



**Making Visible the Invisible:
Using Participatory Action Research to Understand
Living with Brain Injury**



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In Spring 2006 I took an introductory course to narrative analysis with Catherine Riessman at Boston College. My presentation for that course formed the basis for this paper and informed my dissertation proposal.

Today

- Brain injury overview
- This study: Objectives, participants & co-facilitators, methods
- Sample photos & text from exhibit
- Conclusions
- Implications
- References

Brain Injury Overview

- Acquired brain injury (ABI)
- Traumatic brain injury (TBI)
- Cause loss of memory & executive functioning, personality changes, & depression
- Invisible to patient, family, friends, & even health providers
- 1.4 million new TBIs each year in U.S.
- 80 to 90,000 new disabilities per year

A head injury is visually apparent from bruising or lacerations, while a TBI may not be evident visually or clinically; thus, a brain injury may be “invisible” to the patient, family and friends, and even providers (Jagoda et al, 2002). The public health problem of TBI is also “silent,” as the public is generally unaware of both the level of incidence per year—1.4 million new injuries diagnosed in emergency departments in the United States each year, and the injury’s impact—80,000 to 90,000 new disabilities in the United States each year (Langlois et al, 2005; Langlois, 2004).

Study Objectives

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

This was an exploratory study intended to inform my dissertation. I recruited and worked with just one respondent. As specified by my research protocol, she had a cognitive level of at least 7 on the Ranchos Los Amigos Cognitive Level Scale (1 being lowest and 10 being highest), and she received her injury no more than five years ago. We met three times: once to discuss the project and go over the informed consent form, again so I could pick up the camera, and a third time to discuss her photographs. Before giving her the camera, I asked her to take photographs of living with TBI and facilitators and barriers to recovery from her perspective. The camera was a disposable one with 27 images, and I asked her to give it back to me in two weeks. She finished the film after three weeks, and we met a week later to talk about her pictures. We spoke for four and a half hours. For more than two hours she talked about her process taking the photographs and shared some family snaps of people she couldn't photograph for the study. For the last two hours we went through her photos one by one, and she talked about what they meant for her, why she had taken them, and how she had settled on or created the particular images.

Participants and Co-facilitators

- 8 participants in their 40s and 50s
- Members of the 'Amazing' Brain Injury Survivor Support Group, Framingham, MA
- Injured 3 to 31 years ago
- 6 TBI survivors and 2 brain tumor survivors
- Most work part-time and/or volunteer in their communities
- My 2 co-facilitators are also TBI survivors

Methods

- PAR using photovoice
- 10 sessions, from Sept-Nov 2006
- Participants took photographs of living with brain injury from their perspective
- They chose photos to discuss with the group
- They wrote personal narratives for the images that they selected for exhibit
- They grouped their photographs and narratives into categories and named them
- Outreach efforts are ongoing

The Journey



It's a muddy, ruddy, 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...

Chaos



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.

Challenges



...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.

My Advocacy Story



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.

Acceptance



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.

Some Conclusions

- The participants played a participant-expert role in this research
- The outreach phase is providing opportunities to use prior experience with communication, layout, and group dynamics in a supportive environment
- This study became a meaningful experience for participants and facilitators alike

Implications for Policy & Practice

- This type of research helps us gain an insider or patient perspective on living with a chronic condition
- Involving individuals with a disability in research about their lived experience may increase the relevancy of research to real-life situations
- From the perspective of these survivors, healing from brain injury is a gradual process that continues for years

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