Enacting Emotional Engagement with Healing from Brain Injury: Taking Photographs and Writing Text

Disability Activism: The Art of Grassroots Movements
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Outline

• Background/Introduction
• Examples from the brain injury rehabilitation literature
• Examples from participatory visual research with individuals living with disabilities from brain injury
• Discussion
• Conclusion
• **50,000** will die annually as a result of TBI
• **80,000** annually experience the onset of long-term disabilities following TBI
• **5,300,000** Americans currently live with a disability as a result of a TBI

Plasticity of the Central Nervous System

• Until recently, the brain was seen as having limited potential for recovery – esp >6 mo post-injury\(^1,2\)
• Now brain recovery is seen as dynamic, with new cells forming for recovery of function or compensation of lost function\(^3\)
• Long-held beliefs that body (emotion) and brain (cognition) are separate are being shattered\(^4\)
• Neuroscience, social science, and lived experience are challenging old paradigms

1- Cope, Mayer & Cervelli 2005; 2- Thomas & Pollio 2002; 3- Raskin 2011; 4- Stafford 2011
Emotion and Cognition – Separate or Related?

- Rene Descartes proposed that they work separately.
- Current understandings suggest that emotion and cognition work together to influence learning, behavior, and perception of self\(^1\).
- Agreement is growing that emotion plays a major influence on cognitive behavior\(^2\).
- Emotions may be the way we grasp and hold knowledge – e.g. Active knowledge\(^3\).
- Is engaging emotions thus essential to cognitive healing?

1- Damasio 1994; 2- Simon 1967; 3- Polanyi 1958
The Challenge of Emotion in Brain Injury Healing

- Anger, grief, low self-esteem, and feelings of fragility may inhibit healing from brain injury.
- Feelings are vital to reflect on and share in a safe environment – yet difficult to verbalize\(^1\).
- Visuals – photos, videos, drawings, paintings – may enhance the ability of individuals with brain injury to talk about difficult or embarrassing topics, e.g., emotions\(^2\).
- Writing in turn can help to reduce anxiety and depression\(^3\) and increase self-esteem and optimism\(^4\).

Now let’s see some examples from the literature of visuals created by individuals living with disabilities from brain injury
Mary Feldhaus-Weber created paintings of her brain and brain injury to discuss with clinicians\(^1\).

“The painting gave me something to talk about other than myself. Something to talk about when people came to the house. It was a relief to have something to show someone, to have them look at pieces of paper, not to look at me. It also gave me a way to try to talk about what I was living through.”

\(^1\) Feldhaus-Weber 2003:51
Pain #2: 1987 – More pain, more feeling trapped and desperate. I felt this way a long, long time. My painting was often the only way I had to express it.

1- Feldhaus-Weber 2003:56
White Brain: At a certain point I began to make my brain pictures more “decorative,” artistic. I was no longer obsessed with understanding the damage. I was beginning to integrate my feelings about the head injury.

1- Feldhaus-Weber 2003:56
I am a normal person with part of my head off in Never Never Land. (Will I ever retrieve it?)
• Now let’s see some visuals and text created by individuals with brain injury for a research purpose – to understand their lived experience with brain injury
Participants: 8 members of a brain injury survivor support group supported by BIA-MA; & 2 BI co-facilitators; and 6 individuals accessing hospital outpatient services
A Photovoice Path

Ask people to represent their lives, point of view and experience using photographs and narratives\(^1,2\)

1- Wang & Burris, 1997; Lorenz 2010
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After my automobile accident, I was laid up for a long time healing from some serious physical injuries along with my brain injury. I used to spend hours looking out my window staring at this one tree in my backyard. I would marvel at its beauty and strength.

To pass time, I began counting its leaves as they fell to the ground. When it shed all its leaves, I saw branches branching off in all directions. Today, when I look at a bare tree, I no longer see these branches. Rather, I envision my brain trying to generate new pathways.
So, all these trees were green and turning yellow in late September and then into October, and I sort of remember fixating on the one bright red leaf among all the yellow leaves, and I remember thinking, wow, not knowing how long my recovery would take, thinking well, I’ll probably spend the fall here watching all the leaves fall down, and then maybe that will be how I mark time, you know…
Before brain injury, I was a busy doctor. Now I am a retired, handicapped doctor who goes to Spaulding Rehabilitation Hospital in Boston for weekly support groups and therapies.
It’s a beautiful day, but we ARE in a graveyard. My life now has great moments of beauty and peace, BUT I am not where I thought I would be. I feel both grateful and cheated by this turn of events.
That’s an example of me trying to be helpful…my wife doesn’t enjoy doing laundry… what brings me pleasure is reducing her burden, and so in that way, it is pleasurable, and you want to be a good dad, too, and the laundry is there, and you can imagine, three boys so….
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.
Discussion

• Visuals (drawings, paintings, photos) open ‘discursive spaces’ that invite exchange and empathy\(^1\)
• They spur ‘invisible mental leaps’ in understanding\(^2\)
• They become a bridge that helps to connect the present, past, and future
• They enact a visual voice that communicates experience – a type of self-activism – challenging the out-dated paradigm that recovery has an endpoint\(^3\)

1- Katz & Shotter 1996; 2- Stafford 2011; 3- Burton 2000
Conclusion

• Creating visuals and writing text provide opportunities to grieve\(^1\) and to celebrate strengths
• Yet psychotherapy is rarely offered to brain injury survivors\(^2\) – often they must do this type of healing work on their own or with peers
• Conceptually creating visuals and text can foster incremental and never-ending learning that allows for inventive wandering into new territory\(^3\) – perhaps meaning and hope

1- Chamberlain 2006; Feldhaus-Weber 2003; 2- Prigatano 1991; 3- Stafford 2011
References


Thank you!

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