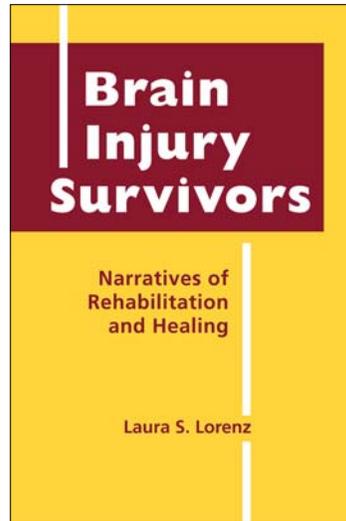


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**Brain Injury Survivors:
Narratives of Rehabilitation
and Healing**

Laura S. Lorenz



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1

Introduction

*I felt a cleavage in my mind
As if my brain had split
I tried to match it, seam by seam,
But could not make them fit.
The thought behind I strove to join
Unto the thought before,
But sequence raveled out of reach
Like balls upon a floor.*

—Emily Dickinson (1830–1886)

This book is about lived experience with acquired brain injury (ABI), or any injury to the brain that occurs after birth and results in impairments in cognitive, physical, or emotional functioning. Causes of brain injury are many and include strokes, brain tumors, epilepsy, near drowning, traumatic brain injury (TBI), multiple sclerosis, and schizophrenia. In *Crossing the Quality Chasm*, the 2001 Institute of Medicine report on quality and health care, the authors call for more person-centered health care, or care that encompasses the patient’s experience of illness and health care and the outcomes for which the patient may hope or aim. Rehabilitation from brain injury, whatever the cause, can be complicated by unpredictability and uncertainty about a person’s potential for recovery of function (Gardner 1975). Providing person-centered care is particularly urgent for persons with brain injury.

However, the majority of the published research on brain injury concentrates on measuring the injury’s impact on a person’s capacities, for example, memory, ability to function, communication skills, and ability

to work. Frequently, research studies focus on proving the utility of instruments for measuring loss of function. Much research has concentrated on the technologies, providers, and costs related to providing services to TBI patients (NIH 1998). A critical gap in the scientific and research literature is the lack of knowledge about what it is like to live with brain injury.¹

After one of the first interviews for this study, I had to drive through the city of Boston (Massachusetts) to get to my next destination. The most direct way involved traveling north through the city on Route 93. The “Big Dig” engineering project was well under way. Route 93’s elevated highway had been pulled down and new tunnels bored underneath, following the path of the old elevated structure. Some parts of the tunnel had recently closed due to falling ceiling tiles. Exits and entrances to the tunnel were under construction. Roads on either side of the main artery were being rerouted.

The traffic came to a standstill just a few miles south of Boston. I exited the highway and began to work my way through South Boston, taking back roads I had learned years ago. At least I thought I had learned them. I turned on my audio recorder.

I’m not quite sure where I am right this minute. I seem to have ended up in kind of a dead end. I may have to turn around. So, I wasn’t quite as smart as I thought [in going through South Boston]. That’s okay. So, I’ll turn around and go back another way. . . . And ended up, oh, gosh, I’m not sure where I ended up. Little Jack Horner Jokes and Magic. Foundry Street. Maybe I’ll be okay.

I reached Atlantic Avenue and crossed over the Route 93/Big Dig tunnel at street level. I turned the recorder back on.

Well, I obviously wasn’t as smart as I thought I was on directions again. Now I’m in downtown Boston during lunch hour. I got a little turned around. Shoot, I may be heading back the way I came! But, not to worry, someday, someday, I’ll get where I want to go. That doesn’t look like it’s going to happen any too soon. Oh gosh. This isn’t working out too well. Guess I just have to be relaxed about being stuck in traffic. . . .

[*A little later*] I think this is the third time I’ve been on this street, circling around . . . and it’s just unbelievable. It seems like I’m going in circle after circle, after circle. And it’s very, very frustrating!

[*Later*] Here I am back again where there’s a stopped car, and a stopped truck. . . .

[*Still later*] It’s hard to get from one place to another. . . . I don’t believe it, this is the fourth time I’ve ended up on State Street. I just, I can hardly believe it, that I got turned around here again. . . . This is very, very confusing.

I circled around the one-way streets, blocked entrances and exits, and dead ends two, three, four times before finally finding an entrance ramp and taking the Big Dig tunnel to reach my destination. A trip that should have lasted five or ten minutes had taken over an hour.

As I learned more about living with brain injury, my driving story—of circling around and around the same (formerly familiar) streets, of feeling quite certain that I knew what I was doing but failing again and again, of taking much longer to do something than I anticipated based on past experience—helped me to understand what it can feel like to live with brain injury, especially when the injury is new. With brain injury, the communication paths in the brain can be blocked, like the city highway and streets disrupted by the Big Dig. Brain damage can slow the usually automatic search for memories or words, ideas or directions. Instead, signals between and among different parts of the brain must take a circuitous route. The signals run into dead ends, one-way streets, and wrong turns. Thought and action get sidetracked and delayed. As one participant in this study said, living with brain injury is like “trying to run on ice without wearing a pair of skates. The faster you run, the more you get nowhere.”

Study Purposes

The purposes of the study that has led to this book were to

- Gain an understanding of brain injury survivors’ experiences living with their injury;
- Use visual research methods to promote researcher-participant dialogue about the experience of living with brain injury;
- Uncover new knowledge about personal, community, and health-policy issues related to brain injury;
- Explore how the study’s methodology and data could inform clinical and research policy and practice and potentially be applied in therapeutic settings.

Background

My study took place during a tremendous surge in interest in brain injury in the United States, due to military personnel returning from Afghanistan and Iraq with traumatic brain injury or a blow or shock to the head that

disrupts brain function. TBI is a silent epidemic in the United States that affects at least 1.4 million people each year and incurs an annual cost of \$48 billion to \$56 billion (Langlois, Rutland-Brown, and Thomas 2004). An estimated 5.3 million people in the United States are currently living with disabilities resulting from TBI, and 80,000 to 90,000 individuals join their numbers every year (Langlois, Rutland-Brown, and Thomas 2005). Each year, the chief causes of TBI in the United States are falls (28 percent), vehicle crashes (20 percent), sports-related injuries (20 percent), and assault (11 percent) (Langlois, Rutland-Brown, and Thomas 2004; NCIPC 2005; Davies, Connolly, and Horan 2001).

No matter what the cause, brain injury can have a devastating impact on the life and functioning of a survivor. Many brain injury survivors can likely relate to the personal consequences described by Jon Prosser (2007:191–192), a noted visual sociologist, after he had a stroke.

Brain injury is traumatic physically, mentally and emotionally. I was scared, confused, psychologically damaged and in a state of shock. Emotionally and cognitively I was a wreck. Behaviorally and perceptually I was a changed person. I was angrier, more irritable, tired, impatient, illogical, selfish, and exhibited a reduced tolerance to stress.

Prosser (2007:195) notes that it took him two years to write the article that includes the quotation above. He writes, “I want my brain back but how will it know when I get there?”

Visuals and the Brain

Neuroscientist Antonio Damasio (1994) theorizes that our thoughts are made up of visual images. He suggests that the brain stores information, retrieves it, reasons, and makes decisions using visual images. Our brain does not hold or store permanent pictures of our thoughts, memories, or words. Instead, our brain creates images that represent a thought, idea, word, or memory in “real time,” by pulling bits and pieces of information stored in various parts of the brain, at any given moment. Knowledge stored as images is vital to human reason and planning, and new knowledge results in changes in our mental images (Damasio 1994).

Damasio’s theory appeared to suggest that participating in a research study that used visuals might help brain injury survivors communicate more easily. I decided to have my study participants “gather their thoughts” and depict their experiences and feelings in photographs.

Photography has served as a powerful tool for illuminating human experience with health and illness. In her work with families to understand what it was like to live with childhood chronic illness, Hagedorn (1996) used photographs taken by family members to generate discussion during individual and family interviews. Her research suggests that placing cameras in the hands of brain injury participants likely would result in a different understanding of living with brain injury than would be gained through interviews without a visual component. Part of the difference in understanding might be explained by the power that participants hold as they create visuals and share them with researchers. Researchers at Children's Hospital Boston, who asked adolescents to make videos of their lives with chronic illness, have found that giving video cameras to participants shifts the power differential between researcher and participant (Rich, Lamola, Gordon, and Chalfen 2000b). Participants become teachers as they show researchers what it is like to live with a long-term health condition.

Communicating after brain injury can be a challenge if thinking and speech are slowed. Persons with brain injury may have mild to medium long-term cognitive difficulties even as they function and live as independent adults. Perhaps asking participants to take photographs and talk about them is more ethical or fair than traditional interview methods because participants have time to reflect on the research question and a way to remember what they wanted to say. In any case, the existing research literature suggests that using visual methods likely generates new research knowledge about what it is like to live with brain injury.²

Why Study Lived Experience with Brain Injury?

Rehabilitation psychologists, neuropsychologists, and others have for many years advocated gaining an insider perspective on living with disability (Bruyere 1993). In his presidential address to the National Academy of Neuropsychology in 2000, George Prigatano acknowledges the importance of scientific study of problems with brain function and says that it is inadequate. He states that, "to be effective in their work, neuropsychologists must understand their patient's experiences" (Prigatano 2000:77). Researchers at Children's Hospital Boston argue that clinicians need to understand "how patients live with chronic health conditions in their daily . . . environments"—home, school, and work (Rich et al. 2000b:156). Another expression for "in-

sider experience” with a chronic health condition is “lived experience” or an “understanding of the nature or meaning of our everyday experiences” (van Manen 2006:9). This book seeks to provide a glimpse into the nature and meaning of the everyday lives of people who have survived a brain injury and returned home to their families and communities.³

Research Methods

Researching lived experience with brain injury requires personal contact with persons who have brain injury. Thus, qualitative research methods and lived experience go hand in hand. I employed two basic research approaches to gathering data for this study: photo-elicitation and photovoice. For the photo-elicitation component, thirteen brain injury survivors took photographs of their lives with brain injury and talked with me about their photos in a research interview (Harper 2002). Photovoice is a group process, in which participants discuss their photographs together and write captions for images they want to share with others (Wang, Burris, and Ping 1996).^{*} For the photovoice component, I worked with members of a brain injury survivor support group, and two brain injury survivors facilitated the project with me.

The data collected for my study are threefold. They include (1) field observation notes of the study’s photo-elicitation and photovoice components; (2) photos taken by participants; and (3) transcriptions of two types of conversations about the study photos: (a) when participants talked about their photographs in interviews with me, and (b) when photovoice participants discussed their photos with the cofacilitators and each other during photovoice project meetings.

^{*}Photo-elicitation has been used in anthropology, sociology, and public health for decades (Collier 1957; Harper 2002; Frith and Harcourt 2007). With photo-elicitation, photographs used to generate discussion in the research interview can be taken by the researcher or research participant, or be archival images or images from newspapers, magazines, or even billboards, for example. The photo-elicitation interview is a dialogic exchange between researcher and participant. Photovoice has been used in public health and development contexts since the early 1990s (Wang and Burris 1997). With photovoice, all photographs are taken by research participants, who discuss their images together. Thus the dialogue that ensues from photovoice involves the sharing of multiple perspectives. My study benefited from the use of both approaches (see Glossary and Chapter 3 for further discussion of photovoice).

Study Sample

Eleven of the thirteen brain injury survivors who took photographs and spoke with me were between the ages of 40 and 60 years, and two were in their early 20s. Seven are women, and six are men. All participants received their brain injuries at least 1 year prior to recruitment; two were injured more than 25 years ago. Eleven have survived TBI, and two have survived brain tumors. One participant has a spinal cord injury in addition to TBI. Six participants were recruited through a rehabilitation hospital where they were accessing outpatient services, and five of them completed the study. The remaining eight participants were recruited through a brain injury survivor support group.

Camera Use

The thirteen study participants who completed the picture-taking assignment used a total of 25 disposable cameras to take 504 photographs, or about 20 images per camera. Three participants took just 15 or 16 photos. Three took more than 50 photos, and one took 70 photos. The average number of photos taken per participant was 39, and the median was 38.

Most participants took their photos over a span of three to five weeks. Two participants took their photos in just one or two days. Three contributed personal snapshots to the study.

Eleven participants used their cameras appropriately and purposefully. Three took a majority of “off-topic” photos with their study cameras. One used up two cameras while on a trip to Arizona with her sisters. Another filled two cameras with photographs of her home. A third took his photos on an outing with his grandfather and did not speak of any of them as relating to his brain injury. Out of 504 photos, only 10 appear to be mistakes.

Study Photos

I have informally grouped participants’ study photos under 19 themes (including “mistakes”).⁴ The most photographed theme is challenges (69 photos), depicted by ten participants. Family and friends was another major theme (58 photos), portrayed by nine participants. Other major themes include nature (34 photos), captured by eight participants, and strategies (42 photos), addressed by seven participants.

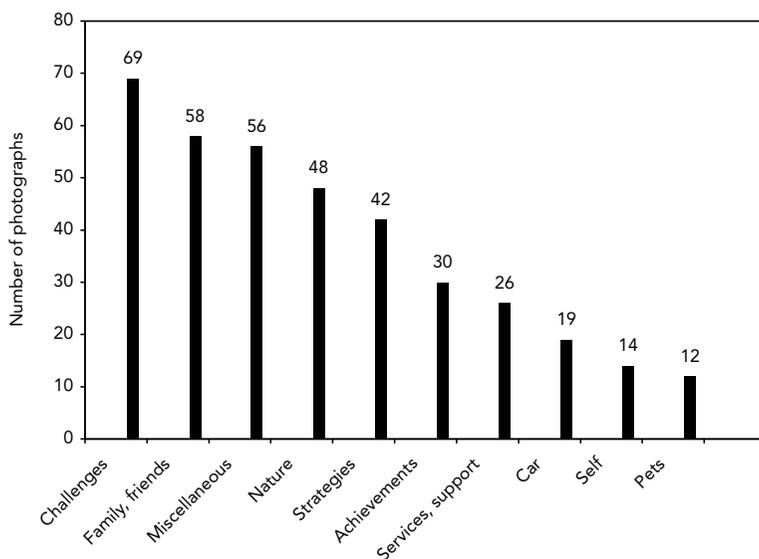
Eight participants took pictures of themselves (14 photos). Seven participants took photographs that were visual metaphors (56 photos),

or photographed their homes (48 photos) or cars (19 photos). Six participants took photos of services and supports (26 photos), or achievements (26 photos), or took photos that appear to be mistakes (10 photos), for example, dark or blurry. Three participants photographed a job or family role (6 photos).⁵ Two participants photographed their pets (12 photos), or took photos with a spiritual theme (8 photos).

Figure 1.1 shows the relative proportion of photos taken under the 10 most popular study themes: challenges (69), family and friends (58), miscellaneous metaphors (56), nature (48), strategies (42), services and supports (26), achievements (30), cars (19), self (14), and pets (12). These 10 categories represent more than 73 percent of all photos taken for the study. Not included in Figure 1.1 are the categories home and tourism (86 photos, or 17 percent of all study photos), as the vast majority (72 photos or 84 percent) of the photos in those 2 categories appear to be off topic. The remaining 7 categories of photos contain from 2 to 8 photos each.

The summary of study visual data described above is useful for providing a general picture of how the participants used their cameras and

Figure 1.1 Major Themes Depicted by Study Participants



Note: The figure includes only the 374 photographs that were considered on topic and used in the study.

to what purpose. The summary does not seem useful, however, for understanding what it is like to live with brain injury. To understand lived experience, I focused instead on the stories of three study participants, chosen as “case studies.” For each “case” I have selected a sampling of photographs and their accompanying interview excerpts to form a visual illness narrative, centered on a common theme (Bell 2002; Rich, Patashnick, and Chalfen 2002).

Analysis Methods

My analytic approach is narrative analysis, a family of four methods: thematic analysis, structural analysis, dialogic/performance analysis, and visual analysis (Riessman 2007). I used thematic analysis in forming the visual illness narratives. I used structural analysis to examine closely what participants said about their photos. Dialogic analysis provided a rationale for reflecting on my impact on the interview data, and the impact of the data on me, in turn. My visual analysis approaches were threefold and involved (1) looking at image details (Becker 1986); (2) reflecting on how the photos were produced and how different audiences interpreted them (Rose 2007); and (3) considering the intersection—or lack of intersection—between the photographs and what people said about them (Riessman 2007; Akeret 2000).

The three cases I selected for closer study represent a range of lived experiences with brain injury: one person was injured one year before participating in the study; the other two were injured four years and seventeen years ago, respectively. The sources of their injuries differ also: one received a “severe” TBI when he fell down his basement stairs, one received a “mild” TBI when a sign fell on her head, and the third survived a brain tumor that was surgically removed and treated with radiation therapy. For each person, the themes that emerge from their photographs and interviews appeared to me to represent something important about the experience of living with brain injury (Williams 1984).

The Chapters

This introduction concludes with a brief overview of the book’s chapters. Chapter 2 introduces brain injury, and presents the incidence, prevalence, and costs related to TBI in the United States. The chapter briefly discusses the consequences of brain injury and current approaches to re-

habilitation. It provides a review of qualitative research on brain injury, which shows the global nature of poor quality of care for brain injury survivors. And finally, the chapter presents two models—one for person-centered health care that illustrates the value of understanding quality from the patient’s perspective and highlights the importance of the patient-provider relationship. The other is an organizational behavior model that provides a useful lens for considering the organizational challenges to improving quality of care for brain injury survivors.

Chapter 3 is a sequential account of what happened in this study (and why). I describe the study’s 11 phases, from “The Beginning” to “Writing Up the Results.” For each phase, I present some key methodological decision points—for example, what type of camera to use, how to equitably gain informed consent from people with cognitive impairments, and selection of the case studies. Insights from the methodological literature support my decisions and, in some cases, present alternative perspectives.

Chapters 4, 5, and 6 are case studies of lived experience with brain injury and form the foundation of this book. Each chapter provides a survivor’s visual illness narrative, with several photographs and their accompanying interview text. In each case study chapter, a “self-reflective meditation” reveals my researcher lens (Van Maanen 1988:106) and shows how my personality, intellect, and experiences shaped the knowledge generated (Reinharz 2002).

In Chapter 4, a participant who asked to be called “Subject D,” an ironic name he chose perhaps because of the isolation and alienation he feels in living with brain injury, shares the frustration and confusion that dominate his life since falling down his basement steps and suffering a severe TBI one year before he participated in the study. Subject D uses his photographs to show us the disorder that he feels daily in his life and his brain. A major source of his frustration and confusion relates to food: shopping for it, cooking it, tasting it, storing it, and cleaning up. Revealing my researcher’s lens, I describe how my life experiences shaped the knowledge generated in working with a survivor of severe TBI whose pessimism about his situation made me feel frustrated in turn—and the implications of my feelings for the patient-provider relationship for brain injury survivors. To close this chapter, Subject D responds to my analysis and provides an alternative perspective.

In Chapter 5, Peggi unfolds the numerous dimensions of darkness and light in her life, which was disrupted by TBI when a sign from an airport bus fell on her head four years before we met. Peggi describes the dichotomy she feels as her “old self” and “new self” bump up against

each other, for example, when she fails at tasks that used to be easy. Like almost 75 percent of the 1.5 million people in the United States each year whose head injuries are treated in emergency medical settings, Peggi's injury was labeled "mild" (Langlois, Rutland-Brown, and Thomas 2004; NCIPC 2005). However, her resulting long-term cognitive, physical, and emotional challenges have been anything but mild (Lewine et al. 2007; Cajigal 2007). I share my feelings of elation and exhaustion in working with a survivor of mild TBI who appears "normal" but has hidden disabilities. To conclude the chapter, Peggi responds to my analysis and contributes a new photograph, to encourage brain injury survivors and their family members to resist the medical community and insurance payer perception that brain injury patients will peak in their recovery at six months.

In Chapter 6, Judy shares several aspects of her identity as a brain injury survivor: the chef who was "lost" with her brain injury, a person with "brain injuries" taking numerous medications each day, and an avid gardener. At this point, 17 years after surgery and radiation for a slow-growing brain tumor ended her career as an executive chef, Judy appears to see the potentially disparate elements of her life before and after brain injury as fitting into a larger context (Reker and Chamberlain 2000). Judy's visual illness narrative describes her process of self-discovery after brain injury—a process that will inspire brain injury survivors, persons suffering from other chronic conditions, family members, and health and social service providers alike. In turn, I reflect on my concerns in being drawn to Judy as hero in her quest for healing, and how an immersion in universal plots from an impressionable age inevitably colored my view of Judy's experience and my choice of a theme for her visual narrative. In responding to my analysis, Judy reveals the downsides of her injury and reflects on why they did not come out when she talked about her photographs.

Chapter 7 pulls together the disparate narrative threads of the three brain injury survivor case studies and puts their lived experiences in perspective using several theoretical frameworks. I propose a theory of selves grounded in the participants' three visual illness narratives and present simple visual models to illustrate my theory of selves. The chapter concludes with a discussion of the implications for healing, medical practice, health-care policy, and future research raised by the three case studies, my research methods, and my proposed theoretical framework.