Experience and Practice with Visual Illness Narratives: Examples of Brain Injury Survivors

Guest Lecture: Health and Gender, University of Toledo, Professor Mark Sherry

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Goal Today

Share my path into using visual methods with individuals with brain injury

Show some benefits and challenges of using participatory visual research methods to:

- Understand lived experience with health and healthcare
- Uncover hidden information
- Inspire mutual learning
- Challenge our assumptions
Outline Today

1) Introduce myself, my path, and my motivations
2) Briefly introduce my research study on lived experience with brain injury
3) Introduce participatory visual methods – photovoice and photo elicitation
4) Share photos and captions by brain injury survivors
5) Discuss some challenges in doing this work
6) So what? Discussion/Conclusions
Glossary

**Acquired Brain Injury (ABI):** An injury to the brain that occurs after birth and results in deterioration of brain function

**Traumatic Brain Injury (TBI):** Harm or damage to the brain caused by a sudden jolt, blow or penetrating head trauma that disrupts brain function

**Lived experience:** An understanding of the nature or meaning of our everyday experiences

**Participatory visual methods:** Research in which participants produce visuals related to their experiences and lives
My Background
My Background
My Background
My Background
My Background
Inspiration
Value

I am a normal person with part of my head off in Never Never Land. (Will I ever retrieve it?)

Prigatano, 1989
Including Survivors’ Perspectives:

A Social Justice Issue
Study Purposes

1) Gain an understanding of brain injury survivors’ experiences living with brain injury

2) Use visual research methods to promote dialogue about lived experience with brain injury

3) Uncover new knowledge about health policy issues related to brain injury

4) Explore how visual methods could be used in therapeutic settings
Sample: 14 ABI Survivors

6 TBI survivors accessing outpatient services at a rehabilitation hospital

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

Ask people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)
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Original Photovoice Path
Mdantsane Township
South Africa
2001
Participant Photo-taking Practices

- Disposable cameras with 27 exposures each
- 1 to 3 cameras each
- 15 to 50 photos each
- Photo content over artistic quality
- Family snaps okay
- Giving camera to others okay
The exhibit themes became a narrative—and a metaphor for "the journey" of living with and healing from brain injury:

The Journey
Lost Dreams
Chaos
Strategies
My Advocacy Story
Comfort and Support
Acceptance
Hope for the Future
A photo that has inspired many others since.

What do you see?

Source: Pre-pilot study 2005
Photographer: Laura Foley
...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
The previous photo inspired this one. What do you see?

Source: Brain Injury X-Posed 2006
Photographer: Judy S
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
What do you see?

Source: Brain Injury X-Posed 2006
Photographer: David S
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.
This photo became the representative image for the group exhibit.

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
Making Visible the Invisible:
Using Photovoice to Understand Living with Brain Injury
Laura S. Lorenz, PhD, MA, MAEd1, Barbara Webster, Barbara Foley2

Abstract. Rehabilitation professionals have advocated for gaining an insider or patient perspective on living with disability, including brain injury, and facilitators and barriers to rehabilitation (Pigott, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al., 2005) and provide an opportunity for those with a chronic condition to play a participatory-expert role in the research process (Booth & Booth, 2003; Boyer, 1993; Bickel et al., 1998). Action research in the tradition of Kurt Lewin involves integrating science and practice in a dynamic group setting and emphasizes the combining of science and social practice (Adelman, 1993). For this study, carried out from September-November 2006, members of the “Amazing” Brain Injury Survivor Support Group in Framingham, MA participated in a 10-week photovoice project (Wang, 1999), supported by BIA-MA and ShIFH. The participating survivors took photographs of living with their brain injury; discussed them in a group, wrote narratives to accompany selected images, and prepared an exhibit to inform and educate policymakers, providers, and peers. Grouped under nine categories, including Choice, Strategies, and Hope for the Future, the images and narratives convey these survivors’ challenges and sense of mutual support as they work to accept their different abilities and move on with their lives.

Research Objective. To gain an understanding of lived experience with brain injury and the issues, concerns, and strengths of brain injury survivors living in the community, while providing an opportunity for survivors to reflect on their lives, use their brains, and employ a variety of cognitive skills.

Sample. The participants are members of the “Amazing” Brain Injury Survivor Support Group, which meets twice a month at the Merritt Wellness Center in Framingham, MA. Eight members volunteered to participate in the study. All are long-term survivors, having received their injuries between three and 31 years prior to the start of the project. Six are traumatic brain injury survivors, one had a malignant brain tumor, and another had a non-malignant brain tumor with co-occurring stroke.

Study Design. This was a participatory action research study using photovoice, a type of action research in which people represent their lives, points of view, and experiences using photographs and narratives (Wang et al., 1999). Action research in the tradition of Kurt Lewin involves integrating science and social practice in a dynamic group setting (Adelman, 1993). The first author, a doctoral student with extensive photovoice experience, worked with two co-authors: the support group founder and a group member with photovoice experience.

The photography and discussion phase lasted 10 weeks, from September to November 2006. Using disposable cameras with 37 exposures, the participants took photographs of living with brain injury from their perspective and discussed them together as a group. They wrote narratives for images that they selected for exhibit, and grouped their photographs and narratives, into nine categories. They held a trial exhibit and reflected on their experience with this project. The group initiated an outreach phase in January 2007, and their efforts are ongoing.

Principle Findings. Taking photographs triggered participatory reflection on their situation and what they wanted to convey to others about living with brain injury. Talking about their photographs with the group prompted deep discussions of emotional (and other) issues that had not surfaced during regular support group meetings. The participants’ images and narratives convey their challenges and sense of mutual support as they work to accept their different abilities and move on with their lives. Study data indicate that the perspective of these survivors, reeling from brain injury is a gradual process that continues for years.

Conclusions. This research project provided the participating brain injury survivors an opportunity to play a participatory-expert role in the research process (Shiraaz et al., 1998; Boyer, 1993). The outreach phase is providing new opportunities to use their expertise to engage other audiences and benefit their families. This project helps to provide a voice for people with brain injuries, in a supportive environment. Participating in this study became a meaningful experience for the participants and facilitators alike.

Implications for Policy and Practice. Rehabilitation professionals have long advocated for gaining an insider or patient perspective on living with disability, including brain injury (Pigott, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al., 2005).
Living with Frustration & Confusion

This man could no longer perform his usual family roles

EXERPT 1: Cans in the Sink
"The disorder that I'm living with right now"

It was supposed to make a point
I keep getting confused and lost
Now everything is disorganized
I feel like I'm living in chaos and it's hopeless
These are appropriate pictures

EXERPT 2: Stuffed Refrigerator
"Nothing's where it belongs"

Too much stuff we never eat
I can't taste
I can't cook
I'm embarrassed to tell people

EXERPT 3: Vegetables on Display
"A supermarket is just, utter confusion to me"

I get confused in here
I'll forget
I just, trying to organize things in my brain
I want to laugh at myself
I was taking pictures of the confusion

EXERPT 4: Summer Salad
"It just has a feeling in your mouth, like rubber"

This is a sad thing
This is part of summer
Couldn't taste a damn thing
This used to be one of my favorite things
Cans in the Sink: “The disorder that I’m living with right now”

It was supposed to make a point
I keep getting confused and lost
Now everything is disorganized
I feel like I’m living in chaos and it’s hopeless
There are appropriate pictures
A Friend’s Floor: “I was trying to get the darkness & the light”

That’s just a friend’s floor
The world of my belief that...meets with...the reality
I convince them and myself that I’m my “old self”
Then the reality keeps comin’ up
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
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
- Parent
- Spouse
- Old Self
- New Brain Injured Self
- Worker
- Friend
- Artist
Challenge: Off-topic Photos

O’Hare Airport in Chicago – People in their own worlds waiting for their planes. We are all waiting for a better flight and good times.
Lost Dreams

...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...
Challenge: 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.
So What? Mutual Learning

- Using the camera results in a shared experience of living with brain injury
- The process evokes emotion: basic to learning
- Participants use their cameras to make sense of their experience—and to teach us
- Their photos and conversation help us to see brain injury in a different way—sympathetic and respectful
So What? Conclusions

• Using the camera brings the environment and ‘real lives’ into health policy and practice

• Participants exercise power and leadership in the research context

• Their stories show that healing progresses over time, even years

• This type of participatory research promotes a model of health care founded on justice and treating patients (not diseases)

• For this work, the camera is a tool for justice
So What? Policy Implications

• **Dialogue**: an underlying aspect of person-centered care

• **Narrative inquiry methods**: Encourage dialogue, mutual learning, and sharing of emotions—empathy

• **Person-centered care** can lead to better outcomes for ABI survivors

• Use visual methods especially to **elicit emotions** and lived experience

• There is potential to transform visual illness narratives so they become **visual healing narratives**


Thank you!

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