assist to change the communities, identify and recommend service and policy changes
Experiential Participants

Refers to participants who have first-hand experience and knowledge. Photovoice participants are involved in examining an issue of concern or focus of research. Participants are considered experiential if they have gained knowledge from actual live experiences.

Photovoice participants!!!
Guidance Committee

Members of a group who are selected to hear the message about the issue of concern conveyed through Photovoice. Members are selected based on their ability or power to influence decisions and policies and to make changes that can improve the lives of community members.

Probably these are educators, activists, social workers, health workers, researchers, members of the media, local leaders!!!
Marginalized Groups

Groups of individuals who are most excluded from public discussion and who have limited access to centers of influence and power. Community members from marginalized groups are able to have their voices heard and bring forth ideas to influence the decisions and policies that affect their lives.

People with disability, health conditions, vulnerable groups, not getting access (limited or inadequate) to services!!!
Decision Makers

Those members of the community who have the ability or power to influence and make decisions on behalf of others. The group of decision-makers includes policy-makers, those who determine public guidelines and policy.

The target audience in Photovoice includes decision and policy makers!!!
Co-Researcher

A member of a group who shares responsibility for planning and carrying out a research project. In Photovoice, community members are co-researchers along with a Photovoice facilitator. Together, they make decisions about the focus of the project, collect and analyze data, create new knowledge and share findings with others.
Data

All of the information gained through the research process. The photographs, taken by community members, and their own words describing and explaining the photographs, are the main data collected in photo-voice.

Photographs with explanations!!!
Data Collection

The process of gathering information through a variety of activities and events. Taking photographs, participating in group meetings, recording discussions, guided dialogue, exhibition feedback and debriefing are all opportunities for data collection in photo-voice. Data collection is ongoing in Photovoice because information is gained right from the beginning until the end.

Capturing the photos and recording dialogues!!!
Codifying

The process of identifying and sorting data into categories of meaningful issues, themes or theories. Codifying takes place in Photovoice through group discussions where participants share photographs and discuss common themes and issues.

Participants show photographs and tell the themes and issues!!!
Contextualizing

Understanding or explaining how something fits within a larger set of circumstances. In Photovoice, contextualizing takes place as participants tell stories about the photographs and discuss what the photographs mean. As they engage in dialogue with other participants they can voice their individual and group experiences. For example, a photo of a sub-standard apartment can lead to a discussion of a larger context which includes the lack of affordable housing, low wages, social service shelter allowance policies and power relationships between tenants and landlords.

Problem identification and or meaningful issues and themes!!!
Data Analysis

The process of carefully exploring, examining and comparing the data collected. In Photovoice, data analysis develops a better understanding of the issue of concern being addressed. By analyzing the data, co-researchers can determine general themes and patterns, and identify how individual issues relate to the experiences of others.

How individual issues relates to others!!!
Ethical Guidelines

All research is governed by strict ethical considerations and guidelines. Researchers are expected to do no harm through research activities. The ethical principles ensure that Photovoice participants and other individuals or groups are not harmed as a result of Photovoice activities.
Informed Consent

Agreement to do something or allow something based on having all the facts and being educated on risks and benefits. Photovoice participants must be educated about the complete photovoice process, the multiple roles and responsibilities and the advantages and the possible risks of participation. Only then, once fully aware can community members agree to participate.
Five key concepts have been identified to unite the different ways in which Photovoice is applied to research (Wang, 1999; Wang & Pies, 2004).

- Images Teach
- Pictures can Influence Policy
- Community members ought to participate in shaping public policy
- Influential policy-makers must be the audience to the perspectives of community members
- Photovoice emphasizes individual and community action
A Quick Glance at the Steps in Photovoice

1. Connecting and Consulting with the Community
2. Planning a Photovoice Project
3. Recruiting Photovoice Participants and Target Audience Members
4. Beginning the Photovoice Project
5. Photovoice Group Meetings
6. Data Collection
7. Data Analysis
8. Preparing and Sharing the Photovoice Exhibit
9. Social Action and Policy Change
STEP ONE: CONNECTING AND CONSULTING WITH THE COMMUNITY

- Establish trusting relationships
- Identify research focus and issues of concern
- Involve community members and potential participants
- Build a bridge between research and the community
STEP TWO: PLANNING A PHOTOVOICE PROJECT

• Funding and budget for a Photovoice project
• Meetings
• Equipment
• Ethics and Photovoice

*Ethical considerations—Facilitator

*Ethical considerations—Participant
STEP THREE: RECRUITING PARTICIPANTS AND GUIDANCE COMMITTEE MEMBERS

Recruiting Participants

Recruiting Guidance Committee Members

• City or town council;
• Media and communication;
• Community-based groups that work closely with issues important to the photographers;
• Education and training;
• Health and human services;
• Interested community members;
• Government agencies and departments
STEP THREE: RECRUITING PARTICIPANTS AND GUIDANCE COMMITTEE MEMBERS

Bridging the divide between Photovoice participants and guidance committee

• Contacting organizations/informing about Photovoice;
• Meeting with individuals from organizations or departments to gain support for the Photovoice concept and project;
• Developing community support;
• Making future arrangements for Photovoice presentations;
• Inviting guests to presentations and showings; and
• Contacting individuals or groups to discuss specific issues that may be in their program area.
STEP FOUR: BEGINNING THE PHOTOVOICE PROJECT

Project Timeline
Establishing a Photovoice Group
Maintaining interest and group participation
  • Potential barriers and ways to reduce them
STEP FIVE: PHOTOVOICE GROUP MEETINGS

Photovoice process
Issues of concern
Identify group goals
Informed consent to participate

Photography
- How to use the camera
- How to take photographs
- Subject matter and theme
- Special consideration for human subjects
Framing the First Questions

- Who are the **people** that make up our community?

- What are the natural and human-made **features** of our community?

- What **social systems** make up our community?
STEP SIX: DATA COLLECTION

Photovoice Data Collection

- Taking photographs
- Recorded discussion and guided dialogue
- Journaling
- Photovoice Exhibit-feedback and debriefing
STEP SEVEN: DATA ANALYSIS

There are three main ways to carry out the participatory analysis of the data (Wang & Burris, 1997):

• Selecting Photographs
• Contextualizing
• Codifying
Describing the Story

What do you **See** here?
*Pretend someone can’t see the picture*

What is really **Happening**?
*Actions and feelings in the picture*

How does this relate to **Our** lives?
*Your feelings and how your experiences are similar or different*

**Why** does this situation, concern, or strength **Exist**?
*Underlying meaning and impacts on you and community*

What can we **Do** about it?
*Actions to be taken to solve problems or build upon strengths*

Develop by Nina Wallerstein and Edward Bernstein and adapted for use in Photovoice by Caroline Wang and Mary Ann Burris. Translated to Spanish by Eva Moya (2008)
Sharing Photos and Stories

Photos courtesy of E. Moya
STEP EIGHT: PREPARING AND SHARING THE PHOTOVOICE EXHIBIT

Preparing the Photovoice exhibit
Sharing the Photovoice findings
Private opening of the Photovoice exhibit
Public showings of the Photovoice exhibit
Voices and Images of Tuberculosis
Ciudad Juárez, México and El Paso, Texas

Sponsored by:
Programa de Investigación en Migración y Salud (PIMSA)
The University of Texas at El Paso, College of Health Sciences
United States-Mexico Border Health Association
2009-2010
Story behind TB Photovoice
Voices and Images of TB

• Claudia Lacson

• Died July 2004 from TB Meningitis

• Health care advocate for the poor

• Suppressed immune system due to pregnancy
TB Photovoice Project:

Objectives

- **Support and mobilize** persons affected by TB to address policy and decision makers
- **Conduct formative research** that can inform communication strategies and program development
- **Disseminate findings** through the local people’s perspectives

Locations

U.S.-Mexico border: El Paso, TX and Ciudad Juárez, México.

**International locations:** In Mexico: Oaxaca, Chiapas, Veracruz, Tijuana, Reynosa, Guadalajara, Monterrey; Rio de Janeiro Brazil, Thailand and South Carolina.
Border Region Context

• Located in the U.S.-Mexico Border are the States with **higher TB rates** than national rates\(^1\)

• The Border is a **high risk environment** for TB and other health risks.

• The Border reports TB **cure rates of less** than 60% in Mexico and between 70-75% in U.S. Border counties\(^1\)\(^2\)

\(^1\)CDC, 2008; \(^2\)Plataforma Unica de Información DGE, 2007
Mexico TB Context

• 54 new cases of TB are reported daily and every 6 hours a person dies from TB¹

• 65% of the TB cases are located in 13 states, 6 of which border with the U.S¹

• The TB rate for 2007 was 21/100,000; representing five times the TB rate in the U.S¹

¹Plataforma Única de Información DGE (2008)
TB Context in the United States

• In 2007, CDC reported a total of 13,293 new TB cases¹

• As of 2006, TB rate declined from 4.2% to 4.4% cases per 100,000, the lowest since 1953¹

• Despite progress, foreign born persons and racial and ethnic minorities continue to bear the burden of the disease (USMBHC, 2003)

• In 2007, TB rates among Hispanics, mostly from Mexican-origin individuals, blacks and Asians were respectively 7.8, 8.3, 22.9 times higher than among non-Hispanic whites.¹

¹MMWR, 2008
Challenges
Factors that Contribute to Elevated TB Rates along the U.S.-Mexico Border

- **Mobility** and migratory flows across the border¹
- **Lower SES**, crowded living conditions, limited access to health care services² (Amaya-Lacson, 2005; De Heer et al., 2008)
- Frequent **crossings** contribute to delays in diagnosis and may impede adherence.
- Language and socio cultural **differences** may contribute to delays in seeking care.
- **Cross-border case** management is complicated. When performed inadequately, compromises health outcomes³
- Impact of **HIV/AIDS¹**, rising prevalence of **diabetes** (Jeon & Murray, 2008)

(¹MMWR, 2001; Carballo & Mbond, 2005; ²Lobato et al., 1998; ³Rubel et al., 1992)
Tuberculosis Care

Photos by D. Schumann, Nuestra Casa Project. 2009
Community Groups

El Paso, Texas
Location: City of El Paso
TB Program
No. of participants: Five (three men, two women)
Age range: 23 to 68 years
No. of sessions: 10
Origin: Mexico, United States

Ciudad Juarez, Chihuahua
Location: Programa Compañeros
No. of participants: Four men
Age range: 28 to 47 years
No. of sessions: 7
Origin: Mexico
Main Themes

El Paso Group

• Stigma and discrimination
• Respect, love, and support for the person affected by tuberculosis
• Dignity, determination
• Tuberculosis free

Ciudad Juárez Group

• Feelings and emotions
• Discrimination related to tuberculosis
• Vital supports for a person affected by tuberculosis
• Actions to mitigate the effects of tuberculosis

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Phobia

“People may feel phobia, rejection and fear toward a person with tuberculosis. This attitude is due to a lack of knowledge, which is why we need to get informed and have educational campaigns.”

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

- Miguel and Micaela
“Just like adults, children are also exposed to diseases. We have no magic power to protect them. We have to educate ourselves about tuberculosis in order to keep them healthy.”

- Raúl
Careful! You Could Be Next!

East El Paso

“What are you doing to fight against tuberculosis? I never thought I would be a victim of tuberculosis.”

- Miguel and Claudia
“And you wanted to consume me, little by little; as if my life were yours (tuberculosis) and I depended on you. Bit by bit, you ate my left lung. You’ve left a scar that everyone can see. I felt how you consumed me, and sometimes, I believe that you haven’t left and are still there. It was a pain, an agony, that didn’t let me breathe.”

- Hilda
“When I was going with my friends to work, I saw the plastic air figure that falls and then 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
“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
“I thought it was impossible to recover from tuberculosis. I felt I had to jump over an enormous obstacle like this wall. I did it thanks to God and the medication. Today, I am recovering.”

- Miguel
Health Promotor

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

- Jesús
First Border Bi-National Voices and Images Forum (El Paso, TX)
Photovoice Methodology Training (Guachochi, CHIH)

Photographs courtesy of O. Vasquez
CALL TO ACTION TO ELIMINATE TB
Reversing the Epidemic by Including Individuals Living with and Affected by Tuberculosis in Efforts to Eliminate TB

We, the Tuberculosis (TB) PhotoVoice participants at the 38th UNION WORLD CONFERENCE ON LUNG HEALTH in Cape Town, South Africa note the toll that tuberculosis places on individuals, communities, and society. Believing that together we can eliminate TB, we call on all global leaders, governments, policy and decision makers, advocates, and communities at large to support and champion this call to action, which consists of three different and complementary aspects requiring your commitment to action.

First, the elimination of tuberculosis requires increased visibility of persons affected by TB, their stories, lives, worries, concerns, vulnerabilities, and aspirations. This requires increasing visibility of the social, economic, and cultural determinants of TB in the context of poverty and disparities, and the human face of TB, beyond the microbacteria and the medical treatment. We believe that TB in and of itself does not kill the person. Rather, long-term disability and death is caused by the lack of access to timely and quality DOTS treatments, lack of humane support services, stigma, discrimination, and negligence. TB is preventable, treatable, and curable.

Second, the elimination of tuberculosis requires inclusion, parity, and the participation of persons affected by TB across all levels of endeavors. The active participation of patients in the treatment and care decisions is essential for the elimination of tuberculosis. Patients require patient-centered care that focuses on the person and not just on the disease requiring the involvement of the patient’s support network. Treatment for TB should not end with the 6, 9, 12, or 18+ months to complete medication. A commitment should be made to assist the person to re-establish their life beyond completion of treatment for TB.

Third, the elimination of tuberculosis requires sustainable and permanent lines of funding through efficient distribution mechanisms. Community-based organizations and Non-Governmental Organizations need support to provide individual, group, and community interventions that strengthen the support systems of persons affected by TB. Efforts must be funded that enhance the ability of individuals to advocate for their autonomous needs, as demonstrated by innovative projects like the TB PhotoVoice Project. Representation of individuals and communities affected by TB must participate in funded information, education, and advocacy campaigns.

Tuberculosis is one of the most deadliest diseases. It has likely killed more people than any other disease in history.

- Every minute, roughly four people die of TB and 15 others newly develop the disease worldwide.
- TB accounts for one in four preventable adult deaths.
- Untreated, a TB patient can infect 10 to 15 others, simply by coughing.
- A full course of TB treatment costs as little as US$15.
- TB is the main cause of death among people with HIV/AIDS.
- More people die of TB in one day in the Western Pacific Region than all global deaths reported from SARS.
- Without increased TB control, an estimated one billion more people will be newly infected, 200 million people will get sick and 35 million people will die by 2020.


Call to Action - Created by Photovoice Participants in South Africa

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Voices and Images
Tuberculosis Photovoice in a Binational Setting

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38th Union World Conference on Lung Health of the Int. Union Against TB and Lung Disease in Cape Town, SA

Photographs courtesy of E. Moya
Limitations and Lessons Learned

- Findings applicable to specific settings, among low income communities.
- Impact and effectiveness to TB across cultures is unknown.
- Time sensitive for participants.
- Possible selection bias.
- Impact of photographs and stories and measures to minimize risks of privacy violations.
- Barriers to participation.
- Measurable outcomes.
Conclusions

- TBPV is aimed at empowering and mobilizing marginalized communities to become advocates.
- Communication and social marketing strategies can play a major role in addressing TB.
- TBPV helps to humanize TB and compellingly informs stakeholders, resulting in improved awareness and resources for TB programs.
- TBPV products are a useful tool to improve awareness, mitigate stigma and inform research and interventions.
If you are thinking about the possibility of Photovoice, here are some things to think about:

• Are you genuinely interested in community-based collaborative research?
• Have you done background reading or learned enough about Photovoice to feel comfortable with this method?
• Have you secured funding for Photovoice research or a Photovoice project?
• Are you prepared to seek funding by writing funding proposals or connecting with funding agencies?
• Do you have, or are you willing to develop, strong connections with the community?
• Is there an issue in your community that you are deeply concerned about?
• Do you have ideas about possible solutions or policy improvements related to that concerning issue?
Discussion

How could you use Photovoice method for your Social Work research? With students? For policy?

Can you give examples of how you could use Photovoice with a classroom of social work students?

Example: MSW students study a poor neighborhood in Houston or in El Paso. Can you name challenges in using the Photovoice method and how would you overcome them (i.e., photographing minors, working in a rough neighborhood, reaching out to vulnerable populations).
Thank you

Welcome your questions, comments, suggestions

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