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Re-establishing a sense of coherence: A typology of brain injury survivor stories

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Abstract. The life disruption of brain injury provides the conditions for creating stories to re-establish a sense of coherence and self. A qualitative research study of lived experience with brain injury has suggested a typology of three brain injury survivor stories. In the first story, the new (brain-injured) self dominates and feelings of hopelessness consume the teller. In the second, the new self and old self are in dialogue and both impairments and strengths emerge. In the third, a multiplicity of selves accepts each other and the teller narrates a range of selves, activities, and strengths as well as suffering. The suggested typology could support listeners as they give the gift of listening, and provide opportunities to note changes in the stories being told. Symbolic transformations of the typology provide simple visual models to support brain injury survivors as they reflect on their situations with support group leaders, clinicians, and peers.

Background. Acquired brain injury (ABI) is an injury to the brain that occurs after birth and results in impairments in cognitive, physical, or emotional functioning. Rehabilitation from ABI is fraught with unpredictability about the potential for recovery (Gardner, 1975). Lack of access to person-centered care for ABI patients is a global issue (Sherry, 2006; Jumisko et al., 2005; Nochi, 1998; Sample & Darragh, 1998), and therapeutic relationships that provide information and emotional support are a key dimension of person-centered quality (Chilingerian, 2004). However, providers may focus on the empirical knowledge they bring to the clinical encounter (Rich et al., 2000). A greater understanding of lived experience with ABI could improve an important dimension of quality from the ABI patient's perspective.

Purpose. The purposes of this study were to 1) gain an understanding of ABI survivors' experiences; 2) use visual research methods to promote dialogue about lived experience with ABI; 3) uncover new knowledge about health policy issues related to ABI; and 4) explore how the methodology and findings could be applied in therapeutic settings.

Methods. I employed two approaches to generating qualitative data for this study: photo-elicitation interviews with 11 ABI survivors, and a photovoice project with 8 members of an ABI survivor support group. Photo-elicitation inserts a photograph into the research interview (Harper, 2002), while photovoice is a similar process carried out in a group (Wang, 1997). The sample consisted of 3 recently injured persons accessing outpatient rehabilitation services, and 8 members of a brain injury survivor support group who were injured between 4 and 35 years ago. The data collected include 1) field observation notes; 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 photo-elicitation interviews with me, and b) when photovoice participants discussed their photos during project meetings.

I used narrative analysis methods to analyze participant photographs and interview text. Methods include thematic analysis, structural analysis, and visual analysis (Riessman, 2007). I used thematic analysis in forming participant visual illness narratives; structural analysis to parse participant interview data into lines and parts (Gee, 1991); and visual analysis in 1) looking at image details (Becker, 1986); 2) reflecting on image production and audience (Rose, 2007); and 3) reflecting on intersection of image and text (Akeret, 2000).

Lived experience with ABI is illuminated through three patient case studies, each centered on a visual illness narrative. One participant was injured 1 year before participating in the study; the other two were injured 4 years and 17 seventeen years ago, respectively. 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. The themes that emerged from their photographs and interviews appear to represent something important about the experience of living with ABI (Williams, 1984). This presentation provides 1 excerpt from each case study's visual illness narrative, each consisting of four or five images and what the patient said about them.

Results. Disruption and a search for coherence are endemic to living with ABI for adults with careers, families, and developed identities (Riessman, 2007). The case studies reveal a process of building a post-ABI identity that suggests a typology of ABI stories. First, the new (brain injured) self dominates and feelings of confusion, loss, and frustration consume the teller. Second, the new self and old self are in dialogue revealing both impairments and strengths. Third, the narrator acknowledges but gives less importance to the brain injured self and instead speaks of a range of selves, activities, strengths, and strategies, as well as suffering. Three visual models illustrate my suggested process of forming a new self after brain injury. They are a "symbolic transformation" representing my "attempt to comprehend, construct, and convey meaning" (Feinstein, 1982, p. 46).

Conclusions. The research and analysis methods in this study support using communication tools with brain injury survivors that incorporate visuals and text together. The abstract designs and simple messages of the three models (Dondis, 1974) may make them useful for reflection. The proposed typology could support ABI survivors' efforts to reconstruct their story and sense of self. Listening to ABI survivor stories may help to improve the quality of care so painfully lacking for persons with ABI on a global scale. Application of the typology in therapeutic settings might encourage listening and mutual learning among ABI survivors, support group leaders, clinicians, and peers.

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Excerpts from 3 ABI Visual Illness Narratives

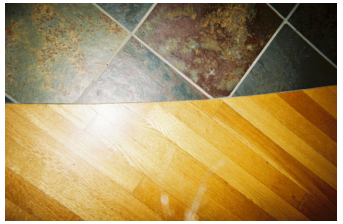
(1) Living with Frustration and Confusion. A one-year survivor of severe TBI reveals the disorder he feels daily in both his life and his brain. A major source of the frustration and confusion he describes in his photographs and interview is food: shopping for it, preparing it, tasting it, storing it, and cleaning up.

Cans in the Sink: "The disorder that I'm living with right now"

"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"

(2) Encompassing Darkness and Light. A four year survivor of mild TBI 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.

A Friend's Floor: "I was trying to get the darkness and the light"



"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"

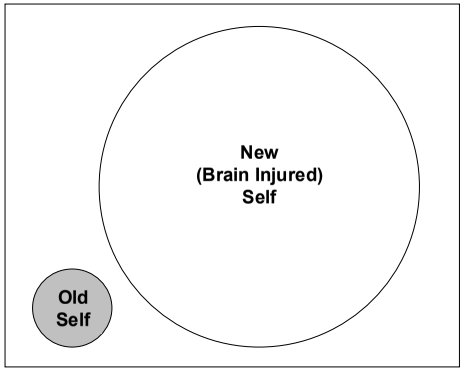
(3) Discovering a New Identity. At this point, 17 years after her injury, this brain tumor survivor appears to see the potentially disparate elements of her life before and after brain injury as fitting into a larger context (Reker & Chamberlain, 2000).

Keys in the Freezer: "What do I make out that, that I want?"

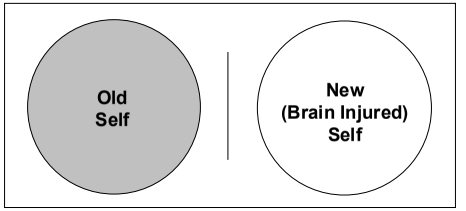
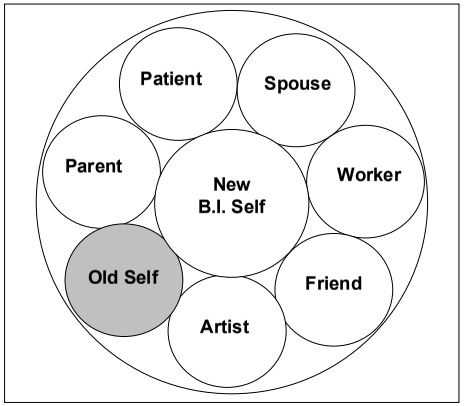
"We as brain injured people put things in weird places
Maybe I was getting a glass of water with some ice cubes
I make things out of nothing
I can do that because I was a chef"

Symbolic Transformations

(1) Brain Injured Self Dominates. The new (brain injured) self dominates the old self. The old self feels lost. The new self feels confusion, frustration, anger, and sense of loss and grief.



(2) New Self and Old Self in Dialogue. The old self and new (brain injured) self are in dialogue. They both resist and acknowledge each other. Feelings of loss and grief are present, but the new self employs strategies. Old self and new self are separate but communicate across the gulf that divides them.



(3) A Multiplicity of Selves Accepts Each Other. The new (brain injured) self can be one among a multiplicity of identities for the long-term survivor. When there is a multiplicity of selves, different concepts of self may gain or recede in importance, depending on context (Mishler, 2004). Both strengths and impairments are recognized, and strengths are emphasized (Crisp, 1994).