Making Visible the Invisible: Understanding Lived Experience with Acquired Brain Injury through Visual Illness Narratives

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Outline

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Acquired brain injury (ABI). Any injury to the brain that occurs after birth and “results in deterioration in cognitive, physical, emotional, or independent functioning”. Examples of ABI include epilepsy, multiple sclerosis, traumatic brain injury (TBI), dementia, and stroke.

Traumatic brain injury. Harm or damage to the brain caused by a sudden jolt, blow, or penetrating head trauma that disrupts brain function.

The study of lived experience seeks “to sense reality and describe it in words rather than numbers” and “emphasizes our ability to relate to the feelings of others” (Bernard, 2000, p. 20). Gaining an understanding of lived experience with brain injury requires personal contact with survivors. It requires qualitative methods.

An illness narrative is a story or account of events describing an individual’s experience living with an illness or chronic condition. A visual illness narrative includes visual images—photographs, video, or drawings, as well as text.
Background

- TBI affects between 1.4 and 3 million people and incurs costs of $48 to 56 billion.
- 5.3 million Americans are living with long-term disabilities from TBI.
- 20-40% of soldiers returning home from Iraq and Afghanistan have TBI.
- Quality of care is a global challenge for ABI patients and long-term survivors.

Every year in the U.S. TBI affects between 1.4 and 3 million people (Langlois et al., 2004; Krause & Chu, 2005) and incurs costs of $48 to 56 billion.

More than 5 million Americans are living with disabilities from TBI (Langlois et al, 2006), and an estimated 98,000 join their numbers every year (Kraus & Chu, 2005).

TBI is the characteristic injury of the Iraq and Afghanistan conflicts, with an estimated 20 to 40% of soldiers returning home with this injury.

Quality of care is a global challenge for survivors of ABI. Qualitative research studies in four countries show that survivors experience lack of recognition and support from health providers for their injury and what they are going through. Getting a diagnosis can take years. People are told they have psychiatric problems. They are not informed about risks, diagnoses, sequelae, or options for rehabilitation services and health care coverage.
In *Crossing the Quality Chasm*, the 2001 Institute of Medicine (IOM, 2001) report on quality and health care, one area targeted for improvement is patient-centeredness, or the patient’s experience of illness and health care. Providing person-centered care is particularly urgent for persons with ABI, for whom each brain injury and each path for healing is different.

Traditional models of rehabilitation “are underpinned by medical principals of cure” (Burton, 2000, p. 301). However, the social dimensions of brain injury recovery and rehabilitation are gaining increasing attention (Burton, 2000).

From the patient’s perspective, quality can be understood in terms of five dimensions: *technical outcomes* in terms of quality of life; *decision-making efficiency* in terms of efficient routes to health; *amenities and convenience*; *information and emotional support* (relationships); and *overall patient satisfaction* (Chilingerian, 2004). This five-pronged concept of quality from the patient’s perspective is illustrated in the Star Quality Model.

The quality dimension of relationships may be improved through empathetic listening and considering the ABI survivor’s life-context. Other dimensions, such as amenities and convenience, are organizational and systemic issues with which clinicians as well as patients may struggle. For example, visit limits of 15 minutes have been described by physician Gretchen Berland as examples of “our dysfunctional health care system” (Berland, 2007).
Study Purposes: To

1) Gain an understanding of brain injury survivors’ experiences living with their injury

2) Use visual research methods to promote researcher-participant dialogue about participant experience living with brain injury

3) Uncover new knowledge about personal, community, and health policy issues related to ABI

4) Explore how the methodology and data from this study can inform clinical and research policy and practice and perhaps be applied in future therapeutic settings

My study purposes included:
1) gaining an understanding of brain injury survivor’s experiences living with their injury;

2) using visual research methods to promote researcher-participant dialogue about living with brain injury;

3) uncovering new knowledge about personal, community, and health policy issues related to ABI;

4) exploring how the methodology and data from this study can inform clinical and research policy and practice and perhaps be applied in future therapeutic settings.
Eleven brain injury survivors participated in my study. Ten were between the ages of 40 and 60 years when they participated, and one was 21 years old. Six are men, and five are women. Eight are survivors of TBI, and two have survived brain tumors.

Three participants were recruited through a rehabilitation hospital where they were accessing outpatient services. The remaining eight were recruited through a Framingham, Massachusetts, brain injury survivor support group.
Methods

- Photo elicitation (Harper, 2002)
- Photovoice (Wang & Burris, 1997)
- Narrative analysis methods (Riessman, 2007)

Photo-elicitation basically means inserting a photo into the research interview to “understand the world as defined by the subject” (Harper, 2002, p. 757). For my study, participants took all photos.

Photovoice is a similar process in a group.

The data collected for this study include 1) field observation notes; 2) photos taken by participants (450 in all!); and 3) transcriptions of conversations about the study photos.

I used narrative analysis methods to analyze my visual and interview data. Narrative analysis is a family of methods that include thematic, structural, dialogic/performance, and visual analysis (Riessman, 2007), and I have used all four approaches.

Narrative analysis is often a case study method. For my study, I selected three participants for more in-depth study. For each case, I identified an illness narrative theme with several photos and their interview text. I analyzed their visual illness narrative by looking at photo details, structuring the interview excerpts into their idea units and parts, and exploring the intersection between image and text.

The three cases are not statistically representative. Rather, I selected them because they appeared to find participating in my study to be meaningful, and their stories in turn seemed meaningful to me. For each person, I will share a quick overview of their visual illness narrative, and then focus on one photo and narrative summary.
The first case is Subject D, a man in his late 50s who was injured about a year ago when he fell down his basement stairs. He was in a coma for several weeks. Before his injury, he was an international development professional for many years, but now he can no longer work and spends most of his days at home.

More than any other participant Subject D used the word “frustrating” to talk about his life with brain injury—five separate times in our interview. A major source of his frustration—and confusion—is his loss of the ability to taste food.

Aspects of food that he finds both frustrating and confusing are cleaning up after it; organizing and storing it; shopping for it; and tasting it.

Now we will look at one photo more closely.
Vegetables on Display
“A supermarket is just, utter confusion to me”

I get confused in here
I'll forget
I just, trying to organize things in my brain
I want to laugh at myself
I was taking pictures of the confusion

Here we see a long shelf of vegetables, neatly arranged. A hidden challenge in this photo and excerpt is Subject D’s loss of executive functioning, which involves setting a goal, then figuring out and accomplishing the steps needed to reach it.

When Subject D talked about his grocery shopping strategies—preparing a list and sticking to it—his sentences shortened and his speech became more staccato. His lines lengthened, however, when he spoke of wandering confused and unfocused from aisle to aisle. Thus, narrative analysis methods help us to learn from the form or structure of data as well as their content.

Working with Subject D, I felt frustrated because I couldn't do anything about his situation, yet I wanted him to feel better about himself. Frustration by providers in the rehabilitation setting for brain injury is common and can lead to anger. Thus, feeling frustrated and being surrounded by frustrated and sometimes angry people—family, friends, and providers—is something that many brain injury survivors face. I needed to focus not on trying to “fix” Subject D, but on listening to him—his view of what has happened to him, what he feels, what he goes through day-to-day in his life.

Could using visual methods help providers and patients to learn to listen to each other? Could they promote engagement and mutual learning in the patient-provider interaction?
For my second case study, I focused on Peggi, a former respiratory therapist, researcher, and trainer. Peggi was injured four and a half years ago when a sign fell on her head as she was exiting from an airport bus. Her injury was labeled “mild” because she did not lose consciousness and her brain damage could not be measured by our current imaging technology. However, her sequelae, or symptoms were anything but mild.

In our photo interview, Peggi described numerous dimensions of the duality or dichotomy of her experience living with brain injury. Her images and her interview text revealed a dichotomy—between black and white, darkness and light, old self and new self. I chose Peggi as a case of focus because I found this dichotomy to be interesting, and I wanted to learn more about it and what it might tell me about living with brain injury.
In this image of a floor, we see dark, pitted tiles flush against a wooden floor whose boards emphasize its linear nature. Seen out of context like this, the two halves of the picture appear to be in opposition, like Peggi’s old self and new self with brain injury. The dark and mottled tiles represent the reality of now, when it is hard to be organized and accomplish tasks that used to be easy. Yet perhaps the distinction between old self and new self is not as sharp as it once was. If Peggi could take this photo again, she might prefer an image that blurs the boundary between these two aspects of herself—as memories of successful coping begin to take root and become her new reality.

Are visual methods particularly useful for brain injury survivors in the search to make meaning in lives disrupted? If so, could they also be useful for persons with other cognitive disorders, such as epilepsy, dementia, autism, or post-traumatic stress disorder?
The third case study is of Judy, who used be an executive chef, a profession which was a central aspect of her identity before her brain injury, 17 years ago. When Judy was 35 years old, her doctors discovered a brain tumor and treated it by surgically removing it from her brain and treating her with radiation. Unfortunately, the treatments caused her brain injuries, though of course they had to be done. Once these essential tasks were completed, her neurologists saw their job as finished. They saw her brain injury sequelae: challenges with vision, executive functioning, and balance—as falling outside their purview.

In her visual illness narrative, Judy shares several aspects of her identity: the chef who was lost with her brain injury, a person with brain injury taking numerous medications each day, and an avid gardener. I chose Judy as a case of focus because her persistent search for a new identity after brain injury seemed both inspiring and interesting—not just to me, but also to the other survivors in the support group I worked with.
Garden
“The new Judy”

I thought, “Oh, I can do that”
I started experimenting
So I have something new
I’m in the roses now
The identity of the chef is no longer the focus of my life

Judy’s image of her garden shows a neat and tidy landscape of plants and mulch. A garden can be seen as a metaphor for regeneration and growth. In this image, Judy shows us what she has accomplished in her garden and in her life after brain injury. The image of Judy’s garden is frozen in time. It is an image of now, and we do not see the struggles she made to create her garden. Her excerpt, however, expands the timeframe of the image as she explains that being successful at gardening was a “process.” She started off with herbs in containers and experimented with flowers before tackling a garden in the ground. Judy’s excerpt helps us to understand that the perennial garden depicted in her photo is a tangible achievement in her ongoing gardening—and healing—process.

What social policies could be put in place to support a brain injury survivor’s quest for meaning that would also be cost-effective and sustainable over time? In gathering data to make these types of social policy decisions, do we need to use methods that are relevant to brain injury survivors’ real lives?
The Kubler-Ross stages of grief can help us to put the process of healing from brain injury into perspective. Denial, anger, bargaining, depression, and acceptance are common reactions to brain injury among survivors—and their families, friends, and coworkers.

Kubler-Ross describes these five stages as “responses to feelings” (p. 18) and says that going through the feelings illustrated by the framework is part of “learning to live with the one we lost” (p. 7). For brain injury survivors, the “one” who is lost is the old self—the person they were before their injury.

However, I fear that in using this framework to view my participants’ data, I am moving away from their lived experience. Perhaps a turn to issues of identity and self is more appropriate. Research that uses visual methods of narrative analysis often appears to express “a thematic interest in identities and subjectivities” (Riessman, 2007, p. 145). For the brain injury survivors with whom I have worked, two identity issues of great importance appear to be 1) learning the new, post-brain injury self, and 2) building a new identity.

Arthur Frank (1998) advises us to listen to the stories of the “deeply ill,” or anyone who perceives their illness as affecting all life choices...and altering their identity. Having a brain injury constitutes being “deeply ill.” Frank suggests using stories as “listening devices” (p. 197).

Based on the visual illness narratives of Subject D, Peggi, and Judy, I created a typology of three types of brain injury stories.
As seen in Subject D’s story, when the brain injury is new, the new (brain-injured) self dominates the old, pre-injury self. The old self feels lost. The new self feels confusion, frustration, anger, and a sense of loss and grief. We may hear this first story any time, whenever illness, confusion, and loss consume the narrator. Perhaps hearing this story is a signal to honor the survivor by listening, and perhaps helping to identify the stresses that may be causing the brain injured self to dominate.
As we saw with Peggi, for some survivors the old self and new (brain-injured) self are in dialogue. They resist and acknowledge each other. Feelings of loss and grief are present, but the new self employs strategies. Old self and new self are separate but communicate across the gulf that divides them. We hear this second story when the teller speaks both of impairments and of strengths and seems to bounce back and forth between feelings of being a new brain injured self and their old self.
As with Judy, the third type of story shows a multiplicity of selves that includes old self and new (brain injured) self. When there is a multiplicity of selves, different concepts of self may gain or recede in importance, depending on context (Mishler, 2004). We hear this third story when the narrator acknowledges but gives less importance to the new, brain injured self and instead narrates a range of selves, activities, life experiences, and strengths and strategies, as well as suffering.
Policy Implications

- Dialogue, relationship, emotions
- Narrative inquiry methods: Encourage dialogue, mutual learning, and sharing of emotions
- Improved quality of care and ABI survivor outcomes?
- Add visual methods to arsenal of research methods for public health—especially when seeking to elicit emotions and feelings
- Visual healing narratives?

An underlying theme of my suggested story typology is dialogue. When the brain injured self dominates, there is no room for dialogue. When old self and new self engage, dialogue is an essential characteristic of the engagement. When a multiplicity of selves co-exists, dialogue is implied in the ongoing experience of self in different contexts. Dialogue is also an underlying aspect of person-centered care. Dialogue is basic to relationships. Two-way communication implies a balance of power and mutual learning. In the clinical encounter, this means that both patients and providers are open to change.

Visual research methods engage and allow for the sharing of emotions. “Emotions are notoriously difficult to verbalize” (p. 71). Visuals—photographs, videos, drawings, or paintings—may enhance the ability of patients to talk about topics that are difficult to articulate or embarrassing. Improving the patient-provider relationship through listening and finding common ground not only improves patient satisfaction; it also improves patient health outcomes and reduces health care costs (Chilingerian, 2004; Stewart et al., 2000).

Narrative inquiry using visuals and other methods that encourage dialogue and mutual learning by both patients and providers, can help to develop evidence and change practice and policy at an essential level in health care: the therapeutic relationship. Perhaps putting in place policies and practices that support this relationship could transform visual illness narratives so they become tools for healing—visual healing narratives.
Research and practice using visuals is burgeoning, as is interest in brain injury. I am grateful to have had this learning opportunity—topic, methods, committee members, participants—at this time.

In closing, I present a photograph taken in Hawaii last October while visiting my two-month-old grandson. We were deep in a valley that houses an arboretum. The canopy of trees seemed to rise impossibly high above our heads. I suggest that this image of branches and leaves against the sky is a metaphor for the professional education that my doctoral studies have engendered. The branches equate to the learning and growth that have occurred. The leaves represent the ideas and relationships generated and nourished by my process. The organic nature of the metaphor implies that the learning continues. The “long-view” perspective of the image suggests that my dissertation is but one leaf of many on the great and ancient tree of knowledge. Thank you.