Brain Injury Survivors: Narratives of Rehabilitation and Healing

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Outline

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- Discovering a New Identity
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My Background
Inspiration
Value

I am a normal person with part of my head off in Never Never land. (Will I ever retrieve it?)

Prigatano, 1989
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
• **50,000** will die annually as a result of TBI
• **80,000** annually experience the onset of long-term disabilities following TBI
• **5,300,000** Americans currently live with a disability as a result of a TBI

40% of TBIs involve alcohol.

How many people here know someone who has had a TBI?
Including Survivors’ Perspectives: A Social Justice Issue
Study Purposes

1) Elicit and understand quality of care from the perspective of brain injury survivors

2) Promote researcher-participant dialogue about living with brain injury

3) Uncover new knowledge about personal, practice, and policy issues related to brain injury

4) Provide an opportunity for participants to reflect on their situation and use their brains
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
A Photovoice Path

Ask people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)
Original Photovoice Path
Mdantsane Township
South Africa
2001
Participant Photo-taking Practices

- Disposable cameras with 27 exposures each
- 1 to 3 cameras each—15 and 50 photos each
- Photo content more important than artistic quality
- Some participants contributed family snaps
- Some gave the camera to others
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
That picture of the scar represents such an important...all the words are coming up in my head, things like freedom and acceptance...I couldn’t have done that 2 years prior. That for me was probably the biggest statement about where my life is now. **So the slice of now, that’s in my photo there.** It shows where I am at right now, how things have changed so differently, how life is so different from what it was, right after my surgery, 5 years after my surgery, 10 years. I was going through different things at those times. And that picture is of now, today. It’s not the end of my story. But **it’s a beginning of a whole chapter.** It’s like the end of the shame, of having to try to cover it up, not wanting people to see that [scar] as the first thing. I never hid it, but now it’s out there. And you know, it makes for interesting conversation. Now it’s just, **well, that’s just part of me,** you know.
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 Accept Each Other
So What? Mutual Learning

• Using the camera results in a shared experience of living with brain injury
• The process evokes emotion: basic to learning; visual metaphors were helpful
• Participants use their cameras to make sense of their experience—and to teach us
• Their photos and conversation help us to see brain injury in a different way—sympathetic and respectful
So What? Conclusions

• The camera brings ‘real lives’ into health policy and practice

• Valid stories, though each a partial telling, frozen in time

• Their stories show that healing progresses over time, even years – contesting rehabilitation limits

• However, negative topics were not always discussed, eg financial challenges after brain injury

• This type of research promotes a model of health care founded on justice and treating patients (not diseases)

• For this work, the camera is a tool for justice
Thank you!

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