Living with Brain Injury: The Survivor’s View

By
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This photo elicitation study of lived experience with brain injury asked adult brain injury survivors to take photographs of living with brain injury from their perspective and talk about them with me. Their resulting visual narratives are evocative portrayals that resist current medical models for rehabilitation from brain injury, engage us in their contexts, and make us feel. Each narrative is a series of images and their interview texts centered on a common theme. A newly injured respondent shows us the disorder in his life and his frustrations around food—buying, storing, preparing, and tasting it. A survivor injured four years ago engages us in her ongoing struggle to reconcile what she calls the “darkness and light” of her life. A third, whose injury occurred 17 years ago, relates a narrative of identity in which she speaks in a “chorus of voices” as chef, gardener, librarian, and brain injury survivor.

Background

Acquired brain injury (ABI) is any injury to the brain that occurs after birth and leads to deterioration of cognitive, physical, emotional, or independent functioning (Sherry, 2006). There are a total of 650 brain-related disorders, including traumatic brain injury (TBI), stroke, epilepsy, and brain tumors; together they affect 50 million Americans per year and account for more long-term health costs and hospitalizations than almost all other diseases combined (Boyle, 2001). TBI, an injury caused by blunt force, trauma, or shock to the head is estimated to affect between 1.4 to 3 million people in the US each year (Langlois et al., 2004; Kraus & Chu, 2005) and are among the injuries most likely to cause death or permanent disability (Langlois et al., 2006). An estimated 5.3 million Americans, or two percent of the population, are living with a long-term disability from TBI that resulted in hospitalization, and “the true number of persons living with TBI-related disability likely is much higher (Langlois et al., 2006, p. 376). Approximately 98,000 persons “who sustain a brain injury each year will have neurological deficit or disability” (Kraus & Chu, 2005, p. 25).

Brain injury, whatever the source, may result in “dramatic alterations in an individual’s cognition, behavior, and emotions” (Arlinghaus et al., 2005, p. 59). Brain injury symptoms (sequelae) can be categorized into four broad domains: cognition, emotion, behavior, and physical symptoms. In an ideal world, rehabilitation for ABI is comprehensive and involves accessing an “array of services” provided by “a diverse group of clinicians and other professionals in a variety of settings to achieve optimal results” (Cope & Reynolds, 2005, p. 559). Rehabilitation for ABI is complicated by uncertainty and unpredictability in an individual patient’s potential for recovery of function. Gardner (1975) notes: “...while actuarial tables and experimental studies can provide important clues about the rehabilitation potential...the different facts of each case preclude authoritative predictions and offer occasional surprises even to the highly experienced neuropsychologist” (p. 18).

Historically, survivors of ABI were expected to have limited potential for recovery, particularly...
beyond six months post-injury. However, acceptance of the “plasticity” of the central nervous system (including the brain) has replaced the old “hard-wired” model (Cope et al., 2005). Brain recovery is now seen as dynamic, not static; new brain cell formation occurs biologically and “plays a role in recovery of function” (p. 129). Current thinking encourages provision of services from one to three years post-injury and “implementation and maintenance of an appropriate life management plan for those persons” who require it (p. 559). ABI survivors and their families, however, typically have difficulty “in obtaining funding and access for in-patient, outpatient, residential, cognitive, and behavioral rehabilitation as well as mental health services” (p. 560). Payer support for comprehensive systems of care for TBI has lagged behind the recommendations of the clinical community (Cope et al., 2005).

One of the challenges to recovering from ABI is that there are no cookie-cutter solutions to rehabilitation and recovery. Each patient’s injury and healing are different, and person-centered care means tailoring rehabilitation plans to the individual. One way to understand an individual’s perspective is to carry out qualitative research that allows for the sharing of experience in an unstructured way. However, as Steadman-Pare et al. (2001) note, “literature on the perceived quality of life of TBI (and all ABI) survivors many years after injury” is scarce (p. 331).

Visual and Narrative Analysis Methods

Gaining an understanding of lived experience with brain injury requires: a) gaining access to survivors’ day-to-day lives and b) “interpreting the meanings of their experiences” (Bloor & Wood, 2006, p. 128). Why use visual methods to gain access to survivors’ day-to-day lives? A photograph can “unlock the subjectivity of those who see the image differently from the researcher” (Harper, 2003, p. 195) and “illuminate a subject invisible to the researcher but apparent to the interviewee” (Clark-Ibanez, 2004, p. 1516). John Collier (1957), in studying the relationship between the environment and mental health in a Maritime county in Canada, was finding it difficult to encourage informants to speak at length about their community and lives. He decided to use photographs (taken for the study) as interview prompts. He found that using photographs as prompts helped to 1) bring out information that remains “submerged in verbal interviews” (p. 854), 2) “overcome the fatigue and repetition encountered in verbal interviews” (p. 857), and 3) bridge the language gap for informants who “lack fluency with words” (p. 858).

Since that early study, photography has served as a powerful tool for understanding people’s lives, illuminating human experience with health and illness, and shifting the power differential between researcher and participant (Worth et al., 1997; Rich et al., 2000b). In her work with families to understand what it was like to live with childhood chronic illness, Hagedorn (1996) found that interviews based on participant-generated photographs encouraged spontaneous storytelling and invited participants to lead the research conversation. For Frith and Harcourt (2007), working with women undergoing chemotherapy, photo-elicitation “provided a window into the private, every day experiences of patients away from the healthcare setting” (p. 1340). Radley and Taylor (2003) found that taking pictures and talking about them provided a means for hospital patients to allude to the trauma of being in the recovery ward. The Video Intervention/Prevention Assessment (VIA) project at Children’s Hospital Boston asked young people to create video diaries of their lives with asthma (Rich et al., 2000a). The visual diaries prompt “a more direct understanding of people, their life experiences, and their perceptions” than is possible with data “collected and controlled solely by the researcher” (Rich et al., 2000c, p.
156). Berland (2007), whose three physically disabled participants filmed more than 200 hours of their lives, argues that film shows details “that are often overlooked, or missed in clinical research conducted in more traditional ways” (p. 2533).

Research methods that combine visual images and interviews or discussion have proven useful in research with people who have cognitive challenges (Booth & Booth, 2003; Dyches et al., 2004). Brain injury survivors may have similar cognitive challenges even as they function and live as independent adults. Slowed processing speed in the brain due to injury can challenge a survivor to respond to a question right away, and short-term memory issues and fatigue may impede participation (McCullagh & Feinstein, 2005). As with young adults with cognitive challenges, using photo elicitation with adult brain injury survivors can facilitate knowledge generation by providing participants with something to talk about and a way to remember. Using visual methods can also inspire hope and plans for the future for persons with cognitive challenges (Paiewonsky, 2005). Similarly, Prosser (2007) used visual images during stroke recovery to “make sense of my immediate environment, plot a path for forward motion, and articulate my fears and ambitions to myself and others” (p. 185).

Interpreting the meaning of people’s experiences—as represented in their photographs and interview text—requires attention to methods. Narrative analysis is a case-based method that “relies on extended accounts that are preserved and treated analytically as units” (Riessman, 2007, p. 12). Bell (2002) provided a model for selecting a series of photographs and accompanying text as narrative. In an article on the activist Jo Spence’s experience of breast cancer, Bell investigates three photographs and related text produced by Spence during her 10-year fight with breast cancer (and the medical community). Three photos and accompanying text form an illness narrative. For my participants also, several photographs and their accompanying interview text form an illness narrative.

Illness narratives can be seen as a type of thematic analysis. Narrative analysis is viewed as a family of methods that includes thematic, structural, visual, and dialogic analysis (Riessman, 2007). Thematic analysis has often been used “to uncover and categorize thematically patients’ experience of illness” (p. 53). Following Williams (1984), I have worked with one person’s data (photographs and interview text) at a time, and illustrated experience with brain injury as revealed in several photographs and narratives centered on a common theme.

I have used structural analysis to look at a visual illness narrative’s component parts—how the story is “made whole, coherent, and understandable” and how the narrator uses “form and language to particular effects” (p. 81). The structural analysis by Gee (1991) of a narrative spoken by a schizophrenic woman served as a useful model for my work with brain injury survivors. The narrative was collected as part of a diagnostic process carried out by the institution where the woman was hospitalized. Doctors found her narrative about exciting episodes in her life to be incoherent. Using a linguistic approach to illuminating the structure and meaning of the narrative, Gee argues that it is in fact a typical example of “human sense making” (Gee, 1991, p. 17). He used “technical poetic strategies” (Mishler, 1990, p. 437) to break the text up into idea units, lines, stanzas, and strophes. His strategy illuminated a structure that reveals the narrative’s images or themes and thus the perspective of the woman who was speaking. The structural analysis shows she was making sense.
Similar to Gee (1991), my analysis structures the interview text excerpts into lines. Each line is about “one central idea, or topic” and in most instances approximates a sentence or a main clause in a sentence (p. 22). I have grouped lines into parts and given them titles that use words and phrases spoken by the participant. The titles allow readers to discern the overall structure and themes of the interview excerpt. However, I have simplified Gee’s approach, for two reasons: 1) I am wary of burdening the majority of readers with a level of analysis that might confuse more than it informs, and 2) I prefer to keep the analysis closer to my participants’ broader stories and the emotional impact of their visual narratives (Riessman, 2007). My adaptation follows the lead of others (Mishler, 1999; Riessman, 2007).

At the same time I have also expanded Gee’s approach. First, I have included my words and sounds in the presentation to illustrate “the interaction between primary speaker and listener” (Riessman, 2007, p. 100) and the dialogical, co-produced nature of the resulting text. Co-creation of data is an inherent characteristic of photo elicitation, which creates a “partnership between the scientists and the subject” (Ziller, 1990, p. 36). The photo elicitation interview, like all research interviews, is a “clear case of co-authorship” (Williams, 1984, p. 181). By being present, we cannot help but “shape the stories participants choose to tell” (p. 50). The dialogic nature of the interaction and subsequent data, thus, become an integral aspect of the analysis as well. Second, I have also expanded on Gee’s approach by creating a visual “outline of the narrative” (p. 24) to form a summary or abstract of a participant’s visual illness narrative. The summary narrative is intended to orient readers to the flow of the narrative and highlight its key components. I hope they prevent my interpretation from subsuming my participants’ perspectives.

My visual analysis strategy involves looking at image details and considering the photograph’s audience. With visual analysis, photographs “become ‘texts’ to be read interpretively (as written transcripts are)” (Riessman, 2007, p. 142). Interpretive reading can involve looking at the details of a photograph for, as Becker (1986) writes “every part of the photographic image carries some information that contributes to its total statement” (p. 231). Considering audience (Rose, 2007; Riessman, 2007) means asking how an image is “read” by different audiences. I have relied on the interview text to understand how my participants read their images. As my respondents talk about their photographs, they are “audiencing” them. When I look at the photographs, listen to what people say about them, and analyze the details of the images and their accompanying text, I am “audiencing” the images. Considering audience raises interesting questions. Do the participants and I see their pictures similarly or differently? What do our differing perspectives tell us about living with brain injury? Akeret (2000) suggests that “when story and image appear to contradict each other, a deeper truth emerges” (p. 224).

Of the 11 people I interviewed for my study, I selected three as cases for closer analysis. Each case “examines a different theme or takes up a different aspect” of living with brain injury (Biklen and Casella, 2007, p. 82). Radley and Chamberlain (2001) argue that “all patients are cases, in that they are illustrations of a disease category and yet unique in how they are affected by the disease” (p. 323). They are not “‘representative’ in any statistical sense” (Williams, 1984, p. 176). Williams argues that a case needs to “represent something important about the experience of illness” (p. 176). Radley and Chamberlain (2001) suggest that the individual’s account of “how they bear their illness in the context of their lives” needs to be an expressive
portrayal “that is...meaningful to the person” and to the listener (p. 329). It must allow us as audience “to enter into the context of the illness situation so defined” (p. 330).

I argue that each of the three cases illustrated here is meaningful and allows us to enter his or her context: a life with brain injury, and each case represents a different theme. One survivor, whose injury is recent, is upset about the disorder in his life and feels frustrated about food—buying, storing, preparing, and tasting it. A second, who has been living with her injury for four years, engages us in her ongoing struggle to reconcile what she calls the “darkness and light” of her life with brain injury. A third, whose injury occurred 17 years ago, relates a narrative of identity in which she speaks in a “chorus of voices,” as chef, gardener, librarian, and brain injury survivor (Mishler, 1999, p. 8). In the sections that follow, I first present the summary narrative for each person, followed by a discussion. I then focus more closely on one image and its interview text, to illustrate my methods of analysis and delve more deeply into the respective narrative theme.

Living with Frustration and Confusion

EXCERPT 1: Cans in the Sink
“The disorder that I’m living with right now”

EXCERPT 2: Stuffed Refrigerator
“Nothing’s where it belongs”

It was supposed to make a point
I keep getting confused and lost
Now everything is disorganized
I feel like I’m living in chaos and it’s hopeless
These are appropriate pictures

Too much stuff we never eat
I can’t taste
I can’t cook
I’m embarrassed to tell people
In eight of the eleven interviews for this study, a brain injury survivor used the word “frustrating” to describe the experience of living with brain injury. In each case, something is frustrating now that was not frustrating before. Frustration in persons with brain injury may be triggered by feelings of confusion when there is light or noise, when several people are talking at once, or when their damaged brain tries to absorb information. It can also be triggered by feelings of inadequacy or loss, when a survivor cannot do things that were easy to do before brain injury, or when people do not acknowledge invisible deficits. This first visual illness narrative of living with brain injury focuses on the frustration and confusion experienced by one brain injury survivor, Subject D.

I selected Subject D to illustrate the frustration and confusion of living with brain injury in part because he spoke about frustration more often than any other participant—five separate times during our photo interview. Others spoke once or twice about frustration. Second, a major source of his frustration, as it emerged during our conversation about his photographs, is his loss of the ability to taste food. Nineteen of his 54 photographs directly related to food, and food was a major theme in our interview. Food is such a basic part of daily life. We purchase and prepare it. We consume it and clean up after it. If food becomes a source of frustration, then the frustration must be constant, a feeling that cannot be avoided, a feeling that irritates every day.

Subject D’s narrative of frustration and confusion has four photographs and their accompanying interview excerpts. In these selected images and interview excerpts, Subject D shares the frustration and confusion that dominate his life with brain injury. Terms he uses to describe these feelings and states of mind and emotion include: “frustration,” “confusion,” “constant disorder,” “chaos,” “drives me crazy,” “flips me out,” and “freaks me out.” These words figure prominently in Subject D’s explanation of why he captured the images I have included in this visual illness narrative of his life with brain injury. All four photographs also depict food and common everyday tasks related to food: shopping for it, storing it, cooking it, tasting it, and cleaning up.
after it, though not in that order in these photos.

I have presented Subject D’s narrative “living with frustration and confusion” in the order in which we discussed its four photographs. The narrative begins with Excerpt 1, a photo of cans in the sink, which are an example of the “disorder” he lives with. It continues with Excerpt 2, a photograph of an open refrigerator, bursting with fruits and vegetables, which bring on confusion. Excerpt 3 shows the vegetable aisle of a local grocery store, where Subject D feels “utter confusion” in his brain. In Excerpt 4, we see a lovely tomato salad that reminds Subject D of “summer” and which he prepared with relish because he “forgot” that he could not taste it.

To explore Subject D’s experience more closely, I will focus on one excerpt from his visual illness narrative: Cans in the Sink. The excerpt begins with a title that first describes the image and then places it in context using Subject D’s own words. The title is followed first by the image and then by its interview text, parsed into lines and grouped into parts (prelude, parts, and/or codas), each with a title, using Subject D’s own words (Gee, 1991, p. 22). Anything I said during the interview is italicized; all other text is Subject D’s. A period indicates a full stop. A comma indicates a brief pause, and a series of two or three dots indicates a longer pause. A discussion follows the excerpt.

**EXCERPT 1: Cans in the Sink**
“The disorder that I’m living with right now”

![Image of cans in the sink]

**Prelude: It was supposed to make a point**

*I think this is beautiful. This is a beautiful photo.*

That’s an accident

*I know, but it’s*

Just the way the light was

*I know, but it’s, it came out, it’s almost like a cartoon*
Well, it is. 
It was supposed to make a point
*Was it?.. What point?*

**Part 1: I keep getting confused and lost**
The disorder that I’m living with right now *Uh huh*
A lot of it’s my fault, because I can’t organize things any more,
Like I go to a store, and I’m supposed to buy maybe ten things.
It takes me an hour and a half.
And I keep getting confused and, lost in the store, and, ..
I get panicked sometimes if I go to a new store and it’s too big *hm hrm.*

**Part 2: Now everything is disorganized**
But the house is the same way.
I can’t get my wife and daughter to put anything where it belongs, you know, just .. *hm hrm*
They put everything on a, table top someplace.
Which they’ve always done, and I just yell at them and not pay any attention, just go on out.
But now it, it, it freaks me out
Everything is disorganized, you know, I can’t find anything *hm hrm*
Then, they keep putting things, you know just, stockpiling things on the front porch for example,
And then they throw it all in the garage,
So the garage is so full now I can’t get in there to get my tools.

**Part 3: I feel like I’m living in chaos and it’s hopeless**
Now I’m talking about something that every family has to deal with, especially if you have a teenage girl and a, um, a disorganized wife, but, um ..
It drives me crazy now, I mean, just, the way my brain’s operating. *hm hrm*
*Your reaction, is different from how it used to be.*
I feel like I’m living in chaos and it’s hopeless, I can’t do anything about it *hm hrm.*

**Coda:** These are appropriate pictures
*These are appropriate pictures.
These are all the chaos*

**Discussion: Cans in the Sink. “The disorder that I’m living with right now”**
This photograph and its interview text ground us immediately in Subject D’s two major concerns as a brain injury survivor: his feelings of frustration and confusion. It was the first photograph we discussed and it set the tone for our interview.

Subject D says that his intent here is to show the disorder that he lives with every day. His wife drinks “soda pop” and leaves the cans in the sink, which “freaks him out.” Subject D is using this image to show us confusion in the sink, but in his interview he talks about not just the environmental “chaos” in his life exemplified here but also his internal “chaos.” Together, this
The interview excerpt reveals coherence. Subject D begins and ends our conversation of his photo by telling me that his pictures “make a point.” They are not images taken at random. Subject D took them for a purpose: to show a non–brain injured person what it is like to live with brain injury. He took pictures to depict the cognitive and emotional chaos in his life.

As Subject D describes in the interview, he can not organize his grocery shopping. He can not get things done efficiently. Confusion at the store or at home get in his way, distract him, and he can not avoid them as he used to. Before his injury, he would leave the house when he could not stand the cans in the sink, or the items strewn on tabletops. Now, he has nowhere to go except to the park, to throw the ball for his dog. He has no control over the throwing of cans in the sink, nor can he can avoid it. Thus he feels “hopeless.” Perhaps Subject D feels hopeless not just about the disorder he sees in this picture, but about the impairments from his brain injury. Concern about his potential for healing may exacerbate his feelings of “hopelessness.” He says that the disorder in his home, exemplified here by cans in the sink, “freaks him out”—another way of saying how frustrated he feels at his situation.

“Frustration” and “confusion” are two common reactions by brain injury survivors to the question “What is it like to be brain injured?” and these terms are “used clinically when describing brain dysfunctional patients” (Prigatano, 1999, p. 33). Yet they seldom appear in the research literature “devoted to understanding brain dysfunction in individuals” (Prigatano, 1999, p. 33). The word frustration does appear, however, in the qualitative literature on brain injury survivors’ experiences. Crisp (1994) describes survivors, struggling to have relationships and achieve goals, expressing “anger, frustration, and disappointment” when they are only partially successful (p. 18). Glover (2000) observes the participant of her case study growing angry, frustrated, stubborn, and unyielding “in his communication with others as he continued to find his situation wanting” (p. 474). Brain injury survivors in Sweden describe feeling “frustrated when they struggled to remember and learn things they had no problems with before” (Jumisko, et al., 2005, p. 46). A clinical psychologist in Canada whose brain was severely injured in a car accident says, “I would become so frustrated at people’s inability to understand me that I would stab the pencil through the paper, crumple it up, or hit out at those around me” (Linge, 1987, p. 322). Burton (2000) finds that one of the issues in emotional recovery for stroke survivors is anger/frustration, linked to loss of control over parts of the body and in their lives.

Frustration in brain injury survivors can be an expression of internalized anger and can lead to pessimism and resentment (Delmonico et al., 1998). Frustration can be debilitating and may be accompanied by pessimism, bitterness, and irritability (Delmonico et al., 1998). It can damage existing or prevent new interpersonal relationships and lead to “social and emotional isolation” (Delmonico et al., 1998, p. 20). For many people with brain injury, Subject D’s reaction could be seen as normal. Prigatano (1993) notes that people with brain injuries “become frustrated” with “difficulties controlling temper,” and may “externalize the cause of their failures” and “blame others” for provoking them (p. 184). Thus, Subject D’s reaction to his situation is not unique to him but represents feelings and behaviors that other brain injury survivors share with him, even when they do not want to.
Subject D’s photo of cans in the sink shows a level of “chaos” that would be more or less normal in my home. For Subject D, however, the image depicts a level of chaos that upsets him greatly. With this image and interview excerpt, I see one thing and hear another. This dissonance between image and text, from my perspective, is emblematic of the dissonance experienced by friends, family members, coworkers, and even service providers, when a brain injury survivor lives with “invisible” disabilities. The “normal” appearance of the friend, husband, coworker, or patient leads others to expect that he or she is capable of making decisions, cooking a meal, or shopping for food—all things that he or she used to handle without experiencing either confusion or frustration. For Subject D, however, his image and interview text coincide. They show and tell of the confusion and frustration he experiences living with a brain injury.

Working with Subject D, I understood for the first time what a nurse practitioner friend calls “bearing witness.” I could not and can not do anything about what Subject D is going through. It is not my job to improve his life. But perhaps just by listening I am affirming his story—his truth, or the version of his truth he shared with me. By listening, by showing interest in what he had to tell me, I am acknowledging his suffering, his struggles, his view of what has happened to him, what he feels, what he goes through day-to-day in his life. In this moment, the future is not important. The “truth” is not important. What matters is the unconditional listening.

Research supports the therapeutic value of listening (Edwards, 1998). In a study of the views of patients, families, and professionals on services for head and neck cancer, Edwards (1998) found that counseling did not help many patients, who said that counselors “had often not listened to them but tried to provide solutions to their problems” (p. 101). Patients said that, in contrast, staff “who had taken time to listen to them...had helped them to come to terms with what they were going through” (p. 101). One physician has noted, “between 40 and 60 percent of all therapeutic benefits can be attributed to a combination of the placebo and Hawthorne effects, two code words for caring and concern, or what most people call ‘love’” (White, 1989 in Carroll, 1998).

Subject D’s injury was still relatively fresh when we spoke. He was still grieving for the abilities and life he had lost. It is possible that with time he will gain a new perspective on his injury and see it in a new light, as others facing life-changing circumstances have done before him (Becker, 1997). He may yet “create meaning from chaos” (O’Connor & Chamberlain, 2000, p. 82). Even with brain injuries as severe as Subject D’s, some people do over time come to “accept their fate” though others continue to “resist and reject it” (Prigatano, 1993, p. 188).

If I could not taste my favorite foods anymore, if I could not drive more than two miles from my home, if I had to live my days thinking of what I’d lost, wondering what the heck it was that I’d forgotten, then maybe I would feel pessimistic, too. And I probably would not appreciate it if someone told me to look on the bright side.

Encompassing Darkness and Light

EXCERPT 1: Skylight
“There’s light in the dark”

EXCERPT 2: A Friend’s Floor
“I was trying to get the darkness and the light”

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

That’s just a friend’s floor
The world of my belief that...meets with...the reality
I convince them and myself that I’m my “old self”
Then the reality keeps comin’ up

EXCERPT 3: The Mural
“You can be grateful...or you can curse”

This is a mural at my son’s school
Promise and hope and creativity...fading into darkness
Sometimes...it’s okay
Other times...it’s coming to get you
You can be grateful...or you can curse
Sometimes I wonder...how different things might have been
One of these life things, you know?

EXCERPT 4: The Chess Set
“This game I used to love...is just a mystery now”

I was trying to show...I’m not able to play that game anymore
I don’t know how to
The world is still playing...and my forces are divided
I don’t know...what I’m supposed to be doing
I’m getting creamed

EXCERPT 5: Dark Branches and Gray Sky
“This is just the new thing”

I was trying to find things that made sense along the way
It’s odd
One day I became somebody else
I don’t want...to be...all I am is a brain-injured person
My friends...say...‘You’re fine now’
It’s good to be, seen, as whole, right?
It’s a step in the right direction

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With this visual illness narrative, Peggi is sharing both the darkness and light of her experience living with brain injury. In North American culture, darkness implies something bad, negative, or evil: In Hollywood movies the bad cowboys wear black hats, and black is the conventional color for mourning. Light in turn implies something positive: In the Western tradition of painting, angels wear robes of white. These broad Western cultural assumptions underlie Peggi’s narrative of darkness and light.

Merleau-Ponty (1962), however, cautions us to see colors in context: When placed next to each other, they reflect each other and are changed; colors are mutable. He warns against “treating the constancy of colors as an ideal constancy attributable to judgment” (p. 355). Applied to living with brain injury, the mutability of colors in context implies that darkness and light are relative concepts that can change over time depending on context, level of healing, and mood on any given day. Merleau-Ponty (1962) posits, “color in living perception is a way into a thing” (p. 355). I suggest that Peggi’s perceptions of darkness and light in her life are a way into understanding her lived experience with brain injury.

Darkness and light are just one of several pairs of opposing terms that Peggi used to represent the dichotomy of her life with brain injury, which she calls both a “blessing” and a “curse.” Physically, Peggi epitomizes the dissonance endemic to living with a condition that is not readily visible. She is striking: tall, blond, and square-shouldered. She exudes confidence, authority, and capability. It is easy to see the confidence and thus miss her unsteady gait, or her scowl when she is overwhelmed by several people talking at once. Peggi’s “mild” traumatic brain injury is not apparent either visually or clinically, and thus is invisible (Jagoda et al., 2002). Her problems with memory, organization, and auditory processing more than four years after her injury are consistently surprising. “Even my family forgets!” she says.

Looking “normal” is an advantage when Peggi prefers to keep quiet about her brain injury. “I don’t tell everybody. I don’t want my new self to be...all I am is a brain-injured person,” she explains. It has also worked against her—most notably when she sued the company responsible for the sign that fell on her head and ended her career as a respiratory therapist, medical researcher, and trainer. During the trial, a “professional witness,” a doctor with “degrees that were as long as my arm,” steadfastly insisted that mild traumatic brain injury “does not exist.” The consistent evidence from three neuropsychological tests, that Peggi has a “terrible time” with organizing and memory, could not convince the jury otherwise. After two weeks of trial, the jury awarded compensation for Peggi’s pain and suffering from the sign falling on her head, but no compensation for the lost decades of professional earnings. The jurors could not reconcile Peggi’s “normal” looks and her long-term cognitive challenges. As Radley (2002) explains, “the acceptability of illness, like disability, is very much one of appearance” (p. 12).

Like almost three-fourths of the 1.5 million people each year whose head injuries are treated in emergency medical settings, Peggi’s injury was labeled mild (Langlois et al., 2004; NCIPC, 2003). However, as with an estimated 15 to 30 percent of people with mild traumatic brain injury, the long-term cognitive challenges resulting from Peggi’s injury have been anything but mild (Lewine et al., 2007; Cajigal, 2007).
Peggi’s brain injury challenges her life daily. She forgets where she is driving, despite placing a note with the destination on her car’s dashboard. She is distracted by “constant background noise”—the television, someone walking past, people talking—that prevents her from focusing “on what’s in front of me.” Tasks multiply “like rabbits” into “moving furry targets” that make her feel “frustrated” and keep her from completing anything that involves multiple steps and careful planning. She relies on a cane for balance and “can’t stand up without” medication whose co-payment increased from $300 to $1,750 per dose when Peggi changed her health insurance.

In our photo interview, Peggi describes numerous dimensions of the duality of her experience living with brain injury. She separates her life into two parts: before and after injury, as qualitative research has found with other brain injury survivors (Chamberlain, 2006; Padilla, 2003). She looks well but has invisible disabilities. She is no longer her “old self” and is learning about her “new self”—another common experience for survivors of brain injury (Nochi, 1998; Pollack, 1994; Chamberlain, 2005; Padilla, 2003). She describes “bad days,” when she dwells in “darkness,” and “good days,” that are “all about the light”—an experience that parallels that of persons living with a range of chronic conditions (Charmaz, 1991). Peggi’s perceptions of the negative (dark) and positive (light) aspects of her life illustrate another dichotomy, one that underlies her narrative. This section explores the dichotomy that Peggi feels and has shared in her photos and our conversation about living with brain injury.

Peggi’s narrative of darkness and light has five photographs and their accompanying interview excerpts presented in the order in which we discussed its photographs. In each of the selected images and excerpts, Peggi shares the dichotomy of her life now, with brain injury, where her “old self,” “bumps up” against her “new self.” The theme of darkness and light recurs throughout the excerpts. The narrative begins with Excerpt 1, a light-filled skylight, which in part represents hope on Peggi’s “dark days.” The narrative continues with a photograph of a floor, where tiles and wood and are symbolic of the dark and light of her life. The third photograph is a mural where “promise and hope and creativity” are “fading into darkness.” In Excerpt 4, a game of chess represents Peggi’s divided world. In the final excerpt, a photo of a leafless tree against a gray sky prompts Peggi to explore the challenge of “learning the new me” now that she cannot be her “old self.” As with Subject D, I will focus more closely on one Excerpt: The Mural.
EXCERPT 3: The Mural
“You can be grateful...or you can curse”

Prelude: This is a mural at my son’s high school
This is a mural at my son’s high school.

Part 1: Promise and hope and creativity...fading into darkness
There’s all this... promise and hope and creativity and...
Then it’s fading into darkness hmmm
So it’s sort of also... like...
Wanting to...attain ...a goal...
But also having this darkness of...
It’s not just about trying to get to the goal,
There’s darkness creeping in.
There’s, you know...
There’s a dark side.
Well, I try not to focus on that stuff.

Part 2: Sometimes...it’s okay
Yeah, the dark, you know,
The... anger, the ...despair, the ...loss, sense of loss.
That you try to pretend isn’t there sometimes,
And sometimes, it’s there
And you accept that it’s there
And you’ve encompassed it
And it’s okay.

Part 3: Other times...it’s coming to get you
But then there are other times
When it’s coming to get you.
So it’s hard to, um...
*Sounds a little scary.*
Yeah, a little scary.

**Part 4: You can be grateful...or you can curse**
I mean, just the loss of;
It’s just, you know, I... ...
You can be grateful...
For huge changes in your life that you didn’t expect...
Or you can curse them...
But you can do both too, you know?

**Part 5: Sometimes I wonder...how different things might have been**
Some things are good.
Some things I wonder if,
That accident hadn’t happened,
If I could have, would have..if
How different things might have been. Hmmm

**Coda: One of those life things**
Yeah, but, but they’re not. Hm mmmm
It’s one of those life things, you know?

**Discussion: The Mural, “You can be grateful...or you can curse”**
A mural at her son’s high school presented an opportunity for Peggi to speak of darkness and light. The quality of light in the image—the “fading into darkness”—results from the limitations of the flash on the project cameras. Peggi used this distortion to communicate her experience. In this excerpt, Peggi equates light with “promise, hope, and creativity” and darkness with “anger,” “despair,” and “loss.” She describes a strategy she uses to avoid being enveloped by darkness: she tries “not to focus on it.” Focusing on the brain injury patient’s “remaining assets” and avoiding a focus on “residual deficits” is a recommended therapeutic approach for brain injury survivors (Pollack, 2005, p. 654).

Peggi delves deeply into the dichotomy of her experience with brain injury and her perceptions of her healing process with this excerpt. She reveals the promise and hope of healing as well as threats to achieving that healing. She acknowledges darkness but resists its presence. She chooses to encompass her “despair,” and “loss,” an act that seems both painful and hopeful.

The word encompass can mean an encircling, in which anger, sense of loss, and injury itself are recognized and embraced as part of the experience (Chapman, 1992, p. 969), which implies acceptance. Encircle also equates with “girdle,” as in wrestling (p. 683), which implies engaging, facing and fighting, struggling and contesting (p. 364). Becker (1997) describes “tension” in a life disrupted as a “fight within the self” (p. 3).

Four years after her accident, Peggi has reached a point where she does not merely “pretend” that
her feelings of loss and grief do not exist. Rather, she interacts with these feelings. She struggles to see her injury as only one part of herself. With this excerpt, Peggi shows us that she is both embracing and resisting “the patient role” and is actively negotiating “the balance of the ‘healthy’ and ‘ill’ aspects” of her life (Radley & Chamberlain, 2001, p. 324). Peggi is not just a “passive” recipient of her brain injury symptoms; rather, she is “actively” interpreting them (Nochi, 1998, p. 869).

Dichotomy of experience plays out as the excerpt continues. Peggi describes the creeping “dark” to me by curling her fingers and placing her hands in front of her face like a monster about to attack. Her words and action evoke bravery as she engages with her sense of loss even when fear threatens to overwhelm. In Part 4, she describes two choices in her life: she “can be grateful...for huge changes” that she did not expect, or she “can curse them.” In the next line, she explains that it is possible to “do both” at the same time.

As with other people whose lives are suddenly disrupted by injury, violence, or illness, none of the survivors I worked with had anticipated 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 a woman’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. No one can prepare for brain injury, making it even more urgent to allow time to grieve. As seen in this excerpt, grieving can be both painful and healing.

Peggi’s excerpt has a wistful quality, a feeling of longing for the past, especially in Part 5 where she wonders “how different things might have been.” Many brain injury survivors live with feelings of regret (Pollack, 2005). One group project participant, who was injured in a car accident 30 years ago at age 19, notes that “in the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear.” With his brain injury, he feels he lost his future (Nochi, 1998). From Peggi’s perspective, her present and future do not include the professional work she found “meaningful.” Instead of designing life-saving training for people with a chronic and life threatening disease, she babysits for a friend’s young child. Yet she is grateful for “good” aspects of her life, as depicted in photos of her boyfriend-partner, her sons, and the members of the brain injury support group, among others.

In the coda, Peggi interrupts her wistfulness with an abrupt reality check. She might wish things were different, “but they’re not.” Peggi acknowledges her wish that things might have been different, and chooses to confront reality instead. Peggi shows us that living with brain injury means struggling with something she cannot change. She can wrestle, confront, embrace, and encompass, or she can feel regret, helplessness, and fear. In this excerpt and in her life Peggi appears to be doing “both.”

This excerpt from Peggi’s narrative of darkness and light appears to show that Peggi has emerged from the despair and isolation of her early years living with brain injury. She no longer hibernates in her room. She engages with the world and her injury by attending support group meetings, babysitting, and volunteering with the parent-teacher organization at her son’s school. Peggi is not entirely reconciled with her new life, however. She continues her struggle to encompass darkness and light in a self that embraces both the “old” and the “new.”
Discovering a New Identity

**EXCERPT 1: Cookbooks**
“Identity lost”

My work as a chef ended with my brain tumor
I didn’t have a life separate from my work
It was always Judy the Chef, not ever Judy
I had to find who I was besides being a chef
I’ve still got over a hundred cookbooks
That was part of making the picture

**EXCERPT 2: Pill Box**
“These are all my brain injuries”

This is my pill box for the week
It would become very confusing
I started coordinating with my doctors

**EXCERPT 3: 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

**EXCERPT 4: Keys in the Freezer**
“What do I make out of that, that I want?”

We as brain injured people put things in weird places
Maybe I was getting a glass of water with some ice cubes
I make things out of nothing
I can do that because I was a chef

My research began as a study of lived experience with TBI, yet the 11 brain injury survivors who volunteered to participate in my study included two brain tumor survivors as well as nine TBI
survivors. The brain tumor survivors asked me to revise my dissertation topic from “lived experience with TBI” to “lived experience with brain injury.” Among the brain injury survivors in my sample, the cause of their injury is irrelevant. All brain injury survivors wrestle with changes in their professional and personal lives after brain injury. All face physical, cognitive, emotional, and spiritual issues as they attempt to heal from or cope with their injuries. Over time, the lived experience of all brain injury survivors, no matter the source of their injury, appears to coalesce. In choosing to focus on lived experience with brain injury by a brain tumor survivor, I am respecting the perspective of my participants. I am valuing their solidarity as collaborators with me and honoring their commitment to communicating their lived experience with brain injury so that other brain injury survivors can benefit (Frank, 1995). I am also following the suggestion by Nochi (2000) that “individuals who seem to succeed in coping with the disabilities [from brain injury] should be examined, too” (p. 1795). Finally, I am pursuing my attraction to the heroism that Judy portrays in coping with and overcoming the myriad challenges she faces living with brain injury (Padilla, 2003).

As Judy explained to me, treatments (surgery and radiation) for a brain tumor caused her brain injuries. Judy was 35 years old and working as an executive chef, managing multiple restaurants, when nausea, headaches, dizziness, and balance issues forced her into bed and then to the hospital. After seven days of diagnostic tests, a magnetic resonance image (MRI) revealed a slow-growing childhood tumor (ependenoma), pressing on her brain stem and causing her symptoms. Judy’s neurosurgeons and radiation oncologist removed the tumor and treated it with radiation to prevent re-growth. Once these essential tasks were done, they saw their job as finished. They appeared to perceive her post-treatment issues of impaired vision; speaking, chewing and swallowing; chronic migraine headaches; loss of short-term memory and executive functioning; and balance issues—all common brain injury sequelae—as falling outside their purview. “They were all worried about the tumor, and I would talk to them about these other things, but no one really paid a whole lot of attention,” Judy explains in a matter-of-fact voice. Her doctors advised patience, as the damage caused by surgery and radiation might be temporary. “But temporary didn’t happen!” Judy says. “It took a long time to figure out all the different things that were affected.”

Judy and her primary care physician strategized together about therapies and treatments to help Judy deal with her sequelae. Bury (1982) calls this type of reaction to Judy’s “biographical disruption” as the “mobilization of resources, in facing an altered situation” (p. 170). Judy worked with a physical therapist, an acupuncturist, and a speech pathologist. She learned to cope, but her sequelae did not improve. She resigned from her job.

On the recommendation of her neurosurgeons, Judy joined a general cancer support group whose members “were learning how to re-integrate” cancer into their lives and move on. Judy says the group was “very good” and provided her with “a lot of support.” The members helped her get enrolled in MassHealth, a public health insurance program for eligible low- and medium-income residents of Massachusetts. Six or seven years later, Judy’s mother noticed an ad in the newspaper for a brain injury support group. When Judy walked into her first support group meeting, she knew that she was “home” as she entered a “family” of fellow brain injury survivors facing symptoms and challenges similar to her own. Judy’s use of the word “home” recalls what Bruner (1987) calls a “place,” in “sharp contrast” to the “real world” (p. 25), which
in Judy’s case means a world where brain injury is less understood. Judy described her first support group meeting for me,

It was like
I walked in the door there
Like everybody says
I walked in the door there
And it was like, “Oh my goodness!”
At the end of the meeting,
I thought, “Oh, boy, I was home!”
And all the things that I was having problems with,
It was big relief

After joining the brain injury support group, Judy started using the word brain injury more. She realized that her bigger problem at that point, years after the surgery and radiation, was her brain injury, not her brain tumor. The brain tumor had been successfully treated. “My new path was now, trying to work on the brain injury,” she says. “And come up with ways to compensate for the deficits...that weren’t going away. I had to figure out some ways that I could live with it.”

Judy’s narrative of identity has four photographs and their accompanying interview excerpts. In these selected images and excerpts, Judy shares several aspects of her identity: the chef who was “lost” with her brain injury, a person with “brain injuries” taking numerous medications each day, and an avid gardener.

This section presents Judy’s narrative in the order in which we discussed its photographs. Her narrative begins with Excerpt 1, a photograph of the French cookbooks that inspired Judy as a chef. It continues with Excerpt 2, a photograph of the cardboard shoe box that holds the pills she takes daily. Excerpt 3 shows a perennial garden Judy has created in front of her house. In Excerpt 4, Judy’s car keys share space in her freezer with soups and other foods that she has made from scratch, using items from grocery store discount tables.

As with the other survivors of focus, I present a closer look at one visual illness narrative excerpt: Keys in the Freezer. Due to space limitations, I have included excerpts from our conversation about Judy’s photo of her freezer. Where relevant, I have noted in brackets the gist of the interview sections that I eliminated (Mishler, 1999).
EXCERPT 4: Keys in the Freezer
“What do I make out of that, that I want?”

Part 1: We as brain injured people put things in weird places
It’s just this bizarre thing,
That we as brain injured people put things in weird places.
It’s just not things that connect.
It shows the disconnectedness of brain injury that
Why would you do that?
It doesn’t make any sense. It makes absolutely no sense.
But yet, if you have a brain injury—
It makes sense. Yes.

Part 2: Maybe I was getting a glass of water with some ice cubes
You know, the non-challenged people think that that’s just really bizarre
Right. And I suppose it is.
It is, yeah, it’s like “okay..” But?
It’s probably because I came in,
And even though I wasn’t putting something in the freezer at the time,
I was so tired

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That maybe I was getting myself a glass of water with some ice cubes Yes
And that’s when I put the keys down,
To get the ice cubes Right
And that’s where they stayed
It never went any further, the connect,
It just disconnected right there and that’s where they stayed Wow

[Deleted: her strategy for keeping track of her keys, and details about the food in her freezer, most of which she made from scratch]

Part 3: I make things out of nothing
So the chef in me is still there
I make things out of nothing

[Deleted: freezes egg whites; nothing goes to waste]

So that’s what my freezer is full of, things like that
And that’s the chef in you
Uh, huh. I’ve been able to live on not a lot of money, food-wise
I’ve been able to really stretch the dollar
Because of your cooking skills and knowledge Right

Part 4: I can do that because I was a chef
I buy what’s on sale
And then I make what I want out of those ingredients
And I can do that because I was a chef Yes
I can make something out of not a whole lot Yes
Something that’s gone by a little bit or something that’s on sale
I don’t have to buy the premium Interesting
What I feel like eating or making
It’s well, this is what’s available,
What do I make out of that, that I want?

Discussion: Keys in the Freezer, “What do I make out of that that I want?”
In this photograph, a set of car keys rests in front of plastic containers of frozen food in Judy’s freezer. More than one brain injury survivor on seeing this photo has exclaimed, “I didn’t know anyone else did that!” In our conversation, Judy first puts her image in context and explains that the “bizarre” behavior it exemplifies shows the “disconnectedness” in the brains of persons who have survived brain injury. In Part 2, Judy speaks of herself as a survivor. She is the person who put the keys in the freezer. She is comfortable with disclosing that she has brain injury. In Part 3, Judy uses the image to bring out her strengths as well as her challenges as a person living with brain injury. She explains that she made much of the frozen food in the image from scratch, using items from the discount table. She can stretch her food dollars this way because she was a chef. She also notes the frozen herbs that she grew herself—revealing that the new, gardener aspect of her identity is also part of the image.
According to Roser and Gazzinaga (2004), specific areas of the brain “carry out highly automatic processes that occur outside of conscious awareness and control” (p. 56) and processing is “distributed around the brain in functionally localized units” (p. 57). When brains are damaged, each hemisphere can receive information that “remains unknown to the opposite hemisphere” (p. 57). Thus, Judy’s image of keys in the freezer portrays the feelings of disconnectedness experienced by many brain injury survivors. In turn, the process of taking this photo, discussing it with others, and writing a caption for it appears to be an example of what Roser and Gazzinaga call “construction of a personal narrative that ties together elements of our conscious experience” (p. 58).

Much of the research literature on brain injury focuses on survivor’s problems or weaknesses, not on their strengths. An article by Coehlo et al. (2005) outlining the “narrative discourse” impairments in both micro- and macrolinguistic processes of their sample of adults with TBI is one small example (p. 1139). Impairments revealed through this and other research involve lack of coherence in a story sequence and “lower propositional density” (in other words, more limited content per sentence or story part) compared to adults without TBI (p. 1143). Yet interventions that measure these deficits are usually carried out in isolation from the subjects’ real lives. They involve activities such as retelling a story after seeing a series of images on a film strip, or generating a story after looking at a painting. In discussing the clinical implications of their work, Coehlo et al. (2005) note that “poor carry over and maintenance” of efforts to improve discourse impairments of TBI patients has been attributed to “the lack of relevance of the treatment materials” to individual life situations (p. 1144). Perhaps the same could be said of results generated by research and testing that do not relate to brain injury survivors’ lives. At the same time, however, being seen by the health system as “normal” can mean that brain injury survivors are excluded “from necessary medical services” (Nochi, 1998, p. 874). Thus, diagnosis of impairments after brain injury can be medically necessary, and perhaps also a necessary part of the healing process.

Judy took a photo of her keys in the freezer to show a challenge that many brain injury survivors face. In “audiencing” (Rose, 2007) her photograph in our interview, however, she focuses as much on the personal strengths inadvertently displayed in this image as she does on the problem the image was meant to portray. In the moment of the interview, Judy “suggests a second reading that emphasizes resistance and agency” (Riessman, 2000, p. 137). She sees in this image strengths and strategies as well as weaknesses and failures. She resists being portrayed only as a brain injury survivor who puts things where they don’t belong and then forgets about them. She acknowledges the disconnectedness experienced by many brain injury survivors and speaks of her agency in developing strategies to cope with it.

At this point, 17 years after her injury, Judy has a part-time job she enjoys, enough money to live on, subsidized health care provided through the state, and meaningful relationships with family, friends, coworkers, and the animals that visit her while she gardens. Judy appears to have no regrets about her lost identity as a chef. She has in a sense returned home from her hero’s journey (Frank, 1995).

I can still take things to pot luck parties
And I can still go to meetings and be the person who brings the refreshments
And not have it break the bank
So that has been a blessing, you know?
I’ve been able to use the past knowledge in a new way.

Judy appears to have reached a point where she sees the potentially disparate elements of her life before brain injury and after brain injury as fitting into a larger context (Reker & Chamberlain, 2000). In her images and our conversation, she portrays her process of discovering a new identity after brain injury through images that depict various aspects of her self experienced and developed over time—a chef, a person with brain injuries, and a gardener. Thus, Judy makes “visible” a self who is a “project of everyday life...articulated in the plural as ‘selves’” (Holstein & Gubrium, 2000, p. 13). Her “storytelling of the self” is “actively rendered” as Judy describes coordinating with her doctors and succeeding in her new passion of gardening (p. 103). Her story is also “locally conditioned”—by her brain injury and by the services and supports available to her (p. 103). Judy’s narrative of identity appears to show that she has created “order out of the discontinuities engendered by ruptures from the normal course of events” (Mattingly, 1998, p. 107).

Judy no longer speaks in one “voice” as chef; neither does she speak in one “voice” as brain injured person (Mishler, 1999, p. 8). Instead Judy speaks “as a chorus of voices” that includes chef, gardener, librarian, brain injury survivor, self-advocate, support group member, person with patience, and lover of nature (p. 8). Through her images and in her interview, Judy reveals “a multiplicity of self-definitions” (p. 154). Judy describes her “road” of self-discovery after brain injury as a process. Mishler (1999) calls this a “process of identity formation” and notes that “life-course disjunctions, discontinuities, and transitions” can be significant for the “formation and achievement of...sub-identities” (pp. 8-9).

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—the organized pill box and the beautiful garden—or minimizing her verbal data, when she describes forgetting to take her medications and falling in her plants and crushing them. Perhaps most useful to consider is the fourth excerpt of her narrative of identity: keys in the freezer. In this image, Judy shows her multiple, shared identities as chef, brain injury survivor, and gardener, “actively formulated” over time as a result of disjunctions and a willingness to experiment, fail, and start again (Holstein & Gubrium, 2000, p. 10). In the final image of her narrative, Judy’s “assembled” selves (p. 10) share space in her life just as her keys, herbs, and home-cooked food share space in her freezer.

Conclusion

As with Williams (1984), I did not select the three cases of focus in this dissertation to be 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. Thus, it appears that visual illness narratives of Subject D, Peggi, and Judy may also support the theoretical argument that “the arrival of chronic illness initiates a process of cognitive reorganization—

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meaning-making” (Riessman, 2007, p. 55). The life disruption of brain injury has provided “the necessary conditions for fashioning accounts essential to the re-establishment of a sense of direction and coherence” (Radley, 1999, p. 782). Defined this way, coherence may be another word for meaning in life, or existential meaning (Zika & Chamberlain, 1992, p. 133). The three stories presented here show that some brain injury survivors do gain perspective on their situation. Their new perspective encompasses the self and life before injury, self and life in the moment of relating the illness account, and a future self and life (Radley, 1999). As with others suffering from chronic conditions, Subject D, Peggi, and Judy are experiencing disruption and a search for coherence that is endemic to living with brain injury, particularly for adults with careers, families, and developed identities (Riessman, 2007).

One could argue that the interpretive process prompted by brain injury is also prompted by the research method used here—taking photographs and interpreting them in dialogue with other survivors and/or with the researcher. Harper (2005) suggests that his photo-elicitation work with dairy farmers resulted in “discussions that went beyond what happened and how to themes such as ‘this was what this had meant to us as farmers’” (p. 757). For my participants, however, their interpretive process began before I initiated this study and has continued since. Instead, the occasion of the study provided an opportunity for them to continue the process of interpreting their lives with brain injury. The stories revealed in their visual illness narratives might have been very different if they had not already been wrestling with issues of grief, healing, and self in support group meetings, therapy sessions, and their daily lives. Perhaps this study indicates the value of using these methods along with other methods to put a biographical disruption such as brain injury into perspective in a life lived.

However, we also need to put this research into perspective. Each of the three case studies is merely a slice in time, despite the responses from the participants and despite my ongoing relationship with Peggi and Judy. All three cases are stories in progress (Riessman, 2007). We do not know the outcomes. Will Subject D become reconciled to his losses and see them from a new perspective over time? Will Peggi continue to bounce back and forth between old self and new or will she over time start to turn her gaze more often on the future than the past? Will Judy’s acceptance of her injury continue to grow or has she reached a plateau of understanding and meaning?

All three of the case studies presented in this dissertation appear here to tell a valid story of brain injury survivor lived experience. Undoubtedly each is a partial telling. However, in using more than one approach to analyzing visual and narrative data, we as researchers and policy makers become part of the dialogue as we ask questions, respond to stories, analyze data, and suggest implications and avenues for future research.

I suggest that we need to see any given individual (brain injury survivor) or any given situation (such as living with brain injury) as having many facets, any one of which might face us as researchers or clinicians at any given moment, depending on our perspective, our method, our lens, our purposes, and our relationship with the person or situation. With crystallization, “there is no single truth” and we have a “deepened, complex, and thoroughly partial understanding of the topic” (Richardson & St. Pierre, 2005, p. 963). My three case studies suggest that we also can view narrative data—including visuals—as having many facets and perspectives. For us as
researchers to presume that we can know the “whole truth and nothing but the truth” from our interpretation of a participant’s narrative, no matter what its form, is hubris. Using several approaches—in my case, thematic, structural, dialogic, and visual narrative analysis methods—to analyze participant data may provide glimpses into different facets of experience. Using more than one method helps us to gain a deeper understanding of what the data can tell us—in this study, about living with brain injury, both for recently injured survivors and for those who have been wrestling with the disruption of their lives and continue to heal for many years.

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