Participatory Visual Methods: Speaking with Pictures

Brown Bag Talk
National Louis University
Chicago, Illinois
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Today

• Share my process of personal and professional growth with photovoice
• Introduce participatory visual methods, esp. photovoice
• Share photos from pv participants in Lowell, South Africa, and Framingham
• Reflect on process and ethics of pv
• Share some visual metaphors
• Review ways to analyze visuals and text
• Consider some limitations of these methods
• View examples of outreach and scholarship
• Discuss some conclusions and implications
My Background
My Background
My Background
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My Background
Including Perspectives of Patients and Community Members: A Social Justice Issue
What is photovoice?

- A group process of community and personal reflection using photographs and written narratives
- Consciousness-raising education
- Dialogue with policymakers, peers, and self (reflection)
- Representing experience and producing knowledge through images and text
Photovoice

• Is similar to qualitative interviews, furnishes opportunity to have a voice—a say—in a research context (Mishler 1986/1991)

• Goes further than qualitative interviews by providing:
  a) Multiple occasions to share experience
  b) Opportunities to contribute to data analysis, codifying efforts, policy and outreach (Wang, Yi, Tao, and Carovano 1998)
Building a Project Rationale

At my professor’s suggestion, I used a Research Methods course to explore the literature around youth and arts-based education:

- Activism—plant a seed
- Identity—understand self
- Learn by doing—deeper learning
- Empowerment—work in a group
- Community resources and voice
- Visual literacy—learn to read photos
Roots of Photovoice

• Paolo Freire popular education
• Photo novela
• Photography as social documentation

“… it becomes necessary, not precisely to deny the fact, but to ‘see it differently.’” (Freire, 2000)
Photovoice Worldwide

• Since 1991, photovoice projects worldwide have created awareness of local conditions and empowered disenfranchised people to act as catalysts for community change

• Check out www.photovoice.com
Photovoice at Girls Inc. Lowell
“My aunt is special to me because she is very cool and teaches me things about life.” Jessica, 14
“This is a sign near my school. I think it’s a good thing to have because it keeps kids safe.” Becky, 13
“When I see trash on the ground it upsets me, and I wish that some day we can get people together to pick up the city of Lowell.” Elise, 13
“This is one of many cracks in our h.s. dance floor. One girl was injured this year. I hope that this photo will help get the floor fixed.” Kerry 17
Ethical challenge
Outcomes for Girls Inc Lowell

- Got the high school dance floor fixed
- Won a national Girls Inc award
- Won a grant for curriculum guide
- Featured in funder publications
- Using pv in school outreach activities
- Holds exhibits at UMASS Lowell
- Continues to do pv with girls – great outreach project in middle schools
- Has seen affiliates in US and Canada do their own projects
- Won a grant for a second curriculum guide (on another staff-developed project)
Photovoice in Mdantsane
WHAT WILL WE DO?

Photovoice Path

1. Plan
2. Training
3. Data Collection
4. Data Analysis
5. Presentation

Hear Ye, Hear Ye!
Promotes Dialogue
Photovoice participants in dialogue with policymakers, Mdantsane Township, Eastern Cape, South Africa, 2001
Problems
“This is a picture of the youth of Mdantsane. They are enjoying themselves by drinking liquor in the tavern. They have nothing to do. It was the time for rest. It was midnight. I think it is a bad thing that they are here and not at home.” -- Zanele
“This is a bad situation. The streets are always muddy even on sunny days. There are insects which bring illness to people. Cars cannot enter in this community. These roads need renovation. If the municipality would contribute gravel, the community would fill in the holes themselves.”--Luyazola
Some Challenges
Photovoice with Brain Injury Survivors

Purposes, to:

Gain an understanding of lived experience with brain injury and the concerns of brain injury survivors living in the community

Provide an opportunity for participants to reflect on their lives, use their brains, and employ a variety of cognitive skills

Create awareness of brain injury in the community
Background

- Acquired brain injury (ABI) vs traumatic brain injury (TBI)
- 1.4 million TBIs diagnosed each year in hospitals; 5.3 million w/ disabilities from TBI
- Executive functioning, communication, memory, fatigue, chronic migraines, slowed processing speed in brain, etc
- Knowledge gap: lived experience with brain injury
Group

- 10-year old brain injury survivor support group in Framingham, MA
- 8 survivors volunteered to participate in a 10 week photovoice project
- Participants were injured 3 to 31 years ago—6 with TBI, 2 with brain tumors
- My 2 co-facilitators are also brain injury survivors—we planned the project for 6 months and facilitated it together
A Photovoice Path

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 you take pictures
• Always ask permission before taking someone’s photo
• Respect their right to refuse
• Be ready to explain the project to others
• Ask permission before putting someone’s photo in an exhibit
• Think of others’ safety and be respectful of their lives
Sample Visual Research Questions

• What is it like to live with brain injury?

• What in my life or community has improved my quality of life living with brain injury?

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

• What do I want to tell other people about living with brain injury?

• How is my life different now from how it was before I developed brain injury? 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
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)
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.
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
Photovoice and Metaphors

Let’s take a closer look…
Sample Representational Photo
What Do You See?

A visual metaphor that has inspired many others since.

Source: Pre-pilot study 2005
Photographer: Laura Foley

Institute for Behavioral Health
That’s How I Felt

…that’s how I felt…right after my accident, that there was no connection and there were so many missing links as I tried to begin living again…it was kind of like living in the middle of nowhere…When I saw that, well, that seemed like a perfect way to sum it all up, you know

Source: Pre-pilot study 2005
Photographer: Laura Foley

Institute for Behavioral Health
What Do You See?

The previous photo inspired this visual metaphor. What do you see?

Source: Brain Injury X-Posed 2006
Photographer: Judy S

Institute for Behavioral Health
Inside My Head

The shell of my life became broken. Inside my head is scrambled with strands of my life no longer blended.

Source: Brain Injury X-Posed 2006
Photographer: Judy S

Institute for Behavioral Health
What Do You See?

Source: Brain Injury X-Posed 2006
Photographer: David S

Institute for Behavioral Health
Imagine yourself trying to run on ice… The faster 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.
What Do You See?

This visual metaphor became the representative image for the group exhibit.

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
Discussion

• Metaphor: the way the brain travels (Charon 2006).

• In creating visual metaphors, participants “traveled” to the past and the future, to reveal the pain they feel at their losses and to share their sources of hope.

• Visual metaphors have allowed participants to transcend time, place, and their identifying condition of brain injury (Radley 2009).

• **A danger:** Seeing participants as so capable they no longer need assistance

• **Greater danger:** Seeing brain injury survivors as merely victims, and not as feeling actors on a journey similar to our own: to find meaning and purpose in life
• Another way to analyze data with both visuals and text...
Thematic and Structural Analysis: An ABI Survivor’s Visual Illness Narrative of Discovering a New Identity

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
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 ...
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 hmmm

[Deleted: conversation that continued in the same vein about work being 24/7]
Cookbooks: “Identity Lost”
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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.
Also possible:
Transform your findings into a visual representation

An example
Brain Injured Self Dominates

New Brain Injured Self

Old Self
New Self and Old Self in Dialogue

Old Self

New Brain Injured Self
A Multiplicity of Selves Accept Each Other

- Patient
- Spouse
- Parent
- Old Self
- New Brain-Injured Self
- Worker
- Friend
- Artist
• Now let’s consider the limitations of our visual approaches to research and analysis and the implications for validity...
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?
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• Now let’s look at some photovoice outreach and scholarship...
Trial Exhibit

- Provided a goal for participants to work toward
- Provided insight into what a formal exhibit could be
- Energized the group to continue and develop a formal exhibit
- Was an opportunity for feedback from family, friends, and health & social service providers
Formal Exhibit: Brain Injury X-Posed

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

Participants and co-facilitators developed exhibit themes together.
Challenges

Trying to run on ice

Imagine your automobile stuck in a snow bank. You let 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 better you run, the more you get nowhere. These images parallel how each and every day of my life begins since I suffered a 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 by spinning tires. On pavement. Oh crap, I seem to be back again. Since my brain injury, this seems to be the story of my life.

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 taken for granted is gone, gone, gone. It is nothing and inevitable. How does it fit into my life now? Why is it so hard to understand? I need to stop asking these questions of the pieces that come from my life without answering all the questions. There is no good answer. It just is. It seems.

Walking around with my head in the clouds

If my brain injury, my life has been turned upside-down. I have more difficulties with memory, concentration, and attention. What does it mean to walk around with my head in the clouds? Furthermore, I am easily distracted. How do you fit this to go through life when you are constantly being hurt, daily reminded, and easily distracted? For me, it is like walking around with my head in the clouds.

In a glass booth in the middle of the room

Remember what it's like in a Where's Waldo? party. You stand in a room full of people eating, drinking, dancing, talking, laughing — just having a good time. Ever experience a brain injury? I seem to find myself alone 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 I was just said, everyone else in the room was now talking and the more and more people behind. It became too much of a joke and everyone laughed. I too would laugh. However, I was not laughing at the joke because I couldn't understand the joke. I laughed along with everyone so as not to stand out of place. Yet, this made me feel more alone and out of place.

Getting through the maze

Getting through the maze of daily medications is a challenge fraught with missed dosages or incorrect timing.

Living with chronic headaches

I often feel as if my head is laden with bricks, making my head heavy without room for thoughts.

Life as a duck

I took a picture of this (these) ducks because it occurred to me when I saw them that there really might be something to looking like a duck. They float, they flap, they move like ducks. They do, they prefer to spend much time near water. How they are different from what they were, how other ducks might perceive their weaknesses, the lack of confidence. It was experienced in their time. Suffice to say, the photographer has experienced all of these.
Scientific poster—photovoice as research.

One photo and caption from every participant

One from every exhibit theme

Facilitators were co-authors

Showed study as research

Showed brain injury research, policymaker, and clinical audiences that brain injury survivors can be researchers and experts—Disruptive!
Flexible, Informal Exhibit
Outreach in Scientific Settings
Brain Injury X-Posed: The Survivor’s View

Laura Lorenz, Barbara Webster and eight members of the Brain Injury Association of Massachusetts
Framingham Support Group

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 to peel away the layers of issues and emotions like the layers of an onion,” says Barbara Webster, facilitator of the Framingham group, who also sustained a TBI.

This project was intended to provide an opportunity...
Brain Injury X-Posed: TBI and Our Vets

Outreach in community settings: Initiated by a photovoice participant

Lee Woodruff spoke; elected officials, media representatives, veterans, and brain injury survivors attended

November 4, 2008

Sponsored by the Brain Injury Association of Massachusetts & the Newton Free Library
Outreach Can Grow Over Time

In March 2009:
Exhibit at Massachusetts’ State House and proclamation by the Governor

The Brain Injury Assoc. of MA takes ownership
When Participants Change Their Minds about Permission

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.

Rights of the Individual? Rights of the Group?
Conclusions and Implications...
Some Takeaways

• With participatory methods (visual and otherwise), participants are experts (Balcazar et al, 1998, Bruyere, 1993)
• Being listened to and “seen” contributes to self-respect and empowerment
• Photovoice helps to overcome communication and memory challenges and provide opportunities to have a say in research, policy, and clinical contexts
• Photovoice can present a multifaceted view:
  Negative — Lost Dreams
  Positive — Acceptance
• Photovoice can be life-changing for all involved
Academics, clinicians, students, policymakers, and other audiences can be transformed by participatory research as well.

Source: Lorenz 2008
Photographer: Author
Implications for Policy & Practice

- Gain an insider or patient perspective on living with brain injury (Prigatano, 2000)
- Increase the relevancy of research to real-life situations (Rich et al., 2000)
- Promote informational and interactional justice in the clinical setting
- With photovoice, the camera becomes an instrument of justice
Implications for Your Research?

- How might you apply the concepts presented today to your research?
- Your thoughts of opportunities, plusses, and minuses?
Implications for Teaching and Training?

- How might you apply the concepts presented today to instructional design?
  - Needs assessment?
  - Instructional content and strategies?
  - Materials development?
  - Evaluation?
- Your thoughts of opportunities, plusses, and minuses?
Photojournalism raises issues from “outsider’s” perspective
With photovoice, “insiders” use voice and reach policymakers
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