

DISCOVERING A NEW IDENTITY AFTER BRAIN INJURY:
A VISUAL ILLNESS NARRATIVE

BY

LAURA S. LORENZ, MEd, PhD

Brandeis University

The Heller School for Social Policy and Management

European Health Psychology Society

Bath, England

September 2008

DISCOVERING A NEW IDENTITY AFTER BRAIN INJURY:
A VISUAL ILLNESS NARRATIVE

Abstract. The emphasis of medicine has changed, from curing acute diseases to managing chronic conditions. Acquired brain injury (ABI) is one example of the chronic conditions that Americans of all socioeconomic status must bear. Historically ABI survivors were expected to have limited potential for recovery, and payer support for rehabilitation care for ABI is limited. Now the brain and its potential for rehabilitation are seen as dynamic, not static; yet payer support lags behind clinical recommendations. This paper seeks to close the gap in the literature on the lived experience of long-term ABI survivors. A 17-year survivor's visual illness narrative reveals her discovery of a post-brain injury identity whose multiplicity of self-definitions includes chef, brain injury survivor, gardener, and self-advocate and whose healing continues. Study results suggest that visual research methods can help to put biographical disruption such as brain injury into perspective as a life lived. Implications for the patient-provider therapeutic relationship are discussed.

Background

Life expectancy for Americans of all socioeconomic status increased dramatically during the 20th century. Thus, the emphasis of medicine has changed, from curing acute diseases to managing chronic conditions (Carroll, 1998). Acquired brain injury is one example of the chronic conditions that Americans of all socioeconomic status must bear. By and large, patients, not doctors, manage chronic disease (Rich et al., 2005) and brain injury is no exception.

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 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). 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.

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). 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” (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 ABI has lagged behind the recommendations of the clinical community (Cope et al., 2005).

One of the challenges to recovering from brain injury is that there are no cookie cutter solutions to rehabilitation and recovery. Each patient’s injury and healing are different, and quality means tailoring rehabilitation plans to the individual. This conceptual shift—considering quality of care from the patient’s perspective—is encouraged in the IOM *Quality Chasm* report (2001), which calls for a person-centered approach to health and healthcare. In a societal context, the shift toward person-centered care has taken place in an environment of increased rights for “all individuals, irrespective of disability...to optimized social access, opportunity, integration, and participation” (Cope et al., 2005, p. 129).

One way to understand patients’ perspectives on living with illness and experiencing health care is to carry out qualitative research that allows patients to share their experiences in an unstructured way. However, as noted by Steadman-Pare et al. (2001) “literature on the perceived quality of life of TBI (and all ABI) survivors many years after injury” is scarce (p. 331). This paper seeks to close the gap in the literature on the lived experience of acquired brain injury survivors by exploring the experience of one survivor, Judy, as seen through several photographs she took of her life with brain injury and our conversation about them.

Methods

Judy and I met through a brain injury survivor support group, whose members participated in a photovoice project from September through November 2006, with outreach activities that have continued for more than a year. Photovoice is a process by which people can

represent their lives, point of view, and experience using photographs and written narratives (Wang & Burris, 1997). Photovoice is a systematic investigation carried out in collaboration with people affected by a particular issue—for example, homelessness, mental illness, or violence (Adelman, 1993; Lykes, 2001). With photovoice, researchers and participants co-create knowledge and build alliances in the “planning, implementation, and dissemination of the research process” (McIntyre, 2008, p. ix). Often photovoice projects provide an opportunity for people whose views are silenced or ignored to make their perspective known. Using cameras, participants take photographs of an issue of concern to them, discuss these issues as seen in the photographs, write captions for selected images, and conduct outreach or education efforts to raise awareness and encourage action (Wang & Redwood-Jones, 2001). In all, eight brain injury survivors participated in the photovoice project, which I co-facilitated with two people, also brain injury survivors. As requested, Judy took photographs of her life with brain injury and discussed several of her photos (of her own choosing) first with the photovoice group and several months later in a one-on-one photo-elicitation interview with me (Harper, 2002).

Narrative Analysis Methods

I analyzed Judy’s photos and our conversation using four narrative analysis methods: thematic, structural, dialogic, and visual analysis (Riessman, 2007). My thematic analysis methods involved creating a visual illness narrative of living with brain injury as revealed in four photographs and their interview excerpts, centered on a common theme (Bell, 2002). My structural analysis method used an ethnopoetic approach that divides the interview into lines, one main idea per line and presents a summary overview narrative (Gee, 1991). I expanded on Gee’s approach by creating a visual “outline of the narrative” (p. 24), or a summary narrative that functions as an abstract of Judy’s images and accompanying text. A more focused look at one

image and my structural analysis of its accompanying interview text provides a deeper glimpse of what Judy's photos and interview text can tell us.

Dialogic analysis assumes co-creation of data, an inherent characteristic of photo elicitation, which creates a "partnership between the scientists and the subject" (Ziller, 1990, p. 36). By handing cameras to participants perhaps we "discover what is really there, because what we see will be what is presented to us rather than what we have created through our control" (Reinharz, 2002/1979, p. 357). By being present, we cannot help but "shape the stories participants choose to tell" (Riessman, 2007, p. 50), as is apparent in my questions and remarks as an active participant in our dialogue (Riessman, 2007). Mishler (1999) writes, "defining interviewing as a dialogic process requires their inclusion" (p. 27). Dialogic analysis also provided a rationale for me to ask her to respond to my analysis of her visual and interview data. Judy's response follows the discussion of her image "Keys in the Freezer."

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 (Becker, 1986). A visual analysis strategy can also involve reflecting on image production, or respondent strategies for creating the study images (Rose, 2007; Riessman, 2007). A third analytic consideration in visual analysis is audience (Rose, 2007; Riessman, 2007). As Judy spoke about her photographs, she was "audiencing" them. I rely on the interview text to understand how Judy reads her images. In turn, when I look at the photographs, listen to what she says about them, and analyze the details of the images and their accompanying text, I am "audiencing" the images. As Akeret (2000) suggests, "when story and image appear to contradict each other, a deeper truth emerges" (p. 224).

Case Selection

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 selected Judy as a case of living with brain injury because her visual illness narrative is an evocative portrayal of the search for a new identity after brain injury. Her success in discovering a new identity is inspiring—not just to me as a non-brain injured person but also to the participants in the photovoice group. In focusing on Judy, I am 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 the myriad challenges she faces in living with brain injury (Padilla, 2003).

Judy’s Narrative of Identity

Judy’s visual illness narrative about discovering a new identity after brain injury has four photographs and their accompanying interview excerpts. In these selected images and excerpts, Judy shares several aspects of herself: the chef that was “lost” with her brain injury, a person with “brain injuries” taking numerous medications each day and placing her keys in the future,

and an avid gardener.

Judy's narrative presents its photos in the order in which we discussed them. It 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. I provide her summary narrative here in hopes that its inclusion will prevent my interpretation of Judy's story from subsuming her perspective.

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

Continued on next page

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

Getting to Know Judy

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. 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 laugh is hearty, infectious, and often ironic. She is short and round and has piercing blue eyes. Her hair calls attention: It stands up in feathery tufts, and she feels it reflects her personality. Judy’s hair was an important topic of discussion during our sixth group meeting, when participants were sharing their photos and the captions they had written. The theme had turned to acceptance, which someone said “can seem like capitulation.” Judy responded:

Acceptance is not giving up of possibilities.
It’s the opposite.
For me, acceptance was more of a positive thing.
It was accepting, well, this is where I am now,
But I don’t have to stay here,
But this is reality now,
And now I know what to work with.

Dave G¹ took up the theme: “Acceptance is like facing the truth...I’m not going to lie to myself that I should be doing what I did before...How can I move forward if I’m lying?” Judy pulled out a photo she had gotten back that day and held it up for the group to see. In the image, Judy is facing away from the camera and toward an outside porch wall painted dark grey. The

¹ The discussion presents interactions from the group project meetings, when brain injury survivors contributed to discussions about each other’s photos. For group project interactions that are embedded in the text, I have identified participants by their first name and last initial. For group project interactions that I have separated from the text and parsed into lines, I have identified the participants by their initials. “J.S.” is Judy.

dark color of the wall blends with Judy's dark blue t-shirt and the grey hair on the top of her head. The hairless back of Judy's head and neck stands out in stark relief. A two- to three-inch scar divides the naked skin there like the spine of an open book. The group responded with gasps of surprise and wonder.

J.S. That's what this picture's going to be about.
I hadn't written a narrative for it, I just got it back today.
But I took a picture of the back of my head.
Having this hair cut really was another step, statement of acceptance.
Because the way I wear my hair now,
Where my scar shows
I don't care
And since I wear it up and crazy (laughter)
It's like that's a part of it, my life is an—
P.R. You're open. You're not hiding
J.S. I'm open.
I'm no longer hiding the back of my head.

Dave G said that, out of all the people in the room, only Judy's hair looked "with it" and "cool." Laughter exploded. Scott D said, "You know, all these weeks I haven't been sure that you knew it looked crazy," prompting more laughter. Judy noted, "I always had parts of me that were very traditional, and yet there was always a streak of really radical, in so much about my life." She said that she is still "making progress," and she didn't realize "how freeing" it would be to stop covering up her surgery scar. Judy said to the group:

Because I didn't really realize,
I was always so careful about the back of my hair.
I lost...all the hair back there
Because of the radiation damage
And it's never going to come back.
So I always wore my hair from the top,
You know, coming down, covering it,
So it didn't look like there was any problem.
But if the wind blew,
It would open it,
And there would be this white streak,
And people were always trying to fix it for me,
So I finally said the hell with it.

The image of Judy's scar became an "anchoring point" for the group (Radley & Bell, 2007, p. 378). In exhibits and presentations of the group's photographs and narratives, this image has invited, commanded, and challenged "the gaze of the viewer" and become a source of "social support" for persons with brain injury (Radley & Bell, 2007, p. 369). Judy's photo exemplifies the "courage and commitment" required by brain injury survivors to "deal with their losses...and face the truth in their lives" (Prigatano, 1999, p. 213). Seventeen years after receiving her brain injuries, Judy is showing herself, her group colleagues, and the world that her healing continues.

Judy as Photographer

Judy took photographs for this study with purposeful intent. Using three disposable cameras she took a total of 52 photographs. Often she took 3 or more images of the same subject to make sure that she captured an image that suited her purposes. Her photo strategy also involved giving the camera to someone else. On her first roll Judy took 12 pictures in and around her home and yard. With her second camera she took 25 pictures, 22 in her home and yard and 3 at her parents' home. With her third camera she took 15 pictures: 2 at home, 4 in her car, and 8 in her physical therapist's office.

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.

Judy wrote a narrative for every theme depicted in her images. In her binder, she grouped her photos by theme, creating a collage with a single caption per page. She purposefully cropped her captions until they were so brief and to the point that they evoke thought-poems or haiku. She felt that short captions without "extra words" best reflected her personality.

The Photo Interview

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. We spoke in 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 made 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 the photos in 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).

Researcher Reflexivity

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, which reached 20 feet across and 10 feet high, much of it genre fiction and classics. From age eight I began to read these books, starting with classics (*The Yearling*, *The Little Princess*, and *Kidnapped*) before moving on to Horatio Alger 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. My 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” and 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).

A Closer Look at One Excerpt: Keys in the Freezer

Below, I provide a closer look at one excerpt from Judy’s visual illness narrative: Keys in the Freezer. The excerpt begins with a title that first describes the image and then places it in context using Judy’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 Judy’s own words (Gee, 1991, p. 22). Anything I said during the interview is italicized; all other text is Judy’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. 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

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?

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.

Discussion

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.

As with Williams (1984), I did not select Judy as a case of focus to be statistically representative. Rather, I selected her because she appeared to find participating in my study to be meaningful, and her story in turn seemed meaningful to me. Thus, Judy's visual illness narratives may support the theoretical argument that "the arrival of chronic illness initiates a process of cognitive reorganization—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 story presented here shows that some brain injury survivors do gain perspective on their situation. Judy's 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, Judy is experiencing a

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). Judy’s interpretive process, however, began before I initiated this study and has continued since. Instead, the occasion of the study provided an opportunity for her to continue the process of interpreting her life with brain injury. 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. As a case study of living with brain injury, Judy’s story is merely a slice in time, despite my ongoing relationship with her through the photovoice project. Her case study is a story in progress (Riessman, 2007). We do not know the outcome. Will Judy’s acceptance of her injury continue to grow or has she reached a plateau of understanding and meaning?

Judy’s narrative of discovering a new identity prompts questions: Is taking photographs and talking about them especially useful for facilitating appreciation of strengths and discovery of meaning in life after brain injury? Could creating visual illness narratives encourage patients and providers to work together harmoniously to resolve health issues and adherence challenges after brain injury? Can the goal of supporting brain injury survivors in their quest for new meaning in life be framed as a public health issue? If so, what social policies could federal and state agencies, institutions, and communities put in place to support a brain injury survivor’s

quest for meaning that would also be cost-effective and sustainable over time? In gathering data to make these types of social policy decisions, do we need to use methods that are relevant to brain injury survivors' real lives?

Judy Responds

Judy and I spoke for two hours about my analysis of her photos and interview text as presented in a chapter of my dissertation. We met in a room at the Natick Library, after a photovoice project outreach meeting. Judy told me that she had read the chapter in stages, a few pages here, a few pages there, because reading often brings on headaches. Before we met she read the chapter over again, this time straight through. Her response consists of excerpts from our conversations about my analysis. For ease of reading, I have removed repetitions, hesitations, or places where she stumbled in her conversation.

I was really impressed, inspired at so many words. When I was reading this, I found it fascinating, what you were able to pull out of our conversations. I think that is part of the brain injury, you forget what you say, and I forgot our conversations. You know, I remember parts of what they were, but there were many things I had forgotten. So it actually brought me back to those afternoons that we had spent the time talking together. The chapter gave a storytelling element to a conversation. My conversation wasn't necessarily a storytelling way, but you were able to put that conversation into something that made sense.

I asked Judy to comment on the downsides of her brain injury.

I tend to talk about the positive stuff. I minimize, I really minimize my struggles, in the sense that I don't focus on that, and I think that's why I strategize so much (laughs). Because I don't want to be there [with the struggles]. I don't really like even acknowledging them. I have to strategize a way out of it. When I'm forced to think about it, yes, I do remember [a] time when the struggles were more prevalent. I would get frustrated and I would throw something against the wall or whatever. But that doesn't help anything. So I don't remain there. Sometimes I think it's hard for me to come back to those days or to remember that [the struggles], because I've already put that in a box and put it away, and said, no, I don't want to look at that any more. So I think maybe you would have to draw it out of me. I don't give it up easily.

I asked her if she would be willing to give an example.

Yeah, sure. Let me go back and think about it. Looking at the picture of the pill box, that was a really negative thing. At one point I had so many pills. I had to take them at different times of the day, multiple times of the day. I just could not keep up with taking pills one and two at breakfast, and two and four at lunchtime, and five and one again at three pm. I just couldn't figure it out. And I'd get so, so frustrated with the whole thing. There would be days when I said, I can't figure this out, I'm not going to take anything.

I asked Judy if money was a downside, because I knew that she had been forced to spend all her savings on health care after she had lost her job and before she enrolled in MassHealth.

Right. I have absolutely no money in the bank, I have no retirement. I just hope and pray that my disability, they tell me that my disability payments will remain the same, that they won't get cut down when I turn 65, but there's no guarantees. I had to spend my retirement fund. I have nothing. I live from month to month. There's really very little opportunity to save anything. It takes months of putting money aside to do something. I have to really live within my budget, you know.... Yeah, there are downsides, definitely, but I don't like to think about them. Some people, they want to know all the negative things and I'm like, why do you want to know this stuff? (laughs) I don't want to know it, why do you want to know it?!

...In my case, money wasn't part of my story because I have always felt it not being a big part of my life, so it didn't even come into my sphere to leave it out. It had a huge impact on my life, but not emotionally. Reflecting back on it, I took pictures of things that affected me more emotionally. I remember seeing Laura Foley's picture of the mess of wires.² When I saw the kinds of pictures that she took, it completely changed my perspective of what to take pictures of. It was the emotional things, the identity lost.

I commented how it had struck me that, when Judy's mother had attended our informal photovoice exhibit for family and friends, she had called Judy's binder of photos and narratives her "happy book."

She would probably remember more of those struggles, especially those first few years, when my brain injury was at its worst. I don't remember those days very well any more, because the brain injury didn't let things sink in.

Toward the end of our conversation, I asked Judy to look reflect on the group members'

² When my co-facilitators and I introduced photovoice to the support group, we shared as examples several photographs that Laura Foley, a photovoice project co-facilitator, had taken when we worked together.

discussion of acceptance and Judy's photo of her scar.

That picture of the scar represents such an important...all the words are coming up in my head, things like freedom and acceptance...I couldn't have done that [taken that picture] two years prior [to our project]. That for me was probably the biggest statement about where my life is now. So the slice of now, that's in my photo there. It shows where I am at right now, how things have changed so differently, how life is so different from what it was, right after my surgery, five years after my surgery, ten years. I was going through different things at those times. And that picture is of now, today. It's not the end of my story. But it's a beginning of a whole chapter. It's like the end of the shame, of having to try to cover it up, not wanting people to see that [the scar] as the first thing. I never hid it, but now it's out there. And you know, it makes for interesting conversation. Now it's just, well, that's just part of me, you know.

Here is the photo of Judy's scar and what she wrote about it for the photovoice exhibit.



New depth of acceptance. In my 17th year of recovery, I am no longer shamed by lack of hair and scar. It represents a new freedom, pride in what I have overcome.

Conclusion

Dialogue is an underlying aspect of the research approach used in this study. It is also basic to person-centered care. Sharing information is two-way communication that implies engagement and reciprocity in conversation (Riessman, 2007). When writing about nursing research with stroke survivors and other patients with chronic conditions, Thomas and Pollio urge practicing nurses to meet with patients “ready to engage in dialogue” (2002, p. 254).

Reflecting on the importance of listening to patients, they comment:

...it is clear that we make contact with one another primarily in conversation. This means that I must hear and listen to you as you must hear and listen to me. And this is the most important lesson: ...to listen respectfully to patient and research participants so that we might understand the unique perspectives of their experiences and of their worlds. (p. 256)

A relationship that has two-way communication implies a balance of power and mutual learning. Thomas and Pollio suggest that in dialogic research, “the researcher is invariably changed by his or her interaction with participants” (p. 254). The physician Gretchen Berland has found that her research to understand disabled patients’ perspectives led her to “listen more carefully” and “consider the time and effort it takes for patients to reach my clinic and how long they have waited before coming to see me with a problem” (2007, p. 2536). Patient-centered care requires learning about patients’ perspectives (Berland, 2007). Listening and “taking the other’s perspective” has also been described as “a necessary step in social change” (Frank, 2000 in Chase, 2005, p. 668).

The potential implications for efficiency in health care of using visual and other approaches that encourage mutual engagement and learning in the patient-provider relationship merit attention in the future. Sensitive care leads to better outcomes (Adler, 2002), thus challenging our usual notions of efficiency (Chilingerian, 2004). Significant health system

savings could potentially be derived from providing care that leads to gains in brain injury survivor healing and health—care that is currently denied to many. Refusing care to brain injury survivors, thus limiting rehabilitation outcomes, has economic implications when it slows the return of individuals and their caregivers to productivity and leads to chronic illness and care. Perhaps revising health care goals from treating symptoms to supporting human development, function, and self-actualization (Maslow, 1987; Gil, 1992/1973) would lead to savings and long-term efficiencies that we have not yet imagined.

References

- Adelman, C. (1993). Kurt Lewin and the origins of action research. *Educational Action Research, 1*(1), 7-24.
- Adler, H. M. (2002). The sociophysiology of caring in the doctor-patient relationship. *Journal of General Internal Medicine, 17*(11), 883-890.
- Akeret, R. U. (2000). *Photolanguage: How photos reveal the fascinating stories of our lives and relationships*. New York, NY: W.W. Norton & Company, Inc.
- Arlinghaus, K. A., Shoaib, A. M., & Price, T. R. P. (2005). Neuropsychiatric assessment. In J. M. Silver, T. W. McAllister & S. D. Yudofsky (Eds.), *Textbook of traumatic brain injury* (pp. 59-78). Washington, DC and London, England: American Psychiatric Publishing, Inc.
- Becker, H. S. (1986). *Doing things together: Selected papers*. Evanston, Illinois: Northwestern University Press.
- Bell, S. (2002). Photo images: Jo Spence's narratives of living with illness. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 6*(1), 5-30.
- Boyle, P. J. (2001). The decade of the brain. *The Park Ridge Center Bulletin: Religion and the Brain*(19), 479.
- Bruner, J. (1987). Life as narrative. *Social Research, 54*(1), 11-32.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4*(2), 167-182.
- Carroll, L. W. (1998). Understanding chronic illness from the patient's perspective. *Radiologic Technology, 70*(1), 37-42.

- Chilingerian, J. A. (2004). Who has star quality? In R. E. Herzlinger (Ed.), *Consumer Driven Health Care: Implications for Providers, Payers, and Policy-makers* (pp. 443-453): Jossey-Bass.
- Coehlo, C. A., Grela, B., Corso, M., Gamble, A., & Feinn, R. (2005). Microlinguistic deficits in the narrative discourse of adults with traumatic brain injury. *Brain Injury, 19*(13), 1139-1145.
- Cope, D. N., Mayer, N. H., & Cervelli, L. (2005). Development of systems of care for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 20*(2), 128-142.
- Cope, D. N., & Reynolds, W. E. (2005). Systems of care. In J. M. Silver, T. W. McAllister & S. D. Yudofsky (Eds.), *Textbook of traumatic brain injury* (pp. 559-581). Washington, DC and London, England: American Psychiatric Publishing, Inc.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: The University of Chicago Press.
- Gardner, H. (1975). *The shattered mind: The person after brain damage*. New York, NY: Alfred A. Knopf.
- Gee, J. P. (1991). A linguistic approach to narrative. *Journal of Narrative and Life History, 1*, 15-39.
- Gil, D. G. (1992/1973). *Unraveling social policy: Theory, analysis, and political action towards social equality* (Fifth ed.). Rochester, VT: Shenkman Books, Inc.
- Harper, D. (2002). Talking about pictures: a case for photo elicitation. *Visual Studies, 17*(1), 13-26.
- Harper, D. (2005). What's new visually? In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (Third ed., pp. 747-762). Thousand Oaks, CA: Sage Publications.
- 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.
- Institute of Medicine (IOM). (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.
- Kraus, J. F., & Chu, L. D. (2005). Epidemiology. In J. M. Silver, T. W. McAllister & S. D. Yudofsky (Eds.), *Textbook of traumatic brain injury* (pp. 3-26). Washington, DC and London, England: American Psychiatric Publishing, Inc.
- Langlois, J. A., Rutland-Brown, W., & Thomas, K. E. (2004). *Traumatic brain injury in the United States: Emergency department visits, hospitalizations, and deaths*. Atlanta, Georgia: Centers for Disease Control and Prevention, National Center for Injury

Prevention and Control.

- Langlois, J. A., Rutland-Brown, W., & Wald, M. M. (2006). The epidemiology and impact of traumatic brain injury: A brief overview. *Journal of Head Trauma Rehabilitation, 21*(5), 375-378.
- Lykes, M. B. (2001). Creative arts and photography in participatory action research in Guatemala. In P. Reason & H. Bradbury (Eds.), *Handbook of Action Research: Participative Inquiry and Practice* (pp. 363-371). London, England: Sage Publications.
- Maslow, A. H. (1987). *Motivation and personality* (Third ed.). New York, New York: Longman.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge, UK: The Cambridge University Press.
- McIntyre, A. (2008). *Participatory action research* (Vol. 52). Los Angeles, CA: Sage Publications.
- Mishler, E. G. (1999). *Storylines: Craftartists' narratives of identity*. Cambridge, Massachusetts: Harvard University Press.
- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine, 46*(7), 869-878.
- Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science & Medicine, 51*, 1795-1804.
- Padilla, R. (2003). Clara: A phenomenology of disability. *The American Journal of Occupational Therapy, 57*(4), 413-423.
- Prigatano, G. P. (1999). *Principles of neuropsychological rehabilitation*. New York: Oxford University Press.
- Radley, A. (1999). The aesthetics of illness: Narrative, horror and the sublime. *Sociology and Health & Illness, 21*(6), 778-796.
- Radley, A., & Bell, S. (2007). Artworks, collective experience and claims for social justice: the case of women living with breast cancer. *Sociology of Health & Illness, 29*(3), 366-390.
- Radley, A., & Chamberlain, K. (2001). Health psychology and the study of the case: from method to analytic concern. *Social Science & Medicine, 53*, 321-332.
- 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.

- Rich, M., Polvinen, J., & Patashnick, J. (2005). Visual narratives of the pediatric illness experience: Children communicating with clinicians through video. *Child and Adolescent Psychiatric Clinics of North America*, 14, 571-587.
- Riessman, C. K. (2000). "Even if we don't have children [we] can live": Stigma and infertility in South India. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp. 128-152). Berkeley and Los Angeles, California: University of California Press.
- Riessman, C. K. (2007). *Narrative methods for the human sciences*. Los Angeles: Sage Publications.
- Rose, G. (2007). *Visual methodologies: An introduction to the interpretation of visual materials* (Second ed.). London: Sage Publications.
- Roser, M., & Gazzinaga, M. S. (2004). Automatic brains--interpretive minds. *Current Directions in Psychological Science*, 13(2), 56-59.
- Sherry, M. (2006). *If I only had a brain: Deconstructing brain injury*. New York, NY and London, England: Routledge.
- Steadman-Pare, D., Colantonio, A., Ratcliff, G., Chase, S., & Vernich, L. (2001). Factors associated with perceived quality of life many years after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 16(4), 330-342.
- Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369-387.
- Wang, C. C., & Redwood-Jones, Y. A. (2001). Photovoice ethics: Perspectives from Flint photovoice. *Health Education & Behavior*, 28(5), 560-572.
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness*, 6(2), 175-200.
- Zika, S., & Chamberlain, K. (1992). On the relation between meaning in life and psychological well-being. *British Journal of Psychology*, 83, 133-145.
- Ziller, R. C. (1990). *Photographing the self: Methods for observing personal orientations*. London, England: Sage Publications.