

Subjectivities of Narrative and Interaction:
Learning from Writing about Acquired Brain Injury

By
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Abstract. Writing up research that used photo-elicitation and narrative analysis methods with adult acquired brain injury survivors in the United States shows the influence of emotions on the processes both of healing from brain injury and of learning by the social science researcher. For three of the 11 brain injury survivors who participated in my study, I selected several photos and their accompanying interview text to form a participant's visual illness narrative, illustrating a theme that emerged during the photo taking and discussion process. Seeing, hearing, and reading participant data engaged my emotions, thus signaling topics—such as frustration, disruption, and passion—to reflect on in my own life, write about, and then explore further in the literature. Citing examples from three brain injury survivor visual illness narratives, this presentation will illustrate insights into brain injury healing, researcher learning, and policy that have emerged from writing this research.

Background

I carried out a study of lived experience with brain injury by giving cameras to a sample of brain injury survivors so they could take photographs of their lives from their perspective and talk with me about their photos. The 11 brain injury survivors who participated—3 recruited through hospital outpatient services, and 8 from a brain injury survivor support group—took 450 photographs in all. More than 12 percent of their photos (55 in all) were visual metaphors, taken to illustrate and talk about the emotions involved in living (and wrestling) with brain injury—for example, the frustration and confusion of trying to do tasks that used to be easy before brain injury; the grief of losing an “old self”; and the passion needed to discover a new identity.

Writing up this research was an emotional experience for the researcher in turn. Writing can be a “method of knowing” in which “knowing the self and knowing about the subject are intertwined, partial, historical, local knowledges” (Richardson & St. Pierre, 2005, p. 962). My writing process began with an outpouring of “subjectivities of investigator and participant alike” (Riessman, 2007, p. 17) in what Van Maanen (1987) might have described as a “confessional tale” of Subject D. In part I took a subjective approach because I wasn't sure where or how to start with the writing. I was also considering my audience: people with many interests and responsibilities competing for their attention. I hoped to “keep [my] audience alert and interested” enough to read my chapter and respond to it (Van Maanen, 1987, p. 106).

I started by writing about the participant who seemed to affect me most strongly from an emotional perspective. I selected several photos and interview text for his visual illness narrative and applied a technical ethnopoetic approach (Mishler, 1999) to explore its meaning. I wrote about how the narrative and my interaction with Subject D made me feel. Neuroscience supports my approach—without emotion, there is no cognition (Damasio, 1994; Martin & Clore, 2001). Reflecting on my emotions in writing up the research served as “self-reflective meditation” and

provided “a deeper sense of the problems posed by the enterprise itself” (Van Maanen, 1988, p. 93). I found that writing up my emotions positioned me “as part of the field, simultaneously mediating and interpreting the ‘other’ in dialogue with the ‘self’” (Riessman, 2007, p. 17) and revealed how my personality, intellect, experiences, and passions shaped the knowledge I was gaining (Reinharz, 2002/1979). I began linking to the literature. And finally, I began to be more analytical by looking more closely at the details of image, language, and structure.

Writing up any research on lives with chronic health conditions can be emotionally wrenching. Yet the visual nature of the research may have increased its emotional impact. Visuals engage and allow for the sharing of emotions. Collier (1957), in a seminal study using photographs as interview prompts, found that the photo prompts helped to “stimulate and release emotional statements” (p. 858) and to encourage seeing the community as if “for the first time” (p. 859). He posits that photographs are “capable of reaching deeper centers of reaction, triggering spontaneous revelations of a highly-charged emotional nature” (p. 858). As noted by neuroscientist Joseph LeDoux (1996): “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. In turn, visuals may intensify the capacity of researchers and clinicians to understand patients’ feelings (Radley, 2002).

Feldhaus-Weber (2003) created paintings of her brain and brain injury after a car accident that ended her career as a film producer and used them to discuss her injury and perceptions of healing with others (including clinicians). She writes (p. 51):

The painting gave me something to talk about other than myself. ...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.

Clinicians have purposely used this approach to work with patients who seemed hard to reach using traditional “talking” methods. Neuropsychologist George Prigatano (2003) describes 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)

Thus, visuals can be metaphors that allow for talking about feelings, which perhaps inevitably evoke feelings in the researcher or clinician as well. As seen in this study, visuals can be a way to bring the patient’s “life world” into the research or clinical interaction (Berland, 2007; Thomas & Pollio, 2002). Like paintings and drawings, photographs “objectify: they turn an event or a person into something that can be

possessed” (Sontag, 2003, p. 81).¹ They are also a way to acknowledge and write about emotions and identify topics that might not have been addressed or discussed otherwise.

My respondents imposed “something of themselves onto the subject of the photographs” when they captured their images and spoke about them with me (Akeret, 2000, p. 36). In turn, my analysis strategies imposed something of myself onto their images. I will now reflect on myself as audience for the photographs and lives of three of my study participants, and how my life experiences and interactions with the respondents may have affected my analysis of their images and interview text. The theme of my interaction with the first participant is “understanding frustration and confusion.” The theme for the second participant is “a life disrupted.” For the third participant, the theme is “a quest for healing.”

Understanding Frustration and Confusion

One of the first participants in my study, who asked to be called Subject D, met with me three times: first to discuss the project and go over the informed consent form, a second time to talk about his photographs, and a third time when I gave him his binder of photographs and a framed picture in appreciation of his voluntary participation in this study. Subject D is in his late 50s and good looking in a mature, virile way, with thick hair and a thick mustache. His voice hints at a life-long habit of smoking cigarettes. He was injured falling down his basement stairs as he descended to fix the water heater. He was in a coma for a month. He participated in this study about year and a half after his injury.

We spoke in Subject D’s kitchen, sitting across the table from each other. He spends much of the day in his kitchen—it’s where he reads the paper and his books and magazines, where he eats and smokes cigarettes, and where he cooks. It’s also where he organizes himself—keeps his organizer and manages his day. He smoked cigarettes while we talked. Listening to the recording of our conversation, I hear the flicker of Subject D’s lighter, the silence of his inhalation, and my dry cough as I inhale the secondhand smoke. He offered me a glass of water. We sat near an open window, which let in the sound of gulls, song birds, carpenters working nearby, and a heavy summer rain that interrupted our conversation when he went out to close the windows of his wife’s car, which he had been detailing when I arrived.

Subject D’s images were all of his current life, but our conversation ranged over a wide period of time, from his childhood to his 30 years in international development, his life on returning to the US, and his life with brain injury now. Some of our conversation touched on our shared experiences living and working overseas. Subject D has much specialized knowledge about international development, wine, cooking, baseball, boxing, and Islam. His wide-ranging curiosity has led him to learn, as he describes it, an “incredible stockpile of useless information that I was really proud of.” He has many stories about his life—stories that he has probably told many times, and which still amuse and entertain a fresh listener.

¹ Auditory functions in the brain also provide opportunities for sharing of emotions by brain injury survivors and for therapeutic work, as seen in work using music with brain injury patients by Gardiner (2008), Sacks (2007), and Nayak, Wheeler, Shiflett, & Agostinelli (2000).

My impressions of and feelings about Subject D may have influenced our interview and my analysis of his visual and interview data. For example, when we first spoke on the phone, I wrote in my notes that his voice sounded “deadened,” not a “natural sound,” and that he sounded a little “confused and angry.” I felt some trepidation about what lay ahead as I drove to his home to ask him to participate in the study. (I have since learned that this deadened sound in a survivor’s voice is a common sequela of brain injury and is called flat affect.)

Second, Subject D reminded me of my grandfather, who also smoked cigarettes and had a permanent tan, thick body, and rich voice. The daily life that Subject D described reminded me of my grandfather’s in his later years—not much change from one day to the next, each day repeating itself in what appeared to me to be an endlessly dull routine. This struck me as a sad contrast to Subject D’s 30 years living and working in countries where one is rarely if ever alone, and where sharing a meal, story, or tennis court with local residents and fellow expatriates can be a daily occurrence.

Our interview was like a game of backgammon, something I used to enjoy playing on summer evenings with my grandfather. There were the standard moves—the standard questions. There were the risks—do I leave a man open or do I cover him up? Do I push Subject D by saying what I think or feel, or do I just listen and encourage? Do I ask him to explain himself—or do I let him slip by and head home? Do I challenge, or do I sit and wait?

There were things about Subject D that also reminded me of myself. We both have lived in the same gritty, Eastern city where he grew up—a city where immigrants fueled industries that blackened the skies and held on to their identities even as they became Americans. We have both lived and worked overseas, where we fell in love with cultures and continents and people that welcomed our technology and money and tolerated our presence—our work and our play. We are both comfortable at being outsiders, surrounded by a culture alien to our own. We have a common sense of service to others, and a desire to make a difference in the world. Like many people, we also want to enjoy life—which for Subject D used to mean cooking, eating, drinking and telling stories, playing softball, and hanging out with the guys and their dogs.

It was easy for me to feel both empathy and sympathy for Subject D and his situation as we talked about his photos and I selected and analyzed his study data. Perhaps most important to the topic at hand, Subject D made me feel frustrated. He did not seem to recognize his many strengths, from my perspective: a curious mind, strong intellect, caring nature, good sense of humor, and wealth of stories to share. I mentioned something positive in his situation several times in our interview; each time he ignored me. He seemed to see no hope in his situation. My feelings of frustration in working with Subject D gave me useful insights about living with brain injury as I explored the conversation that Subject D and I had about his two new constant companions, frustration and confusion, as seen through the lens of his camera.

I will provide one example of Subject D’s photos and interview text: his photo of a summer salad and a summary of our conversation about it. The photo and interview excerpt are part of a visual illness narrative with four food-related photos that reveal Subject D’s feelings of frustration and confusion about his life with brain injury. The excerpt that follows begins with a title for the image that first describes the image and then puts it in context using Subject D’s own words. The

image is then followed by a summary structural analysis of what Subject D said about his photo. The summary follows that modeled by Gee (1991), and consists of titles—in Subject D’s own words—for the sequential thematic sections of our conversation. A discussion follows the excerpt, and I will close the discussion by raising several practice- and policy-related questions that the process of writing up this research has inspired.

Summer Salad

“It just has a feeling in your mouth, like rubber”



This is a sad thing
This is part of summer
Couldn't taste a damn thing
This used to be one of my favorite things

Discussion: Summer Salad, “It just has a feeling in your mouth, like rubber”

I selected this image and interview excerpt in part because of the striking contrast between the image and what Subject D says about it—the lovely summer salad that has “a feeling in your mouth, like rubber.” Layers of red, sliced tomatoes and fresh mozzarella cheese glisten with olive oil. Artfully placed basil leaves garnish the whole. The plate’s leaves and flowers provide a nice frame for the lovely salad, which looks delicious. However, the plate seems suspended in air as it balances precariously on the blue of the counter and is threatened by the darkness looming to the left. The dark shadow and lack of edge to the counter create a tension, implying that the photo has more to tell us than is apparent at first glance.

Subject D says that his beautiful salad represents “summer” and his “mother” and “one of my favorite things,” yet it no longer holds any pleasure for him because he can not taste it. There is irony here. There is beauty, yet there is no real pleasure in the beauty. Rather, for Subject D this image is a reminder of something that used to bring pleasure but now “has a ... a feeling in your

mouth, like rubber.” The photo represents not beauty, but loss—not of the ability to make a tasty summer salad with an attractive presentation, but loss of the ability to enjoy it.

Something that is missing from this photo is people. As much as loss of taste, this image represents loss of quality time with other people. It represents diminished opportunities for relationships. It represents fewer people in one’s life—people who can provide support and friendship, but also, potentially, fewer people to care for, to give to, to nourish.

The loss of relationships and difficulty sustaining relationships are common facts of life for many persons who survive brain injury, in part because of new challenges with patience and give and take (Stoler & Hill, 1998). Confusion and frustration can affect emotions, behavior, and the ability to relate to and work with others (Prigatano, 1993). Survivors frequently talk about losing their friends. This lack of nourishing relationships is a source of sadness for several of the brain injury survivors I know, even survivors who are still with their spouses. Subject D speaks of this salad as a “sad thing.” Loss of relationships is a “sad thing” that, for many survivors, is an integral part of living with a brain injury.

In his reflection, Subject D tells us that his photo of a summer salad is really about his feelings—of frustration because he has lost the ability to taste. Perhaps this image is also about Subject D’s feelings of isolation from other people. Just as his lovely salad sits alone on the counter, perhaps Subject D, like many brain injury survivors, feels alone in his home and his life, alone in his loss.

Subject D’s pessimism about his situation frustrated me in turn. I could see so much in him that is intelligent and funny, wise and caring. Yet he seemed to feel that all these qualities lay in his past. He did not see them in his present or future. He appeared to see himself only as “brain damaged” and “worthless.” I wanted him to feel differently. My decades as a tennis teacher, personal trainer, adult educator, and facilitator—when motivating people to learn, solve, and achieve was expected and valued—did not disappear as I began this research.

My reactions to Subject D and his story inspired me to start looking for information on frustration in the brain injury literature. Feelings of frustration commonly occur in occupational therapists who work with brain injury patients, and can be accompanied by feelings of personal inadequacy, rejection, failure, and guilt on the part of health care providers (Rosa & Hasselkus, 1996). These feelings of frustration can turn to anger (Gans, 1983)—harmful to both patient and therapist, and leading to therapist burnout (Rosa & Hasselkus, 1996). Feelings of frustration can also be evidence of caring and concern for patients and being personally engaged in professional work (Rosa & Hasselkus, 1996). Thus, my feelings of frustration, hopelessness, and caring in working with Subject D are feelings experienced regularly by professionals working with survivors of brain injury. Experiencing these feelings is part of what living with brain injury can be like for many survivors and their families, providers, and friends.

Could the visual methods used for this study be useful in exploring the patient-provider interaction for medical, speech pathology, and occupational and physical therapy students? Could using these methods as a reflection and teaching tool help providers and patients to learn to listen to each other? Could these methods promote engagement and mutual learning in the patient-provider interaction?

A Life Disrupted

Peggi and I met in September 2006 when she attended the recruitment meeting for a participatory research project using photography which I co-facilitated with a brain injury survivor support group in Framingham, Massachusetts. That project, originally planned for 10 weeks, has to date continued for more than a year and a half. Thus, Peggi and I have more than a brief and temporary acquaintance. We have an ongoing relationship, rooted in the deep sharing that occurred as group members talked about photographs, and nourished over time as we created an exhibit and worked on outreach and education activities.

Peggi arrives promptly at group project meetings. She uses a cane to maneuver around the bulky chairs, turned this way and that around the table that fills the room where we meet. On “bad days,” when headaches, noise, or fatigue are “too much,” she wears a baseball cap with the visor pulled low over her face. On “good days,” she wears bright, flowing clothing, and a smile. During the group meetings, Peggi talks regularly about her photos, her photographic process, and her life. She is vocal in asking other participants about their photos. She is enthusiastic in suggesting outreach ideas and volunteering to take on tasks to turn an idea into a reality. She is gracious about sharing responsibilities for executing tasks when she tires and cannot fulfill her prior commitments. As with other participants, her cell phone interrupts our group meetings, particularly around 3:00 o’clock, when her son calls to remind her to pick him up from school.

Many of Peggi’s images are metaphors for her feelings. For example, a gravestone represents the death of her “old self,” a path in the woods designates the “journey” of her life since brain injury, and a skylight in a darkened ceiling indicates the “hope” that keeps her going on her “dark days.” Peggi found these images and metaphors useful for communicating her feelings and experiences during the group project and in our photo interview. Feinstein (1982) might suggest that Peggi’s use of visual metaphors shows her “attempt to comprehend, construct, and convey meaning” in her life with brain injury (p. 47).

Peggi has memories of being in charge. She is comfortable making her needs known. At times I felt challenged when Peggi suggested alternate way of doing things, for example using her own camera instead of a disposable one provided by the project. The thinking required to consider and respond to her questions and suggestions was good learning for the group. Using project cameras instead of our own meant that all participants were on the same footing. No camera was better than any other. It lessened the pressure to take “good” photographs and emphasized photo content over quality. Discussing the many issues that Peggi raised throughout the project and developing group decisions about them was good practice for me in patience and group dynamics when I might rather have said, “Well, that’s just the way it is!”

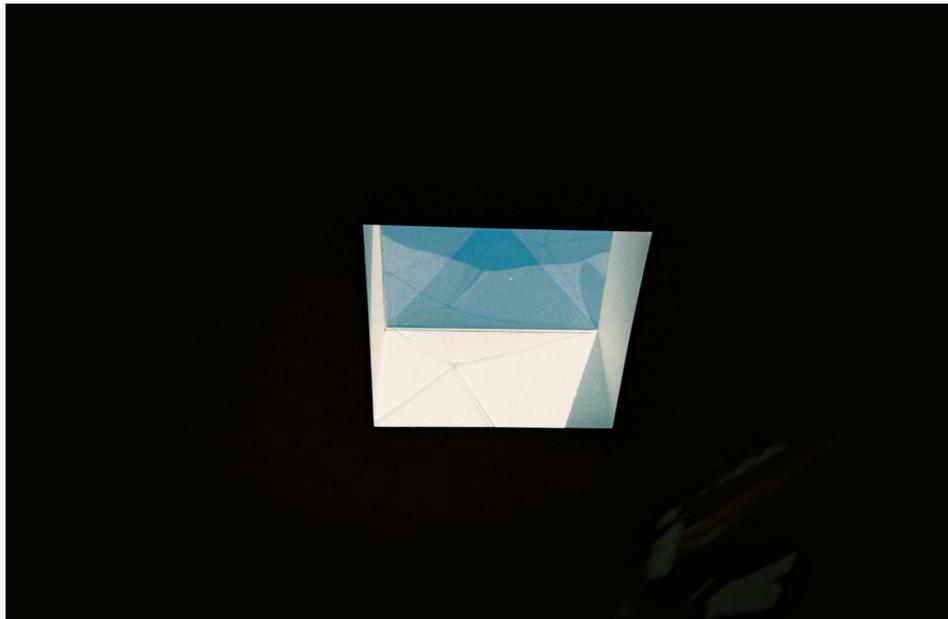
Peggi has a fierce intelligence as well as strong experience in instructional design and marketing. Her skills were invaluable when we began the outreach portion of the group project, for example, designing our exhibit and developing take away materials. Peggi accomplished many significant tasks such as securing funding for printing costs. Yet, due to limitations inherent to brain injury, Peggi could not always follow through on the ambitious ideas she had birthed as they grew into

complex, multi-step tasks. I wrestle with the challenge of follow-through in my own life when my enthusiasms outrace my ability to accomplish them, and I exhaust myself and the people around me. I have learned to be patient about this tendency in myself, which helped me to feel patient with and supportive of Peggi, even as my co-facilitators and I grew exhausted.

Thus, it was both energizing and draining to help furnish a supportive environment in which Peggi and other brain injury survivors could practice old skills and establish new ones. In my experience, this dichotomy, a bouncing between excitement and exhaustion, is endemic to participatory research projects. It was especially true of this one, in which collaborators who look and are skilled also have invisible challenges. My multifaceted relationship with Peggi in the group project inevitably influenced our interview as well as my selection and analysis of her visual and interview data.

As with Subject D, I will provide one example of Peggi's photos and interview text: her photo of a skylight and a summary of our conversation about it. The photo and interview excerpt are part of a visual illness narrative with five photos that reveal the dichotomy of Peggi's experience living with brain injury. The excerpt begins with a title for the image that first describes the image and then puts it in context using Peggi's own words. The image is then followed by a summary structural analysis of what Peggi said about her photo. The summary follows that modeled by Gee (1991), and consists of titles—in Peggi's own words—for the sequential thematic parts of our conversation. A discussion follows the excerpt, and I will close the discussion by raising several questions that the process of writing up this research has inspired.

Skylight
"There's light in the dark"



I'm in a cave sometimes it seems
You can't get out, and you can't get in
But...there's light in the dark

Discussion: Skylight, “There’s light in the dark”

Peggi’s image of a skylight is both striking and abstract. I see a parallelogram whose sharp lines and distinct geometric shapes stand starkly against a field of black. Without the title, I would be challenged to discern what the image portrays.

Peggi’s interview excerpt is brief. Explaining this photo, Peggi conveys a sense of being stuck—aware that she is surrounded by the darkness of her cave, yet unable to get up to the light of the outside world. Peggi concludes her conversation about this photo by explaining that the image is “hopeful” because “there’s light in the dark.” She intimates that the hopefulness is almost out of reach, like the skylight. Peggi is using this image to make known her feelings.

When Peggi spoke of this photo with the group of survivors who participated in the action research project with me, she explained that the image represents a “good day,” when she sees “light and...an escape...a way out of this darkness,” which she also calls “the shadows.” Charmaz (1991), in describing lived experience with chronic illness for persons with a range of conditions, describes a “good day” as a day when illness “remains in the background of their lives” (p. 50). A good day can also mean “being the self one recognizes” and a day when “nagging fears about the future all recede” (p. 50). A “bad day” on the other hand is marked by “isolation” when “illness...takes center stage” (p. 51), and the self bears “little resemblance” to the person one wishes to be (p. 52). Peggi, like Charmaz’s informants, appears to identify a good day as one in which illness recedes to the background. Distinct from Charmaz’s informants, Peggi appears to relate good days and bad days to color: darkness for bad days, and light for good days.

As seen in this photo and interview excerpt, Peggi appears to be establishing a “sense of coherence” in her life with brain injury (Radley, 2002, p. 3). Participating in this study may have provided Peggi with an opportunity to make visible and communicate a “restoration of coherence” that she has been striving for and experiencing for some time (p. 11). Using visual methods such as those employed in this study can help with the process of “confronting the inevitability of disease,” or in this case the inevitability of impairment due to brain injury (Radley, 2002). Perhaps taking pictures for this study, writing captions for them, and speaking about them with me and with the group project participants allowed Peggi to express “feelings that were previously inchoate,” or imperfectly formed (p. 11).

The experience of “the restoration of coherence” occurs both in the “act” of taking photographs and in “the contemplation of the image by others” (Radley, 2002, p. 11) Thus, when we as viewers contemplate Peggi’s narrative—her images and their interview excerpts—we participate in creating “existential meaning” about living with brain injury (Debats, 2000, p. 95). Peggi’s narrative provides both viewer and creator an opportunity to “see” Peggi’s brain injury world and gain a new perspective on the pain and struggles she describes so well. Reading Peggi’s narrative helps us to develop with Peggi a shared understanding of what it is like to live with brain injury as she experiences it (Pollack, 2005).

Emotional sharing of experience using symbols, concepts, and analogies is healing and can contribute to “reestablishment of the injured person’s sense of self (Pollack, 2005, p. 644). Peggi’s narrative provides both viewer and creator an opportunity to feel and to “restore...the

capacity to feel” (Radley, 2002, p. 21). Her narrative “instantiates” or provides a concrete example of her feelings (p. 18). Peggi shows us that living with her brain injury can mean feeling trapped inside a dark place, looking up and out at a world of “light and blue sunny skies.”

Peggi is describing a life disrupted. As with other people whose lives are suddenly disrupted by injury, violence, or illness, none of the brain injury survivors I have worked with were anticipating the sudden life change brought on by brain injury (Becker, 1997). A moose ran into the road and totaled a man’s car. A sign fell on Peggi’s head. A young woman on her way to work hit a patch of ice; her car slid under and was crushed by a truck.

Reflecting on Peggi’s experience as an example of a disrupted life, in which “expectations about the course of life are not met, [and] people experience inner chaos and disruption” (Becker, 1997, p. 4), forced me to reflect on my own experiences of disruption. The most obvious is divorce, which suddenly and involuntarily prompted me to leave overseas work and the nest of a nuclear family, to return to a now alien U.S. culture where I became a single parent working full time. I spent years grieving for the loss of that family and way of life. Certain events, such as the birth of a grandchild, trigger echoes of that grief today.

Over time I stopped cursing the persons who caused the death of my “old self” and began to feel grateful for the birth of my “new” one. The change led me to find meaningful work and a renewed purpose in life, and to “understand how events in [my] life fit into a larger context” (Reker & Chamberlain, 2000, p. 1). It is difficult to imagine facing such a life-changing disruption while wrestling with the cognitive, physical, and emotional impacts of brain injury.

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? Finally, are they only useful in a group setting, or could we also observe meaning-making benefits for patients who use visual methods in a dyad with providers?

A Quest for Healing

Judy is one of the brain injury survivors who participated in the action research project with me, together with seven other brain injury survivors and two co-facilitators with brain injury. Judy has been part of the Framingham brain injury support group for nine years, almost since its founding. She attended most of the project’s first ten sessions but had to miss a few due to migraine headaches or doctors’ appointments.

Judy took her photographs in the fall. Due to the timing of the project, the photos of her gardens did not show them at their best, from her perspective. Judy contributed a garden photo she had taken in the summer, before the study began. I have included this photo in her narrative of identity.

My interview with Judy was one of the last interviews for this study. It was delayed twice when Judy had migraine headaches: first, when the weather was heavy and humid; second, when she

worked extra hours at the library and became exhausted. The interview took place at my home. When Judy first arrived, we hung out for a few minutes in the kitchen to make herbal tea. The interview began when we moved downstairs to my study, where we sat side by side on the couch and faced a table with her binder of photos. On the audio recording, our conversation is punctuated by the sounds of her laughter, tea being poured, and rhythmic tapping on the table when Judy makes a point.

We spoke for about three hours. For the first hour and a half we discussed a wide range of topics. We went over the consent form for use of the photos for research and education purposes, and whether she wanted her name used or not. She shared an article she had brought for me on a youth photo project in South America. I marveled at her binder, which was beautifully organized. She had shared her project binder with her neurologists, and we discussed their potential interest in displaying the group's exhibit at the hospital where they practice.

Judy did not look at her photos for a month before the interview because she wanted to look at them "through fresh eyes." Her action was purposeful. Her strategy means that Judy was "audiencing" her photographs with both an insider and an outsider perspective during the photo interview (Rose, 2007). We looked quickly through her binder before she began to speak at length about individual images. She talked about eight images in depth, choosing them herself.

Our second conversation took place at Judy's home, in her back yard as we sat on a wooden deck with rectangular planters of white and purple pansies. Birds called and flitted across the yard from tree to feeder to tree. Wind chimes rang. Her neighbor's nine-year-old son returned home from school and talked with us before going inside to get a snack. In this hour-long interview Judy explained to me how her tumor was diagnosed, the treatments she'd received, their sequelae, and her healing quest, which included collaborating with her primary care provider to find and access effective treatments and therapies (Frank, 1995).

Reflecting on my choice of Judy as a case study raised a concern for me. Was I overly drawn to Judy as a hero in her quest for healing after brain injury? My childhood home had a wall of books, collected by my father, that reached 20 feet across and 10 feet high, much of it genre fiction and classics. From age eight I began to read these books. I started with classics (*The Yearling*, *The Little Princess*, and *Kidnapped*) and moved on to the Horatio Alger, Ace with Wings, Nancy Drew, James Bond, and other series whose protagonists faced adversity and usually triumphed in the end. Bruner (1987) writes: "As literary forms have developed they have moved steadily toward an empowerment and subjective enrichment of the Agent protagonist" (p. 19). Was I choosing to explore Judy's story because it fulfilled my personal need for a lived experience with brain injury that exemplified agency and enrichment?

My immersion in universal plots from an impressionable age inevitably colored my view of Judy's experience and my choice of a theme for her narrative (Bruner, 1987). Like many people, I am drawn to stories of triumph and transformation. My doctoral training, however, has taught me that success or failure in life is not wholly due to personal characteristics, as implied by the Horatio Alger books or America's culture of rugged individualism. I now appreciate that social capital and socio-economic circumstances play vital roles in determining how individuals 1) achieve access to services, 2) react to life challenges such as healing from traumatic illness, and

3) find meaning in living with a chronic condition such as brain injury.

My “transformative plot” lens poses risks both to my analysis of Judy’s data and to the self-perception of brain injury survivors in general. This lens pushes me toward “romanticizing” the “illness quest” of Judy and the other brain injured persons in my research sample (Frank, 1995, p. 134). I hope that an awareness of my lens will help me to avoid seeing the “renewal” of any brain injury survivor “as complete” (p. 135). I hope that awareness of my lens will keep me from deprecating “those who fail to rise out of their own ashes” or fail to find meaning in life after brain injury (p. 135).

As with Subject D and Peggi, I will provide one example of Judy’s photos and interview text: her photo of her perennial garden and a summary of our conversation about it. The photo and interview excerpt are part of a visual illness narrative with four identity-related photos that reveal Judy’s sense of self as she lives with brain injury 17 years post-injury. The excerpt that follows begins with a title for the image that first describes the image and then puts it in context using Judy’s own words. The image is then followed by a summary structural analysis of what Judy said about her photo. The summary follows that modeled by Gee (1991), and consists of titles—in Judy’s own words—for the sequential thematic sections of our conversation. A discussion follows the excerpt, and I will close the discussion by raising several practice- and policy-related questions that the process of writing up this research has inspired.

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

Discussion: Garden, “The new Judy”

Judy’s image of her garden shows a neat and tidy landscape of plants and mulch. Decorative white stones mark the garden’s front edge. The sun is shining. 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.

Several years of experimentation—trying, failing, trying again, succeeding—preface her picture. As Judy explained to me, she tried gardening for the first time about eight years after brain injury. Her first attempts met with little success; balance issues caused her to keep falling into the plants, and they died. Judy tells how her sister, who studied horticulture and is an avid gardener, took Judy to the annual flower show in Boston where she noticed people in

wheelchairs gardening in containers. This inspired her to try gardening again.

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. Judy explains that being successful at gardening was a process that required "experimenting." Miles and Huberman (1994) define process as "a string of coherently related events" (p. 111). Judy's excerpt helps us to understand that the perennial garden depicted in her photo is a tangible achievement in her ongoing garden—and healing—process. Perhaps Judy's process can be seen as a step "toward changing the concept of oneself" (Rogers, 1980, p. 155).

Judy's training as a chef likely contributed to her success with her new passion. Being a chef involves experimentation and risk. Perhaps Judy's experience as a chef helped her to avoid becoming discouraged and to persevere despite her failures (Frank, 1995). We see Judy's willingness to make mistakes and try again, also in her approach to taking photographs for this study. Judy took nine photos of her gardens: two inside containers, two outside containers, and five of her perennial gardens in the ground. None of these photos fully illustrated what she wanted to portray, so she contributed a photo from outside the timeframe of the study.

Both cooking and gardening require creativity. Prigatano (1999) notes that "creative people often have a fluid sense of identity" (p. 215), which may have helped Judy be willing to let her chef identity recede in importance and to be open to letting a new one take precedence. Being a chef and being a gardener seem to have aroused a sense of "passion" in Judy. Prigatano notes that a "sense of passion helps tremendously with the creative force behind so many discoveries—personally as well as collectively" (p. 210).

A notable contrast between Judy's two passions of cooking and gardening is their locations: outdoors versus indoors. Spending time in nature can be an important source of meaning for people as they enter midlife, with or without a chronic condition like brain injury (O'Connor & Chamberlain, 2000). I asked Judy about this contrast. In the following excerpt, the words I said are italicized, and the rest are Judy's.

And a big difference is, that I notice about it, is it's outside as opposed to inside.

Yes, yeah, because I wanted to be outside more.

That was purposeful, too? Yes. Why?

Because I live in a quiet town where it's quiet and nice and I like being outside,
So I wanted to do something...that would get me out of my house.

When it's nice, I can be out there.

When it's not nice, I don't have to go out there.

I'm not that fanatical of a gardener that I go out there when it's raining.

At least not yet. *Right*

If it doesn't look good, well, this too shall pass.

The outside aspect of gardening attracted Judy. Yet she is not so "fanatical" about her new "passion" that she gardens "when it's raining." She enjoys her new passion without exhausting herself to the point of getting sick or triggering a migraine. She recognizes when she needs to slow down and conserve her energy and her health. "If it doesn't look good, well, this too shall

pass.” Judy is able to take the long view and see that the state of the garden right now is not its static or permanent state. She appears to accept that there is a “transitoriness to all experience,” which in turn enables “continuing opportunities for the creation/discovery of new meaning” (Kenyon, 2000, p. 19).

Judy concludes by explaining that “the identity of the chef is no longer the focus” of her life. She has developed a new self as gardener. Yet gardening is just one of the interests “important” to her now. For example, Judy explained to me that she gets great satisfaction out of working eight to ten hours a week at her local library and learning to make paper by hand. She enjoys working on strength and balance in her physical therapy appointments. Thus, Judy’s road of self-discovery appears to involve finding balance in a life in which “interests” and part-time work have replaced “career” as the focus of her efforts, energy, and sources of meaning.

In Judy’s case, there is danger in seeing her adaptation to living with brain injury as taking a “linear, progressive course” because we are seeing and hearing about her life now, 17 years post-injury (Mishler, 1999, p. 151). We must take care to avoid aggrandizing her visual data or minimizing her verbal data, when she describes falling in her plants and crushing them. We must acknowledge her willingness to experiment, fail, and start again (Holstein & Gubrium, 2000, p. 10).

Judy’s narrative of identity prompts questions: Is taking photographs especially useful for creating visual illness narratives that facilitate appreciation of strengths and discovery of meaning in life after brain injury? Could visual illness narratives encourage patients and providers to work together harmoniously to resolve health issues and adherence challenges after brain injury? In gathering data to make practice and policy decisions, do we need to use methods that are relevant to brain injury survivors’ real lives?

Conclusion

Theoretical frameworks can help us to put into perspective the process of healing from brain injury that Subject D, Peggi, and Judy are experiencing. Much of the healing is emotional. Consider the five stages of grief described by Kubler-Ross and Kessler (2005): denial, anger, bargaining, depression, and acceptance. During the denial stage, “the world becomes meaningless and overwhelming” (p. 10). The anger stage is part of the grieving person’s “emotional management” (p. 12) and “a natural reaction to the unfairness of loss” (p. 16). The stage of bargaining is described as a time of growing confidence that “we can restore order to the chaos that has taken over” and can involve wondering “what if” (pp. 19-20). Depression can be a withdrawing from life or a “fog of intense sadness” (p. 20) that “clears the deck for growth” (p. 24). Acceptance involves “accepting the reality” that the change that has occurred is permanent, and learning to “live with that loss” (pp. 25-26). As Kubler-Ross and Kessler emphasize, the stages of grief are not linear. Persons surviving a loss (of a loved one, a marriage, a job, an old self) can experience any of the five stages of grief in any given minute, hour, or day. Or they can remain for longer in one stage.

Kubler-Ross and Kessler (2005) describe these five stages as “responses to feelings” (p. 18),

noting 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. The Kubler-Ross stages of grief may be a useful lens for considering the process of healing from brain injury.

In Subject D’s visual illness narrative, he shares feelings that suggest stages of anger and depression. Perhaps he is just being, as he says, his “crotchety old self” as is his “reputation.” He continues to grieve when he says that the salad—and the loss of his ability to taste it—is a sad thing. He reveals frustration—perhaps a synonym for anger in Subject D’s context—when he refers to his salad as “the damn thing.”

Peggi appears to be making use of several stages of grief at once in her visual illness narrative. We hear bargaining when she says “You can’t get out, and you can’t get in.” She reveals depression when she describes herself in a cave after her injury. She indicates the beginning of acceptance when she says, “But...there’s light in the dark.”

Judy appears to exemplify the stage of acceptance. She has accepted the loss of her identity as a chef, and enjoys her new identity as a gardener, an identity built over time and with much effort. She says she “has something new.” She is “in the roses now.”

An important aspect of healing from brain injury is cognitive healing. Emotion—and writing about emotion—is essential to cognition. No longer do we believe that emotion and cognition work separately, as first proposed in the 1600s by the French philosopher Rene Descartes. Rather, we have come to understand that they work together to influence our learning and behavior and perception of ourselves (Damasio, 1994; Shreeve, 2005). In an article on motivational and emotional controls of cognition, Simon (1967) argues that “in actual human behavior motive and emotion are major influences on the course of cognitive behavior” (p. 29). He quotes psychologist Ulrich Neisser: “human thinking begins in an intimate association with emotions and feelings which is never entirely lost” (Neisser, 1963 in Simon, 1967, p. 29). Thus emotional healing is basic to cognitive healing.

Emotion is also basic to learning. Polanyi (1958) proposes that emotions such as lust and fear are “the most primitive manifestations of the active principle by which we grasp knowledge and hold it” (p. 173). For Polanyi, emotion is essential to active knowledge, “which is the difference between experiencing and making sense of that experience” (Reinharz, 2002/1979, p. 247). Differently stated, active knowledge, initiated in emotion, is the difference between living life and learning from life. Perhaps active learning is vital for learning the “new self” after brain injury. In turn, active learning through writing about emotions can be vital for understanding lived experience with a chronic health condition like brain injury.

The methods used in this study appear effective for eliciting emotions and feelings about living with brain injury. They appear to be effective for engaging the emotions and feelings of viewers as well as participants. These and other illness accounts bear “witness to suffering in ways that have implications for those who are well, in addition to those who are ill” (Radley, 1999, p. 779).

From 1991 through 1997 I worked as a freelance photojournalist for international development

agencies. This work required me to visit refugee camps, urban slums, rural health posts, and remote villages to ask people about the development programs that were ostensibly improving their lives. Basically, I was hired to tell people's stories for them, usually for the benefit of my employer, first, and me, second (because I was earning a fee for the assignment). Over time I became concerned about two things: 1) were the people who willingly spoke to me, and let me photograph them, benefiting from my work, and 2) did the development work I was "espousing" have unintended negative consequences? Some articles I wrote—for example, promoting agribusiness development in rural India—seemed to have negative consequences for child agricultural workers, particularly girls. I felt ill-equipped to ask questions that would help me understand the negative consequences of my work. I enrolled in a doctoral program in part because I hoped that I would be able to ask better questions in the future.

In doing research with elderly Americans in the US, Gaskins (1995) found that service to others emerged as a major source of hope. Her participants said that "their contributions to their communities and other people enriched their lives" (p. 22). My transformation from journalist to researcher helps me to feel of greater service to others—and, as a result to feel a greater sense of hope in my life. Service to others seems more tangible when I know the "others." In turn, as I write about the experiences of "others" living with brain injury, I learn more about myself—and I ask better questions.

References

- Akeret, R. U. (2000). *Photolanguage: How photos reveal the fascinating stories of our lives and relationships*. New York, NY: W.W. Norton & Company, Inc.
- Becker, G. (1997). *Disrupted Lives*. Berkeley, California: University of California Press.
- Berland, G. (2007). The view from the other side--Patients, doctors, and the power of a camera. *The New England Journal of Medicine*, 357(25), 2533-2536.
- Bruner, J. (1987). Life as narrative. *Social Research*, 54(1), 11-32.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, New Jersey: Rutgers University Press.
- Collier, J. J. (1957). Photography in anthropology: a report on two experiments. *American Anthropologist*, 59, 843-859.
- Damasio, A. (1994). *Descartes' error: Emotion, reason, and the human brain*. London: Penguin Books.
- Debats, D. L. (2000). An Inquiry into existential meaning: Theoretical, Clinical, and phenomenological perspectives. In G. T. Reker & K. Chamberlain (Eds.), *Exploring Existential Meaning: Optimizing Human Development Across the Life Span* (pp. 93-106). Thousand Oaks, CA: Sage Publications, Inc.
- Feinstein, H. (1982). Meaning and visual metaphor. *Studies in Art Education*, 23(2), 45-55.
- Feldhaus-Weber, M. (2003). An excerpt from the Book of Sorrows, Book of Dreams: A first person narrative. In E. B. Crepeau, E. S. Cohn & B. A. B. Schell (Eds.), *Willard &*

- Spackman's Occupational Therapy* (Tenth Edition ed., pp. 49-56). Philadelphia, PA: Lippincott Williams & Wilkins.
- Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, IL: The University of Chicago Press.
- Gans, J. S. (1983). Hate in the rehabilitation setting. *Archives of Physical Medicine and Rehabilitation*, 64, 176-179.
- Gardiner, J. (2008). The magic of music for improving the mind, *3rd Annual Black Hills Brain Injury Conference*. Rapid City, SD.
- Gaskins, S., & Forte, L. (1995). The meaning of hope: Implications for nursing practice and research. *Journal of Gerontological Nursing*, 21(3), 17-24.
- Gee, J. P. (1991). A linguistic approach to narrative. *Journal of Narrative and Life History*, 1, 15-39.
- Holstein, J. A., & Gubrium, J. F. (1998). Phenomenology, Ethnomethodology, and Interpretive Practice. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (pp. 137-157). Thousand Oaks, CA: Sage Publications.
- Kenyon, G. M. (2000). Philosophical foundations of existential meaning. In G. T. Reker & K. Chamberlain (Eds.), *Exploring existential meaning: Optimizing human development across the lifespan* (pp. 7-22). Thousand Oaks, CA: Sage Publications, Inc.
- Kubler-Ross, E., & Kessler, D. (2005). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. New York, NY: Scribner.
- LeDoux, J. (1996). *The emotional brain: The mysterious underpinnings of emotional life*. New York, NY: Simon & Schuster Paperbacks.
- Martin, L. L., & Clore, G. L. (Eds.). (2001). *Theories of mood and cognition: A user's guidebook* (Paperback ed.). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Mishler, E. G. (1999). *Storylines: Craftartists' narratives of identity*. Cambridge, Massachusetts: Harvard University Press.
- Nayak, S., Wheeler, B. L., Shiflett, S. C., & Agostinelli, S. (2000). Effect of music therapy on mood and social interaction among individuals with acute traumatic brain injury and stroke. *Rehabilitation Psychology*, 45(3), 274-283.
- O'Connor, K., & Chamberlain, K. (2000). Dimensions and discourses of meaning in life: Approaching meaning from qualitative perspectives. In G. T. Reker & K. Chamberlain (Eds.), *Exploring Existential Meaning: Optimizing Human Development Across the Life Span* (pp. 75-91). Thousand Oaks, CA: Sage Publications, Inc.
- Polanyi, M. (1958). *Personal knowledge: Toward a post-critical philosophy*. Chicago, IL: The University of Chicago Press.
- Pollack, I. W. (2005). Psychotherapy. In J. M. Silver, T. W. McAllister & S. D. Yudofsky (Eds.), *Textbook of Traumatic Brain Injury* (pp. 641-654). Washington DC and London, England: American Psychiatric Publishing, Inc.
- Prigatano, G. P. (1993). Maintaining work after traumatic brain injury: Experiences from two neuropsychological rehabilitation programs. In D. F. Thomas, F. Menz, E. & D. C.

- McAlees (Eds.), *Community-Based Employment Following Traumatic Brain Injury* (pp. 179-195). Menomonie, Wisconsin: University of Wisconsin-Stout.
- Prigatano, G. P. (1999). *Principles of neuropsychological rehabilitation*. New York: Oxford University Press.
- Prigatano, G. P. (2003). Challenging dogma in neuropsychology and related disciplines. *Archives of Clinical Neuropsychology*, 18, 811-825.
- Radley, A. (1999). The aesthetics of illness: Narrative, horror and the sublime. *Sociology and Health & Illness*, 21(6), 778-796.
- Radley, A. (2002). Portrayals of suffering: On looking away, looking at, and the comprehension of illness experience. *Body & Society*, 8(3), 1-23.
- Reinharz, S. (2002/1979). *On becoming a social scientist: From survey research and participant observation to experiential analysis*. New Brunswick, NJ and London, England: Transaction Publishers.
- Reker, G. T., & Chamberlain, K. (2000). Introduction. In G. T. Reker & K. Chamberlain (Eds.), *Exploring Existential Meaning: Optimizing Human Development Across the Life Span* (pp. 1-4). Thousand Oaks, CA: Sage Publications, Inc.
- Richardson, L., & St. Pierre, E. A. (2005). Writing: A method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (Third Edition ed., pp. 959-978). Thousand Oaks, California: Sage Publications.
- Riessman, C. K. (2007). *Narrative methods for the human sciences*. Los Angeles: Sage Publications.
- Rogers, C. R. (1980). *a way of being: the founder of the human potential movement looks back on a distinguished career*. Boston, Massachusetts: Houghton Mifflin Company.
- Rosa, S. A., & Hasselkus, B. R. (1996). Connecting with patients: The personal experience of professional helping. *The Occupational Therapy Journal of Research*, 16(4), 245-260.
- Rose, G. (2007). *Visual methodologies: An introduction to the interpretation of visual materials* (Second ed.). London: Sage Publications.
- Sacks, O. (2007). *Musicophilia: Tales of music and the brain*. New York, NY: Knopf.
- Shreeve, J. (2005, March). The mind is what the brain does. *National Geographic*, 2-31.
- Simon, H. A. (1967). Motivational and emotional controls of cognition. *Psychological Review*, 74(1), 29-39.
- Sontag, S. (2003). *Regarding the pain of others*. New York, NY: Picard.
- Stoler, D. R., & Hill, B. A. (1998). *Coping with Mild Traumatic Brain Injury*. New York, NY: Penguin.
- Thomas, S. P., & Pollio, H. R. (2002). *Listening to patients: A phenomenological approach to nursing research and practice*. New York, NY: Springer Publishing Company.
- Van Maanen, J. (1988). *Tales of the field: On writing ethnography*. Chicago, IL and London, England: The University of Chicago Press.