

Living with Traumatic Brain Injury: A Narrative Analysis of a Survivor's Photographs and Interview

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Problem



This picture here, there's no connection and ... that's how I felt ... right after my accident, that there was no connection and there were so many missing links as I tried to begin living again ... When I saw that, well, that seemed like a perfect way to sum it all up, you know



Paperwork ... is a great obstacle for me ... It's also a symbol for the disorganization I encounter in my mind ... paperwork was never a forte for me, even prior to the brain injury ... how much of it is just my own pre-existing trait, and how much of it is the disability? Maybe here it's like 50-50



... you said not to forget, that also obstacles, need to be highlighted, because they are part of life with TBI ... and having this ... flu, was more of an obstacle ... than previous to my disability, because when you don't drive, and you rely on ... others, and you're not feeling good, you just don't have the energy to get out there



... this is a burnt cake, and it symbolizes my forgetfulness ... now there is a joke in my house, where if I ever were to open up a restaurant, it would be called the well done cafe, because I tend to like to make everything well done ... but this is pushing it ... so that is my well done cake ... and to have a sense of humor about this whole thing is critical

Action



... in the early to mid stages of my recovery ... it was nice for Paul and I just to be able to get away, and ... we would have our own house away from home. And with my brain injury, and already experiencing a lot of confusion ... with three college age kids, and friends coming in and out, and, just, busy life ... it served a good function in that way



My forgetfulness is such that ... if I really wanted to remember something, I would have to ... place it right in the middle of the floor, and otherwise, it would most likely be forgotten. Lists, you know, lists just wouldn't work ... I was trying to remember to take a picture that day



This is ... a neighbor who has become a good friend of mine ... in our walks every morning ... we've been able to confide in each other a lot, and she's a great listener ... and ... walking in the morning, has helped me tremendously with my day ... I feel very alert by the end of the walk, and it's just a great help, to have someone to walk with like that



I wanted to show that ... by the decision not to drive, I have ... slowed my life down, drastically ... driving is a responsibility, and it is taxing ... if you were to take your focus for ... a second, away ... you are not only endangering your own life, but the lives of other people ... so it is a very stressful activity, but we all ... take it for granted

Action...Continued



... when I took his picture I said to myself, humm, what would I really want Paul to be doing ... he loves to work with plants, and so, I ... said ... just do something with this plant ... because I wanted it to be a metaphor of how he took care of me ... He has a lot of what it takes, mostly patience ... very understanding



... these two people are dear, dear friends of mine, and also wonderful teachers, mentors for me ... what they represent for me ... is how emotionally supportive they have been, for me ... I am able to show them ... my frailty ... I'm able to ... feel very safe and comfortable around them



And here we have my daughter ... she lives with us ... and she has been very supportive ... and understanding, right from the start, of the disability ... She sees a lot of my compensatory strategies ... and she works with children with, special needs We have this now, and we help each other. So that's a wonderful thing ... I love having her. So, so, that's why she's here!



I have a lifelong characteristic, of ... caring for others. And when it comes to myself I don't do quite so much ... I think what matters is ... to the degree that we neglect ourselves. And I think there was a time in my life when I did it, to the point of neglecting myself ... I've always taken other people, seriously ... at work, at home, everywhere. But now it may be time to truly take my situation seriously

Resolution



... dishes that need to be done ... the sense of getting this cleaned up every day is, a wonderful feeling ... it's concrete, it's easy, it's uncomplicated, and it's just a matter of getting it done ... so this is a joy ... I never look at this, any longer as a chore ... I really enjoy being able to clean it all up, it probably just gave me such a sense of accomplishment, and a job done



... now this one here is again, another connection, but it ... has nice, big ... bulky connections ... (and) it's a whole picture ... everything's working, connected, and it's behind the scenes ... and those connections being made behind the scenes is what makes everything go. So that's why I look that it's just, kind of simple, but yet it personifies a pretty big thing. A pretty big thing



I wanted to take her [Janet's] picture ... where she would be happy and proud. The pride that you can see ... as she stands there, is the pride that I feel in my accomplishments. And it's very similar to the pride of a young child as she's growing ... she symbolizes for me the hope, for the future

Discussion

Grouping the study photographs and their text excerpts into plot categories brings out movement in the participant's healing over time and reveals her hopes for the future—information that would be more difficult to glean from analyzing a single photograph and its interview data, frozen in time

For this study, the respondent used several strategies for taking photographs. Some images she took when she saw something that reflected her experience with TBI; others she set up on purpose to create the image. For some, she gave the camera to someone else. She created several images with someone else's participation and worked with them in several distinct ways to create the images she wanted, by:

- *asking photographic subjects to pose in a way that reflected an aspect of their relationship;
- *giving them the camera to take a picture;
- *seeking their participation in determining how to express an emotion, attitude, or experience

A major question when considering narrative analysis is: What is narrative? For this study, narrative is the series of photographs and interview text generated by the respondent. Narrative analysis is often a case-centered approach, which is certainly true for this study. Rich et al (2002) and others have referred to a series of respondent images (video) and text as a visual illness narrative (Rich et al, 2002; Rich et al, 2006). For this TBI respondent, four years after her injury, her series of images (photographs) and text could be called a visual healing narrative.

References

Jagoda, A. S., Cantrell, S. V., Wears, R. L., Valadka, A., Gallagher, E. J., Gottesfeld, S. H., et al. (2002). Clinical policy: Neuroimaging and decisionmaking in adult mild traumatic brain injury in the acute setting. *Annals of Emergency Medicine, 40*(2), 251-249.

Langlois, J. A., Rutland-Brown, W., & Thomas, K. E. (2005). The incidence of traumatic brain injury among children in the United States – Differences by race. *Journal of Head Trauma Rehabilitation, 20*(3), 229-238.

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.

Mishler, E. (2004). Historians of the self: Restoring lives, revising identities. *Research in Human Development, 1*, 101-121, p. 108.

Rich, M., Patashnick, J., and Chalfen, R. (2002). Visual illness narratives of asthma: Explanatory models and health-related behaviors. *American Journal of Health Behavior, 26*(6), 442-453.

Rich, M., Lamola, S., and Woods, E. R. (2006). Effects of creating visual illness narratives on quality of life with asthma: A pilot intervention study. *Journal of Adolescent Health, 38*(6), 748-752.

Background

Traumatic brain injury (TBI) is a serious problem affecting not only injured individuals but also their families and communities. A TBI is an injury to the brain caused by an external physical force, and may not be evident visually or clinically (Jagoda et al, 2002). Common sequelae include headaches and memory loss, problems with initiation, attention, focus, and follow-through, and depression, irritability, impulsiveness, and altered personalities. An estimated 5.3 million Americans are currently living with disabilities resulting from TBI, and 80,000 to 90,000 individuals join their numbers every year (Langlois et al, 2005; Langlois et al, 2004). Research that provides a deeper understanding of the patient's perspective can provide clinicians and others with valuable insights into the lives of TBI survivors and the facilitators and barriers to recovery from their point of view.

This Study

I carried out this pre-pilot study in October 2006 with approval from the Brandeis Human Subjects Research Committee and recruited one respondent. As specified in the protocol, she had a cognitive level of at least seven on the Ranchos Los Amigos Cognitive Level Scale (one being lowest and ten being highest), and she received her injury no more than five years ago. She took photographs of living with her injury and facilitators and barriers to recovery from her perspective using a disposable camera with 27 exposures. She finished her camera after three weeks, and we met a week later to discuss her pictures. She told me what each photograph meant for her, why she had taken it, and how she had settled on or created the image.

My two research questions were:

- *What is the lived experience of people who have a traumatic brain injury?
- *What are the facilitators and barriers to recovery from the perspective of someone who has a TBI?

The Analysis

This narrative analysis of 15 respondent photographs and interview excerpts follows an approach inspired by Elliot Mishler (2004) to see "the basic story parts, in temporal order: an initial problem, action to deal with it, and a resolution?" (p.108). Grouped into the plot categories of problem, action, and resolution, the photographs and text excerpts show us "the prologue to a more extended story" as the respondent moves on with her life, four years after her injury (Mishler, 2004, p.108).

For the analysis:

- *I removed all duplicate photographs and photos that were "mistakes" (e.g., a photograph of the ground).
- *I did not include some photographs of family members, due to their repetitive nature.
- *We discussed her photographs in the sequence in which she took them. The analysis transformed that sequence.
- *Within each category, only the last photograph is placed purposefully, as it appears to lead to the next category of photos.