



Discovering a New Identity After Brain Injury: A Visual Illness Narrative

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Background

Acquired Brain Injury (ABI): Any injury to the brain that occurs after birth and “results in deterioration in cognitive, physical, emotional, or independent functioning”. Examples of ABI include epilepsy, multiple sclerosis, traumatic brain injury (TBI), dementia, and stroke.

Judy had a slow-growing childhood tumor whose symptoms manifested when she was 35 years old, 17 years before participating in the study. The tumor was surgically removed and treated with radiation, which, as she explained to me, caused her brain injuries.



Sample & Methods

11 ABI survivors: 3 accessing outpatient services through a rehabilitation hospital; and 8 members of an ABI survivor support group

Photovoice: a process by which people represent their lives, point of view, and experience using photographs and written narratives (Wang & Burris, 1997)

Photo-elicitation: insertion of a photo into the interview (Harper, 2002)

Narrative analysis methods: thematic, structural, dialogic, and visual (Riessman, 2007)

Visual illness narrative: 4 participant-generated photos and their accompanying interview text (Bell, 2002)



Why Selected Judy as a Case Study of Living with ABI

Her visual illness narrative is an evocative portrayal of the search for a new identity after brain injury.

Her success in discovering a new identity is inspiring—both to me as a non-brain injured person and to other ABI survivors in her support group.

Nochi (2000) suggests that “individuals who seem to succeed in coping with the disabilities [from brain injury] should be examined, too” (p. 1795).

Finally, I am pursuing my attraction to the heroism that Judy portrays in coping with the myriad challenges she faces in living with brain injury (Padilla, 2003).

Discovering a New Identity: An ABI Survivor's Visual Illness Narrative

EXCERPT 1: Cookbooks
“Identity lost”



My work as a chef ended with my brain tumor
I didn't have a life separate from my work
It was always Judy the Chef, not ever Judy
I had to find who I was besides being a chef
I've still got over a hundred cookbooks
That was part of making the picture

EXCERPT 3: Garden
“The new Judy”



I thought, “Oh, I can do that”
I started experimenting
So I have something new
I'm in the roses now
The identity of the chef is no longer the focus of
my life

EXCERPT 2: Pill Box
“These are all my brain injuries”



This is my pill box for the week
It would become very confusing
I started coordinating with my doctors

EXCERPT 4: Keys in the Freezer
“What do I make out of 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



Sample Raw Interview Text

J: Yeah, this one here is identity lost. My work as a chef ended with my brain tumor. But I also lost my “who I was.” Yes

L: So, what it seems to me you're saying there is that, work, in, to a certain respect, work was your identity.

J: Oh, yes, my whole, I, my whole, my, it was so, my identity was so entwined with my work, there was, no difference. (right) I didn't have a life, tru, that was truly separated from my, from my work. It was 24 hours a day. (hmmm) Being a chef, is, like being an athlete, in that, you're, you're never off, (hm hmmm) you're, you're, that you're off, there are other professions that are like that, that, you've just, it's just part of your day continuously. (yes) It's not like the stockbroker where you go into work, and then (right) you end it and you leave it behind. It was 24 hours a day, um, whether it was my vacation, it was always, it was always there. When I was watching TV, it was always there. I'm looking at ads, I'm looking at, you know, how did they [laughter] It was never

...



Structural Analysis (Gee, 1991)

Part 1: My work as a chef ended with my brain tumor

This one here is identity lost.

My work as a chef ended with my brain tumor,
But I also lost my “who I was.”

[Deleted: discussion of written narrative for group project]

Part 2: I didn't have a life...separate from my work

So what it seems to me you're saying there is that work, to a certain respect, work was your identity

Oh yes, my whole, my identity was so entwined with my work,
There was no difference *right*

I didn't have a life that was truly separate from my work
It was 24 hours a day *hmm*

Being a chef, is like being an athlete in that, you're never off *hmmm*

[Deleted: conversation that continued in the same vein about work being 24/7]



Cookbooks: “Identity Lost”

My work as a chef ended with my brain tumor
I didn't have a life separate from my work
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I had to find who I was besides being a chef
I've still got over a hundred cookbooks
That was part of making the picture



Pill Box: “These are all my brain injuries”

This is my pill box for the week
It would become very
confusing
I started coordinating with my
doctors





Garden: “The new Judy”
I thought, “Oh, I can do that”
I started experimenting
So I have something new
I’m in the roses now
The identity of the chef is no
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Keys in the Freezer: “What do I make out of 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
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Conclusions

Judy appears to have reached a point where she sees the potentially disparate elements of her life before brain injury and after brain injury as fitting into a larger context (Reker & Chamberlain, 2000).

In her images and our conversation, she portrays her process of discovering a new identity after brain injury through images that depict various aspects of her self experienced and developed over time—a chef, a person with brain injuries, and a gardener.

Thus, Judy makes “visible” a self who is a “project of everyday life...articulated in the plural as ‘selves’” (Holstein & Gubrium, 2000, p. 13).

Judy’s narrative of identity appears to show that she has created “order out of the discontinuities engendered by ruptures from the normal course of events” (Mattingly, 1998, p. 107).



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.

