



Making Visible the Invisible:

Using Action Research to Understand Living with Brain Injury

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Today

- Brain Injury Overview
- Research Objectives
- Population Studied
- Study Design
- Participant Photos & Text
- Conclusions & Implications



Brain Injury Overview

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



Research Objectives

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
- employ a variety of cognitive skills

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Population Studied

- 8 participants in their 40s and 50s
- Members of a brain injury survivor support group in Framingham, MA
- Injured 3 to 31 years ago
- 6 TBI survivors and 2 brain tumor survivors
- 5 work part-time and/or volunteer in their communities

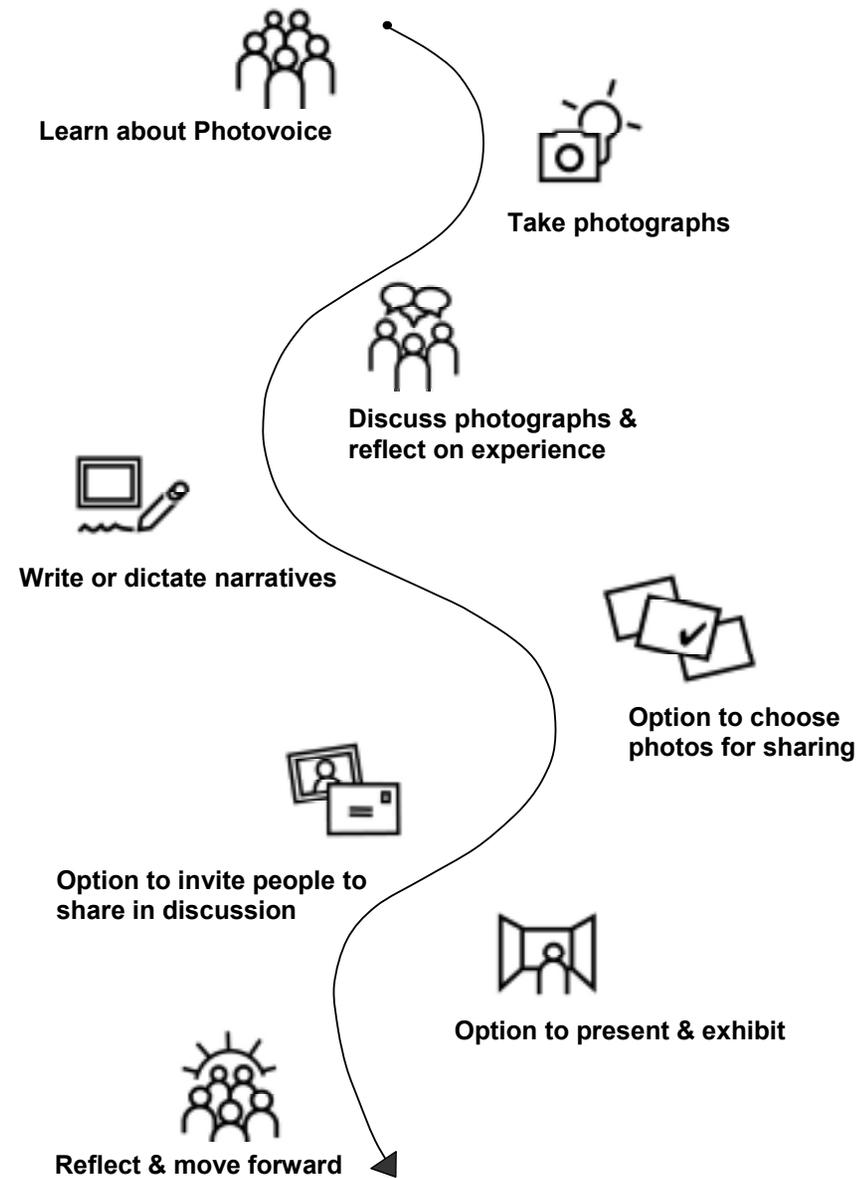


Study Design

- Photovoice: Representing lives, point of view, and experience using photographs and narratives (Wang et al 1996)
- Action research: Integrating science and social practice in a dynamic group setting (Adelman 1993)
- 2 co-facilitators, also TBI survivors
- 10 sessions, from Sept-Nov 2006 culminating in a trial exhibit
- Outreach efforts continue



A Photovoice Path





Brain Injury X-posed: The Survivor's View

- Participants grouped their 50 photos and narratives into 9 categories and named them
- The Journey, Lost Dreams, Chaos, Challenges, Strategies, My Advocacy Story, Comfort and Support, Acceptance, Hope for the Future
- They chose the background color for each category
- Here: one photo from each category, and at least one photo per participant



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.... 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 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

- Taking photos triggered participant reflection on their situations & what they wanted to say
- Talking about the photos prompted deep discussion of emotional and other issues
- The participants played a participant-expert role in this research
- This study became a meaningful experience for participants and facilitators alike
- The outreach phase is providing opportunities to use prior experience in a supportive setting



Implications for Policy & Practice

- Helps us gain a patient perspective on living with a chronic condition (Prigatano 2000)
- Involving individuals with a disability in research may increase relevancy to real-life situations (Rich et al 2000)
- From the perspective of these survivors, healing from brain injury is a gradual process that continues for years



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