Brain Injury: Narratives of Rehabilitation and Healing

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Spotlight: Disability and Qualitative Inquiry: Rethinking an Abelist World
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Outline

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- Inspiration
- Methods
- Living with Frustration & Confusion
- Encompassing Darkness & Light
- Discovering a New Identity
- Symbolic Transformations
- Conclusions
Glossary & Purposes

Acquired Brain Injury (ABI) Traumatic Brain Injury (TBI)
Lived experience Visual illness narrative

Purposes, to:

• Gain an understanding of brain injury survivors’ experiences living with their injury
• Use visual research methods to promote dialogue about living with brain injury
• Uncover new knowledge about personal, community, and health policy issues related to living with ABI
• Explore how the methods and data could inform policy and practice
Inspiration
Methods - Sample

6 individuals accessing outpatient services
8 members of a brain injury support group
Methods - Data & Analysis

- Photo elicitation (Harper, 2002)
- Photovoice (Wang & Burris, 1997)
- Narrative analysis methods (Riessman, 2008)

- Participants used 25 disposable cameras to take 504 photographs.
- 3 participants selected as “cases”
- For each, a visual illness narrative with 4-5 photos and what they said about them
Living with Frustration & Confusion
I: I think this is beautiful. This is a beautiful photo
P: That’s an accident
I: I know, but it’s--
P: Just the way the light was
I: I know, but it’s, it came out, it’s almost like a cartoon.
P: Well, it is. It was supposed to make a point.
I: Was it? ..What point?
P: The disorder that I’m living with right now. (uh huh) A lot of it’s my fault, because I can’t organize things any more, like I go to a store and I’m supposed to buy maybe 10 things. It takes me an hour and a half. And I keep getting confused and, lost in the store and, ..I get panicked sometimes if I go to a new store and it’s too big. (hm hmm) But the house is the same way. I can’t, um, get my wife and daughter to put anything where it belongs, you know, just.. (hm hmm) they put everything on a, table top someplace. Which they’ve always done, and I just yell at them and and not pay any attention, just go on out. But now it, it freaks me out, everything is disorganized, you know, I can’t find anything. (hm hmmm) The, then, they keep putting things, you know, just stockpiling things in on the front porch for example, and then they throw it all in the garage, so the garage is so full now I can’t get in there to get my, get my tools. Now I’m talking about something that every family has to deal with, especially if you have a, a teenage girl and a, um, a disorganized wife. But, um, ..it drives me crazy now, I mean, my, it just, the way my brain’s operating (hm hmmm).
Prelude: It was supposed to make a point
I think this is beautiful. This is a beautiful photo.
That’s an accident
I know, but it’s
Just the way the light was
I know, but it’s, it came out, it’s almost like a cartoon
Well, it is.
It was supposed to make a point
Was it?.. What point?

Part 1: I keep getting confused and lost
The disorder that I’m living with right now Uh huh
A lot of it’s my fault, because I can’t organize things any more,
Like I go to a store, and I’m supposed to buy maybe ten things.
It takes me an hour and a half.
And I keep getting confused and, lost in the store, and,..
I get panicked sometimes if I go to a new store and it’s too big hm hmm.

Part 2: Now everything is disorganized
But the house is the same way.
I can’t get my wife and daughter to put anything where it belongs, you know, just .. hm hmm
They put everything on a, table top someplace.
Which they’ve always done, and I just yell at them and not pay any attention, just go on out.
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
There are appropriate pictures
Encompassing Darkness & 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
Discovering a New Identity
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
Brain Injured Self Dominates

New (Brain Injured) Self

Old Self
New Self and Old Self in Dialogue

Old Self

New (Brain Injured) Self
A Multiplicity of Selves Accepts Each Other

New B.I. Self

Patient

Spouse

Parent

Worker

Friend

Artist

Old Self
Conclusion

• Dialogue
• Visual metaphors – acknowledge and share emotion
• 3 valid stories, each is a partial telling, frozen in time
• Each story has many facets, revealed through multiple methods of analysis (crystallization)
• Negative topics were not always discussed, eg financial challenges after brain injury
• These stories show that healing from brain injury is an ongoing process that can take many years
• Listening to stories is essential to policy and practice
Thank you!

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