Brain Injury X-Posed: Seeing Life with Brain Injury Through Survivors’ Eyes

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Goal Today

Show the power of participatory visual research to:

• create awareness about brain injury
• inspire mutual learning among researchers and survivors
• encourage survivor healing
• generate action
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
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My Background
Inspirations

Prigatano, 1989
Foundations

Patient Perspective on Quality of Care

- Patient Satisfaction
- Relationships: Information & Emotional Support
- Star Quality
- Amenities & Convenience
- Decision-making Efficiency
- Patient Outcomes Related to QOL

(Chilingerian, 2004)

Fair Process

- Evaluating
- Engaging
- Exploring
- Expectations
- Explaining
Including Survivors’ Perspectives: A Social Justice Issue
Study Purposes

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

2) Use visual research methods to promote researcher-participant dialogue about living with brain injury

3) Uncover new knowledge about personal, community, and health policy issues related to brain injury

4) Provide participants with an opportunity to reflect on their situation and use their brains
Sample: 14 ABI Survivors
**Participatory Visual Methods**

**Photo elicitation** (Harper, 2002): Inserting a photograph into the research interview to “understand the world as defined by the subject” (p 757)

**Photovoice** (Wang & Burris 1997): A type of action research that asks participants to represent their lives, point of view and experience using photographs and narratives

For my study, all photographs were taken by participants
Photovoice Path

What we did
8 Photovoice Participants

- 6 have survived TBI, and 2 have survived brain tumors
- Injured between 3 and 31 years ago
- Four were working part-time or volunteering in their communities
- My 2 co-facilitators are also brain injury survivors
- **Original project:** 10 weeks from Sept-Nov 2006 and outreach is ongoing
Photo-taking Assignment

- Participants used cameras to show their point of view on living with ABI and things that help or slow down their recovery
- They used disposable cameras with 27 exposures each
- Each participant used 2 or 3 cameras and took between 15 and 50 photos
- Photo content was emphasized over artistic quality
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 snowbank. You lift the gas pedal, and all the ton does is spin. Now imagine yourself trying to run on ice without wearing a pair of skates. The faster you run, the more you fall over. 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 nowhere accomplished.

Thank God there's a handrail

This is the front steps of where I'm living. There are three main steps. It makes it difficult to walk up there. 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. Next week, my first reaction is to move forward by.

Spinning Time: On Movement

Spinning Time: On Movement

On days, 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 actions. This, putting things in places that have no meaning. Like keys in the freezer.

Fitting the pieces into my life

When photos of every week there is something in my life that was once always and as I move into the air, that is in a subtle change and almost unnoticeable. The biggest challenge is to stop taking these questions and move on to fitting the pieces into me without answering all the questions. There is no great answer. Many is at it is.

Walking around with my head in the clouds

Since my brain injury, my brain has been turned upside down. I have become aware of my mental habitat. Conseal me in my mental health, and I am not comfortable. You’re doing it. I am in my mental and under my head in the clouds.

Life as a duck

I took pictures of this Brandeis duck because I noticed it was when I saw that there really might be something going on. They didn’t have brains. They can’t do the best. They could do better and. It goes deep, they probably don’t care more. Consistently about what other. When they estimate their ducks. For me, they are different. They are not thinking about anything. The lack of confidence. The magnitude to this have. Suffice to say, the photographer has experienced all of these.
The Journey

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....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........
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...
I feel chaos. I leave the dishes to be done later. I procrastinate…I make no time for completing my tasks…I watch cable television or daydream so I don’t have to deal with what I should be doing. This is the piano that I should and would love to learn how to play. I must practice.
…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.
Strategies

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.
These are my counselors at Metro West Independent Living Center. They helped me to focus by bringing me to the statehouse to talk to my Senator and Representative.
Comfort and Support

With TBI certain parts of my life have added much comfort and support. God has blessed me with Teddy and Betty Marie. They welcome me home with hugs and slurps, we eat together, they sleep beside me and muzzle their noses into my neck and face to gently wake me in the morning. They delight me with their personalities and antics. They warm my heart and comfort me. They make me smile and laugh. God has Blessed me with a little glimpse of heaven.
Whose grave is this? Surely it’s not mine. This is not my fate, is it? I need to make the best of this situation, but how? It’s all suddenly complicated...This was not my doing, nor my choice! I’m trying to be gracious. I need to accept this death of my “old self.”
Hope for the Future

New Identity. New passion of gardening. First baby step was planting in containers so as to not fall into dirt because of imbalance. My garden has progressed as my new life has. Now I not only can plant in the ground, I dig up grass and now have three perennial gardens.
Scientific Poster: Seeing the project as research, and brain injury survivors as researchers.
Flexible, Informal Exhibit
Some Reflections

- Photovoice allows participants to share both a personal story and a group story.
- The formal exhibit depicts a group narrative that takes a storied form.
- Acceptance appears to be a goal for many participants.
- Healing from brain injury is not linear (does not follow a straight line).
Brain Injury X-Posed: TBI and Our Vets

A major outreach effort 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 Continues

In March, exhibit at Massachusetts’ State House—proclamation by Governor
So What? Mutual Learning

- Photovoice results in shared experiences: An “interpretive account” of living with brain injury
- Both the process and the products evoke emotion: basic to learning
- Survivors use photovoice to make sense of their experience—and to teach us
- Survivors help us to see brain injury in a different way—sympathetic and respectful
So What? Conclusions

- Using photovoice brings the environment and ‘real lives’ into health policy and practice
- Survivors’ exercise power and leadership with photovoice
- Results show that healing progresses over time, even years
- Participatory research promotes a model of health care founded on justice and treating patients (not diseases)
- Photovoice is an example of fair process in action
- With photovoice, the camera is a tool for justice
Thank you!

And especially, thank you Theresa Rankin, for inspiring us all.

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