Using Participatory Visual Methods in Social Science Research

Lunchtime Research Talk for SID MA Advanced Study and Joint Degree Students

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Including Perspectives of Patients and Community Members:

A Social Justice Issue
2 - Participatory Visual Methods

Participants—individually or in teams—create:

Art
Photographs
Maps
Videos

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
3 - 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
- Multiple opportunities to share experience
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”
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 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
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?
Traumatic Experiences
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: 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
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.

Implications for outreach products – static or flexible?
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
Photovoice participants trying out their cameras, Mdantsane Township, Eastern Cape, South Africa, 20001
Source: Photovoice participant
Sample Representational Photo
A metaphor...

What do you see?

Source: Brain Injury X-Posed 2006
Photographer: Peggi R
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

*Based on Paolo Freire’s work*
Freire: Critical consciousness

“The fact exists; but both the fact and what may result from it may be prejudicial to the person. Thus, it becomes necessary, not precisely to deny the fact, but to ‘see it differently.’” (Freire, 2000)
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.
Develop Themes Together

• Something I insist on in every project
• With TBI group, started with flip charts and a photo
• Easier the second time we tried: homework assignment
• Co-facilitators and I finalized the groupings
• One theme was a personal story
• Chaos, Challenge, and Strategies had the most photos
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 tires spin. Now imagine yourself trying to run on ice (without wearing a pair of skates). The harder 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 by spinning tires on pavement. Oh crap, I seem to be stuck 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 obvious and easy to see. It’s now confusing and almost unrecognizable. How should I fit in my life now? Why is it so hard to understand? I need to stop asking these questions and proceed to fitting the pieces into my life. It is the only way of answering all the questions. There is no good answer. It just has to be a fit.

Walking around with my head in the clouds

Since my brain injury, my life has been turned upside down. I have numerous difficulties daily. Confusion is now my middle name. Furthermore, I am easily distracted. How do you think it feels to go through life when you are constantly looking behind, rearward, uncertain? I think it’s 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 Eve party. You are in a room full of people eating, drinking, talking, laughing, having a good time. Ever since my brain injury, I am not only more than what I was in a crowded room full of people. It now is as if I was all alone in a glass booth in the middle of the room. People would be all around me talking. However, I couldn’t 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. However, I was not laughing at the jokes because I couldn’t understand them. I laughed along with everyone so 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 designs or incorrect timing.

Living with chronic headaches

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

Life as a duck

I took a picture of this (very) duck because it seemed to show when I saw them that there really might be something to worry a duck. They didn’t have things they couldn’t do that they could do before and, if they do, these problems don’t have much context about them. My brain injury gave me the sensation that there was a sense coming from what they were, how other ducks might perceive their weaknesses, the lack of confidence they have registered in their lives. Suffice to say, the photographer has experienced all of these.
Outreach in the Community
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 via the Internet

Brain Injury X-Posed: The Survivor's View

Laura Lorenzo, 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.
4 - 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 hmmm

[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
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?”
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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
A Multiplicity of Selves Accepts Each Other

New B.I. Self

Old Self

Patient

Spouse

Parent

Worker

Friend

Artist

Lorenz, 2010
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.
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?
### Health-Related QOL Domains

<table>
<thead>
<tr>
<th>Function Domain</th>
<th>Participant Rating</th>
<th>Clinician Rating</th>
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</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>50%</td>
<td>34%</td>
</tr>
<tr>
<td>Social</td>
<td>23%</td>
<td>26%</td>
</tr>
<tr>
<td>Physical</td>
<td>14%</td>
<td>17%</td>
</tr>
<tr>
<td>Cognitive</td>
<td>11%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Carlozzi et al 2011 –The key here is the 4 domains
Emotional Health

...this picture symbolizes what living with brain injury can be like....On an overcast day...I gazed up at the sky and took this picture through a tube. ...In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear... (Brain Injury X-Posed: The Survivor’s View 2007)
Having Mark in my life helps me to avoid “meltdowns”---episodes lasting hours during which I get severely confused, depressed and irrational. I can’t talk coherently, I take off some of my clothes in public, I feel like I want to die, etc.---by constantly and carefully observing my behavior and coaxing me back into reality whenever necessary---often several times a day. What Mark communicates to me at these times is honest and comforting: “Your brain was damaged in a car accident. It’s not your fault. You are still a good person. And I love you very much.” Living with brain injury without Mark is unthinkable. (Brain Injury X-Posed: The Survivor’s View, 2007)
Physical Health

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. (Brain Injury X-Posed: The Survivor’s View, 2007)
Cognitive Health

Using crossword and word searchers to reconnect pathways in the brain. (Brain Injury X-Posed: The Survivor’s View, 2007)
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”
5 – Conclusion and Q&A
Photojournalism raises issues from “outsiders” perspective
With photovoice, “insiders” use voice and reach policymakers
Reflection Questions

• 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!

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