Using Participatory Visual Methods in Social Science Research

Lunchtime Lecture for SID MA Advanced Study and Joint Degree Students

Laura S. Lorenz, PhD, MEd, CBIS
Institute for Behavioral Health
The Heller School for Social Policy & Management
Brandeis University

October 24, 2011
Table of Contents

• My background
• Participatory visual methods
• Photovoice: process, ethics & examples
• Analysis methods and validity
• Conclusion, questions, brainstorm
My Background
My Background
My Background
My Background
My Background
Including Perspectives of Patients and Community Members:

ON THE FAST TRACK IN COLOR SUNDAYS

A Social Justice Issue
Participatory Visual Methods

Participants—individually or in teams—create:

Art
Videos
Photographs
Maps

Representing experience and producing knowledge through images and text
Used with Individuals & Groups

Photo-elicitation: 6 patients accessing outpatient services at a rehabilitation hospital

Photovoice: 8 members of a brain injury survivor support group supported by BIA-MA

Option: Start with photovoice—add individual interviews about photos after
Photovoice:

- Participatory action research (Lorenz & Kolb, 2009)
- Is similar to qualitative interviews in that it furnishes opportunity to have a voice—a say—in a research context (Mishler, 1986/1991)
- Goes further than qualitative interviews by providing:
  a) Opportunities to communicate with images not just words
  b) Multiple occasions to share experience
  c) Opportunities to contribute to data analysis, codifying efforts, policy and outreach—develop new research skills (Wang, Yi, Tao, and Carovano, 1998)
Range of Participants

- Illiterate women in rural China
- Youth—in US and overseas
- Teen mothers
- Homeless
- Medical and nursing students and their patients
- People living with chronic conditions: mental illness, HIV/AIDS, asthma, brain injury, spinal cord injury, tuberculosis & substance abuse
Needs assessment and evaluation:
  • Understand lived experience with health, illness, and community
  • Gain perspectives of local stakeholders and populations on problems, resources, knowledge
  • Inform or initiate action

Advocacy and policymaking:
  • Raise awareness—among community members, policymakers, patients

Healing:
  • Provide opportunities for communities and individuals to recover from trauma, have a “voice” or be “seen”
Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)
Learn about Ethical and Safety Issues

- Make sure you are “safe” when taking pictures
- Be ready to explain the project to others
- Always ask permission before taking someone’s photo
- Ask permission before putting someone’s photo in an exhibit
- Think of others’ safety and be respectful of their lives
Consent is a Tiered Process

Consent by participants to:
• Participate--take photographs and discuss in the research setting
• Share photographs outside the research context, for educational and other purposes

Consent by photographic “subjects” to:
• Have photo taken
• Share photograph outside the research context

Consent by guardians is required for photos by or of minors or persons with cognitive challenges

Different communities and cultures may have different approaches to ethics and consent
Respect the Right to Refuse
Permission Can Be Ongoing

To compensate for my poor memory and organizational skills, I need to put labels on everything in my home. Where are my socks? Which of these is my schedule book? On which shelf did I put my Bible? These labels are necessary 3 years after my accident and probably for many years to come. It is painful to remind myself about all of the brain power which I lost at the time of my car accident.

What matters most: Rights of the Individual? Rights of the Group?

Implications for outreach products – static or flexible?
Sample Visual Research Questions

• What is it like to live with a chronic condition?

• What in my life or community has improved my quality of life living with a chronic condition?

• What in my life or community has affected my quality of life in a negative way as I live with a chronic condition?

• What do I want to tell other people about living with this condition?

• How is my life different now from how it was before I developed this condition? What is better? What is worse?

• What are my hopes for the future? And what might help me get there?
A Photovoice Path

Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)
Photo-taking Options

• Use disposable cameras – or choose another option
• Let participants work alone or in teams
• Provide 1 to 3 cameras or photo opportunities per person--15 and 50 photos per participant or team
• Emphasize photo content
• Allow participants to contribute family snaps or historical photos
• Allow participants to give the camera to others
• Encourage photos that are representational and metaphorical
Sample Representational Photo
A metaphor...

What do you see?

Source: Brain Injury X-Posed 2006
Photographer: Peggi R
'It’s a muddy, rutty, hands-and-knees crawl up to the first rung of the ladder that begins to make some semblance of sense—and then you get to begin to really struggle. The climb does not and will not end. There is no final healed bone or mended tear of the skin to get over. Sometimes weekly, and sometimes daily there is a new step to attempt to get to your “new self.” You can’t even ever hope to get back to your “old self.” Oh well Maybe there will be a good view on this journey that I hadn’t expected...’

Source: Brain Injury X-Posed 2006
Photographer: Peggi R
A Photovoice Path

Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)
SHOWED...

What do you **SEE** here?
What’s really **HAPPENING** here?
How does this relate to **OUR** lives?

**WHY** does this problem/situation/strength exist?
How could this image **EDUCATE** the community/policy makers/ etc.?

What can we **DO** about it (the problem/situation/strength)?

Source: Wang and Burris, 1997
A Photovoice Path

Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)
Writing narratives, Mdantsane Township, Eastern Cape, South Africa, 2001
Source: Author
Outreach Considerations

WHO do you want to reach?

WHAT are your messages?

WHY? What action(s) do you want them to take?

HOW? What types of media and products will reach them?

Outreach efforts can generate valuable critical thinking and life skills
Trial Exhibit

- An opportunity for feedback from family, friends, and health & social service providers
- A first step in further outreach
- Participants and co-facilitators developed exhibit themes together
Formal Exhibit: Brain Injury X-Posed

• The Journey
• Lost Dreams
• Chaos
• Challenges
• Strategies
• My Advocacy Story
• Comfort and Support
• Acceptance
• Hope for the Future
Challenges

Trying to run on ice
Imagine your automobile stuck in a snow bank. You hit the gas pedal and all the tire does is spin. Now imagine yourself trying to run on ice (without wearing a pair of skates). The longer you run, the more you get nowhere. These images parallel how each and every day of my life begins since I suffered my brain injury. I seem to spend a whole lot of time getting nothing accomplished.

Thank God there's a handrail
This is the front steps of where I'm living. There are three stone steps. It makes it difficult to walk up them. Thank God there's a handrail.

I walked without falling
I walked over these broken stones through the water without falling in the brook. This was a challenge.

What do you do at a stop sign?
What do you do at a stop sign? My first reaction is to stop. No wait, my first reaction is to move forward. - Finger Trees On Pavement

Keys in the freezer
My thoughts no longer correspond to action. Thus, putting things in places that have no meaning: like keys in the freezer.

Fitting the pieces into my life
What a photo! Every week there is something in my life that was once obvious and easy to see, but now confusing and almost unrecognizable. How does it fit in my life now? Why is it so hard to understand? I need to stop asking these questions and move on to filling the pieces into my life. I am not getting all the questions. Time is a good answer. It just is.

Walking around with my head in the clouds
Since my brain injury, my life has been turned upside down. I have become more difficult to identity. Confusion is now my middle name. Furthermore, I am easily distracted. How do you think it looks to go through life with you are constantly mistaking, vastly confused, and you don’t even notice it? If I do, it like walking around with my head in the clouds.

In a glass booth in the middle of the room
Remember what it was like at a New Year's party. You are in a room filled of people laughing, talking, drinking, talking, laughing, and having a good time. Ever since my brain injury, I now feel more alone than when I was in a crowded room full of people. It was as if I was alone in a glass booth in the middle of the room. People would be all around me talking. However, I could not remember what was being said. The more I tried to remember what was just said, everyone else in the room was now talking about something else. I was always one or two conversations behind. I would try and laugh along. However, I was not laughing at the joke because I could not understand them. I laughed along with everyone as not to feel out of place. Yet, this made me feel even more alone and out of place.

Getting through the maze
Getting through the maze of daily medications is a challenge thought with mixed desires or incorrect timing.

Living with chronic headaches
I often feel as if my head is laden with brick, making my head heavy without reason for thought.

Life as a duck
I took a picture of this duck while it was swimming. I am not sure why I did this. Maybe it struck my fancy.
Scientific poster—photovoice as research.

One photo and caption from every participant

One from every exhibit theme

Facilitators were co-authors

Showed brain injury research, policymaker, clinical, and family audiences that people with brain injury can be researchers—Challenged assumptions and hierarchies
Outreach in the Community
Outreach in Scientific Settings
Outreach via the Internet

Brain Injury X-Posed: The Survivor's View

What does it feel like to live with a brain injury? What are the issues and concerns of survivors? How do they cope? Where do they find comfort, support, and hope?

Brain Injury X-Posed: The Survivor's View is a photographic exhibit created by eight members of the Brain Injury Association of Massachusetts Framingham Support Group. Each participant in the project took photographs and wrote personal narratives that reflect their experience living with brain injury. The exhibit was on display during March 2009 at the Massachusetts State House in Boston.

"Taking photos and talking about them helped...."
Analysis Approaches & Validity
Thematic and Structural Analysis:

A visual illness narrative of discovering a new identity after brain injury

EXCERPT 1: Cookbooks
“Identity lost”

My work as a chef ended with my brain tumor
I didn’t have a life separate from my work
It was always Judy the Chef, not ever Judy
I had to find who I was besides being a chef
I’ve still got over a hundred cookbooks
That was part of making the picture

EXCERPT 2: Pill Box
“These are all my brain injuries”

This is my pill box for the week
It would become very confusing
I started coordinating with my doctors

EXCERPT 3: Garden
“The new Judy”

I thought, “Oh, I can do that”
I started experimenting
So I have something new
I’m in the roses now
The identity of the chef is no longer the focus of my life

EXCERPT 4: Keys in the Freezer
“What do I make out of that, that I want?”

We as brain injured people put things in weird places
Maybe I was getting a glass of water with some ice cubes
I make things out of nothing
I can do that because I was a chef
Sample Raw Interview Text

J: Yeah, this one here is identity lost. My work as a chef ended with my brain tumor. But I also lost my “who I was.” Yes

L: So, what it seems to me you're saying there is that, work, in, to a certain respect, work was your identity.

J: Oh, yes, my whole, I, my whole, my, it was so, my identity was so entwined with my work, there was, no difference. (right) I didn’t have a life, tru, that was truly separated from my, from my work. It was 24 hours a day. (hmmm) Being a chef, is, like being an athlete, in that, you’re, you’re never off, (hm hmmm) you’re, you're, that you’re off, there are other professions that are like that, that, you’ve just, it’s just part of your day continuously. (yes) It’s not like the stockbroker where you go into work, and then (right) you end it and you leave it behind. It was 24 hours a day, um, whether it was my vacation, it was always, it was always there. When I was watching TV, it was always there. I'm looking at ads, I'm looking at, you know, how did they [laughter] It was never ...
Structural Analysis (Gee, 1991)

Part 1: My work as a chef ended with my brain tumor
This one here is identity lost.
My work as a chef ended with my brain tumor,
But I also lost my “who I was.”

[Deleted: discussion of written narrative for group project]

Part 2: I didn’t have a life...separate from my work
So what it seems to me you're saying there is that work, to a certain respect, work was your identity
Oh yes, my whole, my identity was so entwined with my work,
There was no difference right
I didn’t have a life that was truly separate from my work
It was 24 hours a day hmm
Being a chef, is like being an athlete in that, you're never off hmm

[etc]
Cookbooks: “Identity Lost”
My work as a chef ended with my brain tumor
I didn’t have a life separate from my work
It was always Judy the Chef, not ever Judy
I had to find who I was besides being a chef
I’ve still got over a hundred cookbooks
That was part of making the picture
Pill Box: “These are all my brain injuries”
This is my pill box for the week
It would become very confusing
I started coordinating with my doctors
Garden: “The new Judy”
I thought, “Oh, I can do that”
I started experimenting
So I have something new
I’m in the roses now
The identity of the chef is no longer the focus of my life
Keys in the Freezer: “What do I make out of that, that I want?”
We as brain injured people put things in weird places
Maybe I was getting a glass of water with some ice cubes
I make things out of nothing
I can do that because I was a chef
Reflections

• Who has controlled this analysis?
• What does this analysis leave out or miss?
• How can we rectify these analysis and representational challenges?
That picture of the scar represents such an important...all the words are coming up in my head, things like freedom and acceptance...I couldn’t have done that 2 years prior. That for me was probably the biggest statement about where my life is now. So the slice of now, that’s in my photo there. It shows where I am at right now, how things have changed so differently, how life is so different from what it was, right after my surgery, 5 years after my surgery, 10 years. I was going through different things at those times. And that picture is of now, today. It’s not the end of my story. But it’s a beginning of a whole chapter. It’s like the end of the shame, of having to try to cover it up, not wanting people to see that [scar] as the first thing. I never hid it, but now it’s out there. And you know, it makes for interesting conversation. Now it’s just, well, that’s just part of me, you know.
That picture of the scar represents such an important...all the words are coming up in my head, things like freedom and acceptance...I couldn’t have done that 2 years prior. That for me was probably the biggest statement about where my life is now. So the slice of now, that’s in my photo there. It shows where I am at right now, how things have changed so differently, how life is so different from what it was, right after my surgery, 5 years after my surgery, 10 years. I was going through different things at those times. And that picture is of now, today. It’s not the end of my story. But it’s a beginning of a whole chapter. It’s like the end of the shame, of having to try to cover it up, not wanting people to see that [scar] as the first thing. I never hid it, but now it's out there. And you know, it makes for interesting conversation. Now it’s just, well, that’s just part of me, you know.
Visual Analysis (Rose, 2007)

- **Image Production**: Who took the image? Under what circumstances and social or cultural conditions? In what context?

- **Content**: What does the image contain?

- **Counting**: How often do we see a particular topic/theme?

- **Reflexivity**: What is your personal frame? How is it affecting what you see?
Limitations and Validity Considerations

• Who is participating? How representative of the community?

• Who is generating the data—are parents or peers involved? What are the data implications?

• How does the iterative photo-taking and discussion process influence the data?

• Have the ethical requirements affected participant photo-taking?

• Have language or cultural barriers impacted participant discussions or captions?

• Member-check—do participants or the community agree with your analysis?
Limitations and Validity Considerations

• Who is participating? How representative of the community?

• Who is generating the data—are parents or peers involved? What are the data implications?

• How does the iterative photo-taking and discussion process influence the data?

• Have the ethical requirements affected participant photo-taking?

• Have language or cultural barriers impacted participant discussions or captions?

• Member-check—do participants or the community agree with your analysis?
Limitations and Validity Considerations

- Who is participating? How representative of the community?
- Who is generating the data—are parents or peers involved? What are the data implications?
- How does the iterative photo-taking and discussion process influence the data?
- Have the ethical requirements affected participant photo-taking?
- Have language or cultural barriers impacted participant discussions or captions?
- Member-check—do participants or the community agree with your analysis?
Limitations and Validity Considerations

- Who is participating? How representative of the community?
- Who is generating the data—are parents or peers involved? What are the data implications?
- How does the iterative photo-taking and discussion process influence the data?
- Have the ethical requirements affected participant photo-taking?
- Have language or cultural barriers impacted participant discussions or captions?
- Member-check—do participants or the community agree with your analysis?
Limitations and Validity Considerations

• Who is participating? How representative of the community?
• Who is generating the data—are parents or peers involved? What are the data implications?
• How does the iterative photo-taking and discussion process influence the data?
• Have the ethical requirements affected participant photo-taking?
• Have language or cultural barriers impacted participant discussions or captions?
• Member-check—do participants or the community agree with your analysis?
Limitations and Validity Considerations

• Who is participating? How representative of the community?
• Who is generating the data—are parents or peers involved? What are the data implications?
• How does the iterative photo-taking and discussion process influence the data?
• Have the ethical requirements affected participant photo-taking?
• Have language or cultural barriers impacted participant discussions or captions?
• Member-check—do participants or the community agree with your analysis?
“The disorder that I’m living with right now”

“Truth” versus “Narrative truth”
Conclusion
Photojournalism raises issues from “outsiders” perspective
With photovoice, “insiders” use voice and reach policymakers.
Questions and Brainstorm

Questions for me on these methods in social science research?

Some questions for you:

• How use these methods in your work?
• Who might participate?
• What would be your purposes?
• How might you adapt these methods?
• How would you analyze the data?
• What might be some risks? Some benefits?
Thank you!

Laura S. Lorenz, PhD, MEd, CBIS
The Heller School for Social Policy & Management
Brandeis University
Waltham, MA

Email: llorenz@brandeis.edu
URL: www.lslorenz.com