

Making Visible the Invisible: Using Photovoice to Understand Living with Brain Injury

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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.

Study Design. For this action research study, eight members of the Amazing Brain Injury Support Group in Framingham, MA participated in a 10-week Photovoice project. Photovoice is a type of action research in which people represent their lives, points of view, and experience using photographs and narratives (Wang et al., 1996). Action research in the tradition of Kurt Lewin involves integrating science and social practice in a dynamic group setting (Adelman, 1993). The author facilitated this project with two brain injury survivors: the support group founder and a group member with Photovoice experience. Using disposable cameras with 27 exposures, the participants took photographs of living with brain injury from their perspective and discussed them in a group. They chose which photographs to discuss during the meetings and include in the exhibit. In two instances adding photos taken before the start of the project. They wrote personal narratives for their selected images, developed the exhibit categories, and purposefully chose the colors. The group initiated an outreach phase in January 2007, and their efforts are ongoing.

Population Studied. The participants are members of the Amazing Brain Injury Survivor Support Group, which meets twice a month at the Metrowest 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, and two had brain tumors (one with a co-occurring stroke). Five have been working or volunteering part-time in the community.

Principle Findings. The participants entitled their final exhibit, "Brain Injury X-Posed: The Survivor's View," which contains 50 photographs and narratives grouped under nine categories: The Journey, Lost Dreams, Chaos, Challenges, Strategies, My Advocacy Story, Comfort and Support, Acceptance, and Hope for the Future. Taking photographs triggered participant 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 from the perspective of these survivors, healing 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 participant-expert role in the research process (Balazsar et al., 1998; Bryman, 1993). The outreach phase is providing new opportunities to use prior experience with communication, layout, and group dynamic skills in a supportive environment. Participating in this study became a meaningful experience for 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 (Pigazzari, 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., 2000).

Examples of Project Highlights

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The Journey

Maybe there will be a good view



...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...
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 end and will not end...Sometimes weekly, and sometimes daily there is a new step to attempt to get to your "true 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

A light at the end of the tunnel?



...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...
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Chaos

I feel 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 daytime tv. 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.

Inside my head is scrambled



The shell of my life became broken. Inside my head is scrambled with strands of my life no longer bonded.

Trying to run on ice



...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.

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, dancing, talking, laughing—but having a good time. Draw since my brain injury, I never felt more alone than when I was in a crowded room full of people. It was 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. Thus, I was always one or two conversations behind. If someone told a joke and everyone laughed, I never would laugh. However, I was not laughing at the joke because I couldn't understand the joke. I laughed along with everyone as to not be left out of place. Yet, this made me feel even more alone and out of place.

Strategies

To compensate for my poor memory and organizational skills



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 BB? 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.

Determined to remake my life



I was depressed after two brain surgeries: one to put in a shunt and one to clean up the blood on my brain. I was unable to walk. That's why I'm in the wheelchair. It took me a year and a half to learn how to walk. When I was learning how to walk, I was determined to remake my life, ergo my advocacy story. Perseverance has helped me reach my goals: an apartment and a job.

My Advocacy Story

They helped me



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

They make my heart sing



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 burps, we eat together, they sleep beside me and ruzzle 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

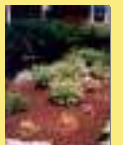
I need to accept this death of my "old self"



Whose grave is this? Surely it's not mine. This is not my fate, no 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 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.