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

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Approximately 5.3 million Americans whose injuries were diagnosed in hospital emergency departments are estimated to be living with a long-term disability after being hospitalized for TBI, and the true number of persons living with TBI-related disability likely is much higher (Langlois, Rutland-Brown, and Wald 2006). Worldwide an estimated 10 million people are affected by long-term deficits from TBI (IOM 2011). Between 80,000 and 98,000 persons hospitalized for TBI each year in the U.S. have chronic issues with brain function (Faul et al. 2010). Thus brain injury is an important and persistent public health problem in the U.S. and elsewhere.

Acceptance of the plasticity of the central nervous system (including the brain) has replaced the old “hard-wired” model (Cope, Mayer, and Cervelli 2005), in which individuals were expected to have limited potential for recovery from brain injury beyond six months post-injury (Thomas and Pollio 2002). Instead, brain recovery is now seen as dynamic, with the brain forming new cells that play a role in recovery of function (Cope et al. 2005) or in compensation for lost function (Raskin 2011). Current understandings suggest that any individual, no matter their age, could benefit from rehabilitation intended to improve brain function, although any one individual’s ability to improve is uncertain (Raskin 2011). Researchers, philosophers, scientists, and artists are now shattering long-held beliefs that body (emotion) and brain (cognition) are separate (Stafford, 2011), perhaps inadvertently providing a basis for challenging policies that limit access to cognitive and emotional therapies, and limit access to any type of rehabilitation therapy 6 to 12 months post-injury.

No longer are emotion and cognition seen to work separately, as first proposed in the 1600s by the French philosopher Rene Descartes. Rather, current understandings suggest that they work together to influence our learning and behavior and perception of ourselves (Damasio, 1994). Agreement is growing that emotion plays a major influence on cognitive behavior, and human thinking and emotions have an intimate connection (Simon, 1967). Emotions such as lust and fear are said to be the way “we grasp knowledge and hold” knowledge; further, emotion is
essential to active knowledge, which in turn is the difference between living life and learning from life (Polanyi, 1958: 173).

However, emotions such as anger, grief, low self-esteem, and feelings of fragility may inhibit individuals with brain injury from communicating their feelings and thus may in turn inhibit the process of healing. “Emotions are notoriously difficult to verbalize” (LeDoux, 1996: 71). Visuals—photographs, videos, drawings, or paintings—may enhance the ability of patients to talk about topics that are difficult to articulate or embarrassing.

Feldhaus-Weber (2003: 51), who created paintings of her brain and brain injury to discuss with others (including clinicians), has noted:

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.

Neuropsychologist George Prigatano (2003) has described his work with a young woman who suffered a gunshot wound to the head and with whom he felt he was “getting nowhere” in their therapy sessions. He asked her to go home and “draw ‘anger’” (p. 818). She brought her picture back to the next session:

Her drawing had no mouth and no eyes, but it did have tears. She had a lot of sadness and a lot of anger...She was lonely. She was scared. She was isolated. She was confused. She was angry. She felt like she was falling away from others and not maintaining social contact...I was moved by this picture and told her that she had captured what many brain dysfunctional patients experience....This event was a major turning point in our working alliance. (pp. 818-19)

Visuals (drawings, paintings, photographs) thus make connections between individuals. They open “discursive spaces” that invite exchange and empathy (Katz and Shotter, 1996). They can also be seen to spur “gap-jumping,” or “invisible mental leaps” in understanding (Stafford, 2011: 7). When generated by individuals living with a chronic neurological condition such as traumatic brain injury, visuals can help to level the inevitable power imbalance between persons living with disabilities and their clinicians. Patient-created visuals in effect transfer a measure of power to individuals with brain injury as they enact a visual voice that communicates experience and contests outdated understandings and policies. Taking photographs and talking about them can be seen as an act of continued healing – and a type of self-activism in standing up to contest
out-dated paradigms claiming that recovery has an endpoint (Burton, 2000).

I provide here an example of a photograph and caption taken by an individual living with brain injury to illustrate his own changes in perception of his injury and healing over time (Figure 1). The photographer was part of a participatory research project for which eight individuals living with disabilities from brain injury used photovoice to explore and communicate their lived experience through photographs and text (Lorenz, 2010b). Eight years before joining the study, the photographer was seriously injured in a car accident while traveling to Montreal to buy hockey equipment for his three sons. Formerly a banking executive analyzing large databases, he was not working at the time of the study. He has since begun working as a teacher’s aide in a local elementary school.

Figure 1: From passing time to generating new pathways

After my automobile accident, I was laid up for a long time healing from some serious physical injuries along with my brain injury. During this time, 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.

In this paper I will (1) explore current thinking in neuroscience, visual arts, and philosophy and the implications for healing from brain injury, (2) provide examples of emotional engagement with healing as seen in photographs and text produced by individuals with brain injury for a qualitative research study on their lived experience, and (3) suggest further avenues for arts-based research providing opportunities for individuals who are usually the subjects of research to have a voice in learning and teaching about brain injury and the potential for rehabilitation even many years after injury (Lorenz, 2010a,b; Lorenz, 2011).
References


