Using visual metaphors to communicate lived experience with an invisible injury

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Outline Today

• Intro to Photovoice
• Visual metaphors
• Examples of visual metaphors by brain injury survivors
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• Conclusion
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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Participant Photo-taking Practices

- Disposable cameras with 27 exposures each
- 1 to 3 cameras each—15 and 50 photos each
- Photo content more important than artistic quality
- Some participants contributed family snaps
- Some gave the camera to others
- 24 of the 50 photos they discussed and selected for wider sharing were visual metaphors
A Photovoice Path

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Photovoice

• Photovoice is participatory action research (Lorenz and Kolb 2009)
• Similar to qualitative interviews, furnishes opportunity to have a voice—a say—in a research context (Mishler 1986/1991)
• Goes further than qualitative interviews by providing:
  a) Multiple occasions to share experience
  b) Opportunities to contribute to data analysis, codifying efforts, policy and outreach (Wang, Yi, Tao, and Carovano 1998)
Metaphor

• Transfers the attribute of one entity to another: e.g. “crazy as a loon”
• Allows people to express experiences and feelings that may be difficult to convey through words alone or are otherwise elusive (Ortony 1975; Charon 2006)
• Is commonly used in everyday communication—but the metaphors they used were not “common”
How Photovoice Works

Creating visual metaphors of experience involves

• Critical thinking
• Giving shape to understanding
• Distilling the meaning of experience (Wang et al 1998; Feinstein 1982)

Discussing visual metaphors and writing about them for outside audiences

• Contributes to making meaning and coping with the realities portrayed (Charon 2006)
Inspiration for this Study

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

Prigatano 1989
A visual metaphor 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 visual metaphor. **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 visual metaphor 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, MEd, Barbara Webster, Laura Foley

Abstract. Rehabilitation professionals have advocated for engaging 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 relevance of research to real-life situations (Rich et al., 2000) and provide an opportunity for those with a chronic condition to play a participant-expert role in the research process (Booth & Booth, 2000; Broyde, 1993; Sikazwe et al., 1998). Action research in the tradition of Kurt Lewin involves integrating science and practice in a dynamic group setting and emphasizes the coming together of science and social practice (Adelman, 1993). For this study, carried out from September-November 2006, members of the ‘Amazing’ Brain Injury Support Group in Framingham, MA, participated in a 10-week photovoice project (Wang, 1998), supported by BMA-MA and SHIP. The participating survivors took photographs of their brain injury and 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 Chaos, 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 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, 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 closely 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 them thematically and sarcastically. They held a tri-weekly 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 participants’ reflection on their situation and what they wanted to convey to others 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 (Sikazwe et al., 1998; Broyde, 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 engaging 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 relevance of research to real-life situations (Rich et al., 2000).
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
Discussion

- Visual metaphors bring emotions and life experience into the research conversation (Lorenz 2010; Berland 2007).
- Taking photographs that depict metaphors gets at tacit (invisible) aspects of experience—both suffering and healing.
- Visual metaphors contribute to dialogue as they create a bridge between the lifeworld of the survivor and the larger society and foster new knowledge (Shiff 1979)
- Creating visual metaphors that reflect experience is a cognitive act.
Discussion

• Although visual metaphors are “frozen records” of reality, the act of creation changes experience and reality (Feinstein 1982).
• The symbolic nature of metaphors encourages audiences to construct new meaning through the lens of their personal experience.
• Negotiating meaning can lead to developing new insights and meanings—all cognitive processes that can contribute to healing from brain injury (Ylvisaker et al 2008).
• Dialogue about abstract representations of life experience can be transformative when it helps survivors to gain perspective on their lives and helps audiences to gain greater awareness of and empathy for survivors’ struggles in turn.
Discussion

• Does the transformative nature of photovoice stem from the fact that it is a PAR methodology?
• Does the transformative aspect require a group context?
Experience with individual survivors suggests that the group context is not essential.

What do you see?

Source: Personal photovoice project 2009

Photographer: Molly R
I was like a bird hatching and ready to leave the nest to try a new beginning. Did I have the courage to fly on my own? I sure was scared. Now I know I can soar, yes I “can”.

Source: Personal photovoice project 2009
Photographer: Molly R
Conclusions

• Visual metaphors played an important pedagogic role in communicating experience and emotional reality (Ortony 1975).
• They stimulated new associations and tapped ‘new, different, or deeper levels of meaning’ (Feinstein 1982)
• Grouping photos and captions into themes fostered a sense of shared experience among participants and resulted in an ‘interpretive account’ of living with brain injury (O’Connor and Chamberlain 2000).
• Study process and products appear to have helped participants and audiences to see lived experience with brain injury in a different way, perhaps more sympathetic and respectful.
• The mutual learning that occurred affected me as well.
What do you see?

Source: Lorenz 2008
Photographer: Author
Conclusions

• Metaphor: the way the brain travels (Charon 2006).
• In creating visual metaphors, participants “traveled” to the past and the future, to reveal the pain they feel at their losses and to share their sources of hope.
• Visual metaphors have allowed participants to transcend time, place, and their identifying condition of brain injury (Radley 2009).
• Photovoice helped brain injury survivors to overcome communication and memory challenges and experience success at having a say in research, policy, and clinical contexts.
Conclusions

• Photovoice exhibit presents a multifaceted view of brain injury:
  Negative view—Lost Dreams
  Positive view—Acceptance

• **A danger:** Seeing participants as so capable they no longer need assistance

• **Greater danger:** Seeing brain injury survivors as merely victims, and not as feeling actors on a journey similar to our own: to find meaning and purpose in life
References


Thank you!

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