



## Making Visible the Invisible: Using Photography and Narrative to Understand Living with Traumatic Brain Injury



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## Today

- Research objectives
- Pre-pilot study: Methods, analysis
- Group project: Population, methods, sample photos & text from exhibit
- Conclusions
- Implications
- References

## Research Objectives

To gain an understanding of lived experience with brain injury and the issues, concerns, and strengths of brain injury survivors living in the community, while providing an opportunity for survivors to reflect on their lives, use their brains, and employ a variety of cognitive skills

## Pre-Pilot Study

- Exploratory, to inform dissertation proposal
- 1 respondent, with a cognitive level of at least 7
- Took 27 photographs of living with TBI and facilitators and barriers to recovery
- 4.5 hours interview: Her experience taking pictures, what the photos meant, and how she created the particular images
- Narrative analysis of visuals and interview text

## What is Narrative Analysis?

- A family of approaches
- Diverse kinds of texts
- A storied form
- Preferred narrative (versus “truth”)
- Sequence and consequence
- A particular audience
- Interpreting the world and experience
- Ways of knowing and communicating

## 3 Narrative Analysis Methods

- Looking at the details of a single photograph (Becker, 1986)
- Interpreting the discourse structure of an interview excerpt (Gee, 1991)
- Grouping her series of photos and text into 3 plot categories: problem, action, and resolution (Mishler, 2004)

What do you see?



## Raw Interview Transcript

LF: I thought that kind of depicted it, you know, the challenge right there, that photo, um, there's a lot of unsaid things there, but I mean as you look at that, you know, to live your life with that kind of connection, or lack of connection, lack of connection, yup.

LL: *when you say lack of connection, do you mean connection to the past? to the person...*

LF: oh, I mean lack of connection in terms of my brain. um, that, it was kind of like um, uh, (laughs) when you, you know, have a thought, that you didn't know what it was going to, latch on to, it was kind of like living in the middle of nowhere, um, there was no sense of connection, um, uh, and uh, to your environment, to other people, um, it was as though you were just born anew, um, uh, yes there were things you knew how to do, it wasn't like you were a newborn, (laughs) but in a sense you were. so um, everything was new, and um, life without connection, um, hard to explain, you know, hard to articulate, and um, and I I basically laughed through every day. There was this laughter that just went on, constantly, uh, you know, just this giddiness, laughter, um, again, living at that crest of the wave, and when you are living at the crest of the wave, to maintain that level of um of uh, that level, ... um.. it was just as though you had lost the connection with reality? um, to some degree? or reality as you knew it? and you know it all had to like be reestablished, or, the connections, over time, is how I see it now, in hindsight, um, for me I think it was more, you know, the passage of time uh.. and you know, doing, you know, taking small steps, uh... and things were just kind of re-knitting .. themselves, you know, just you know, in the healing...

## Structuring the Discourse: "Living without Connection"

Part 1: Why I took this picture

Stanza 1: That's how I felt

1. This picture here there's no connection;
2. And that's why I took it because that's how I felt,
3. I felt as though right after my accident, that there was no connection;
4. And there were so many missing links, as I tried to begin living again.

Stanza 2: I thought that kind of depicted it

5. And so I thought that that was a good, that again is a very good beginning,
6. Because this is probably where I was starting out, was with this kind of, this type of ...
7. *Sounds challenging, yuh!*
8. And I thought that kind of depicted it, the challenge right there, that photo.

Coda: A lot of unsaid things there

9. There's a lot of unsaid things there, but I mean as you look at that,
10. To live your life with that kind of connection, or lack of connection, lack of connection, yup.

Living without Connection

## Summary of the Discourse Structure

Part 1: Why I took this picture

- Stanza 1: That's how I felt  
Stanza 2: I thought that kind of depicted it  
Coda: A lot of unsaid things there

Part 2: Everything was new

- Stanza 3: It was like living in the middle of nowhere  
Stanza 4: It was as though you were just born anew  
Coda: Hard to explain  
Stanza 5: I basically laughed through every day

Part 3: How I see it now in hindsight

- Stanza 6: It all had to like be reestablished  
Stanza 7: I had so many gaps in my brain  
Stanza 8: My reaction was this laughter  
Coda: A perfect way to sum it all up

Part 4: I couldn't feel really connected, in lots of ways

- Stanza 9: Are you really, truly connecting  
Stanza 10: That's what I meant

## Problem



...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...it was kind of like living in the middle of nowhere...When I saw that, well, that seemed like a perfect way to sum it all up, you know

## Action



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.

## Resolution



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

- We become part of the dialogue as we ask questions and respond to stories
- All 3 analyses tell a valid story; each is a partial telling
- Using 3 approaches may help us to gain a deeper understanding of the data
- Visual illness narrative or visual healing narrative?
- Dissertation: Photo-elicitation and narrative analysis methods with a sample of 12 rehabilitation hospital outpatients and long-term survivors in the community

## PAR Project Using Photovoice

- 8 participants in their 40s and 50s
- Members of the 'Amazing' Brain Injury Survivor Support Group, Framingham, MA
- Injured 3 to 31 years ago
- 6 TBI survivors and 2 brain tumor survivors
- Most work part-time and/or volunteer in their communities
- 2 co-facilitators--also TBI survivors

## Methods

- PAR using photovoice
- 10 sessions, from Sept-Nov 2006
- Participants took photos of living with brain injury from their perspective
- They chose photos to discuss with the group
- They wrote personal narratives for their selected images: 50 in all
- They grouped their photos and narratives into 9 categories and named them
- Outreach efforts are ongoing

## The Journey



It's a muddy, ruddy, hands-and knees crawl up to the first rung of the ladder that begins to make some semblance of sense—and then you get to begin to really struggle. The climb does not and will not end....Sometimes weekly, and sometimes daily there is a new step to attempt to get to your "new self". You can't even ever hope to get back to your "old self". Oh well! Maybe there will be a good view on this journey that I hadn't expected.....

## Lost Dreams



...this picture symbolizes what living with brain injury can be like...On an overcast day...I gazed up at the sky and took this picture through a tube. ...In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear...

## Chaos



I feel chaos. I leave the dishes to be done later. I procrastinate...I make no time for completing my tasks...I watch cable television or daydream so I don't have to deal with what I should be doing. This is the piano that I should and would love to learn how to play. I must practice.

## Challenges



...Imagine yourself trying to run on ice...The faster you run, the more you get nowhere. These images parallel how each and every day of my life begins since I suffered my brain injury. I seem to spend a whole lot of time getting nothing accomplished.

## Strategies



To compensate for my poor memory and organizational skills, I need to put labels on everything in my home. Where are my socks? Which of these is my schedule book? On which shelf did I put my Bible? These labels are necessary 3 years after my accident and probably for many years to come. It is painful to remind myself about all of the brain power which I lost at the time of my car accident.

## My Advocacy Story



These are my counselors at Metro West Independent Living Center. They helped me to focus by bringing me to the statehouse to talk to my Senator and Representative.

## Comfort and Support



With TBI certain parts of my life have added much comfort and support. God has blessed me with Teddy and Betty Marie. They welcome me home with hugs and slurps, we eat together, they sleep beside me and muzzle their noses into my neck and face to gently wake me in the morning. They delight me with their personalities and antics. They warm my heart and comfort me. They make me smile and laugh. God has Blessed me with a little glimpse of heaven.

## Acceptance



Whose grave is this? Surely it's not mine. This is not my fate, is it? I need to make the best of this situation, but how? It's all suddenly complicated...This was not my doing, nor my choice! I'm trying to be gracious. I need to accept this death of my "old self."

## Hope for the Future



**New Identity. New passion of gardening. First baby step was planting in containers so as to not fall into dirt because of imbalance. My garden has progressed as my new life has. Now I not only can plant in the ground, I dig up grass and now have three perennial gardens.**

## Some Conclusions

- The participants played a participant-expert role in this research
- The outreach phase is providing opportunities to use prior experience with communication, layout, and group dynamics in a supportive environment
- This study became a meaningful experience for participants and facilitators alike

## Implications for Policy & Practice

- This type of research helps us gain an insider or patient perspective on living with a chronic condition
- Involving individuals with a disability in research about their lived experience may increase the relevancy of research to real-life situations
- From the perspective of these survivors, healing from brain injury is a gradual process that continues for years

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