Writing, Emotion, and Learning: The Influence of Researcher Identity and Experience on Analysis and Findings

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Inspiration
Glossary

**Acquired Brain Injury (ABI):** An injury to the brain that occurs after birth and results in deterioration of brain function.

**Traumatic Brain Injury (TBI):** Harm or damage to the brain caused by a sudden jolt, blow or penetrating head trauma that disrupts brain function.

**Lived experience:** An understanding of the nature or meaning of our everyday experiences.

**Participatory visual methods:** Research in which participants produce visuals related to their experiences and lives – photo-elicitation and photovoice.
Clinicians have long advocated for gaining an insider perspective on patients’ experiences.

Prigatano, 1989
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
Study sample: 14 ABI Survivors

6 TBI survivors accessing outpatient services at a rehabilitation hospital

8 members of a brain injury survivor support group supported by BIA-MA
Procedure: Photo-elicitation

(Harper, 2002)

Using photos as interview prompts:

- Unlocks subjectivity, perspective, and emotion  
  (Harper, 2003; Collier, 1957)

- Surfaces information that might otherwise remain submerged  
  (Frith & Harcourt, 2007; Radley & Taylor, 2003)

- Encourages participants to see their lives with fresh eyes  
  (ibid)

- Provides participants with a greater measure of control over the research process  
  (Rich et al, 2000)

For this study, all photographs were taken by participants
A Photovoice Path

Ask people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)
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Analysis Method: Narrative Analysis

**Thematic:** Interrogates what is spoken and shown, rather than how

**Structural:** Looks at a narrative’s component parts and how form and language are used

**Dialogic:** Assumes co-creation of data by two active participants who jointly construct meaning

**Visual:** In which images become texts to be read interpretively

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(Riessman, 2007)
A Case Study of “Subject D”

- He chose the pseudonym for himself – evidence of his ironic sense of humor and feelings of powerlessness
- A white male in his late 50s who worked until he fell down his basement stairs and hit his head
- He was in a coma for several weeks
- He had not been able to return to work and no longer drove on the highway
- He accessed outpatient services intermittently for over a year as his insurance coverage waxed and waned
His First Reaction to Taking Photos

I don’t have a very complicated life
There’s not too many things I can think to take pictures of
No?
I hang around the house most of the day,
And I go walk the dog in the afternoon
And I come back and cook dinner and watch the baseball game,
  go to bed
That’s what I do every day.
Well, even documenting your day
I mean that’s part of living with brain injury, the things you do in your day.
You could just take photos of those and talk about them if you want.
It’s kind of hard to take pictures of myself taking naps
Interview and Photo Process

- All interviews took place in his home, in his kitchen
- He used his study camera in one day—and immediately bought a second camera and shot a second roll of film
- No photos of people
- First camera: 24 photos in and around his house, yard and garage
- Second camera: 22 photos outside his home in his community (grocery store, restaurant, park), and 5 more inside his home
- We spoke about his photos for 2 and a half hours
Researcher Reflexivity

- On the phone, his voice sounded ‘deadened’ and he seemed confused and angry
- He reminded me of my grandfather
- His life seemed boring and lonely
- We had both lived in the same US city and even in the same West African countries doing similar work
- I inevitably filtered his experience through my own
Case Selection

• He really affected me – I felt for him and his changed life circumstances
• 19 of his 54 photos related to food – an everyday part of life
• He made me feel frustrated – why didn’t he recognize his residual strengths?
• He represented some whose injury was relatively new and early healing ongoing
Writing to Learn

• What would interest my dissertation committee – all busy people without much time?
• I wrote what interested me – my impressions of this man and how his photos made me feel
• My first draft was an outpouring of subjectivity – Got good reactions from my committee
• I gradually became more analytical and consolidated the reflexive writing to consistent sections in each chapter
Living with Frustration & Confusion

EXCERPT 1: Cans in the Sink
“The disorder that I’m living with right now”

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
These are appropriate pictures

EXCERPT 2: Stuffed Refrigerator
“Nothing’s where it belongs”

Too much stuff we never eat
I can’t taste
I can’t cook
I’m embarrassed to tell people

EXCERPT 3: Vegetables on Display
“A supermarket is just, utter confusion to me”

I get confused in here
I’ll forget
I just, trying to organize things in my brain
I want to laugh at myself
I was taking pictures of the confusion

EXCERPT 4: Summer Salad
“It just has a feeling in your mouth, like rubber”

This is a sad thing
This is part of summer
Couldn’t taste a damn thing
This used to be one of my favorite things
Cans in the Sink: “The disorder that I’m living with right now”

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
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.
But now it, it, it freaks me out. Everything is disorganized, you know, I can’t find anything. 

Then, they keep putting things, you know just, stockpiling things 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 tools.

Part 3: I feel like I’m living in chaos and it’s hopeless
Now I’m talking about something that every family has to deal with, especially if you have a teenage girl and a, um, a disorganized wife, but, um..
It drives me crazy now, I mean, just, the way my brain’s operating. 

Your reaction, is different from how it used to be.
I feel like I’m living in chaos and it’s hopeless, I can’t do anything about it.

Coda: These are appropriate pictures
These are appropriate pictures.
These are all the chaos
Discussion

I saw one thing and heard another
The dissonance was a crucial learning moment that forced me to see and feel through his eyes
I had empathy for his losses
I needed his photo and what he said about it to have empathy and understanding for his life now, for the meaning of his experience to him

Next… the conversation continues
Asking Permission to Publish

A scary proposition – what if he refused?

“I’m not sure I can offer much…not to impose insulting observations, but I really don’t have a clue what your thesis is about”

“An important observation might be how our conversation and photos express both frustration at the Loss of formerly instinctive thoughts and activities and the compensation mechanisms involved in the efforts to bring them back in speech or photos”

“If we hadn’t been in the kitchen, I might have obsessed about landscaping frustrations or the destruction of our species by Bush and his ilk…”
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Discussion

Subject D was performing a multiplicity of selves

- **Someone with power** – to contest my analysis and quit smoking
- **An iconoclast** who refused to be pigeonholed by my analysis and was generous in allowing it to be shared in print
- **A former professional** whose brain still functioned well, at least some of the time
I spent 6 months straightening out the front yard... My good daughter and her friend were gonna help wash the windows one day... so there's my yard... But a lot of people think it's an art work, and that I did it on purpose, I've been known to do things like that
Perhaps I felt strongly about Subject D in part because I felt strongly about my prior work in international development.
Discussion/Conclusions

• Using the camera brings the environment and ‘real lives’ into health policy and practice

• ‘Bearing witness’ – my first real experience

• Not just to ‘feel’ but to commit an ‘act of recognition’ and move beyond empathy to restoring power or control to those who suffer (Charon, 2006, 181)

• I was constructing a good story – but not telling or even recognizing the ‘whole truth’

• Continuing to write about Subject D has helped me to continue to learn

• When photos help us to hold critical, self-reflective conversations with ourselves, the healing potential of visual methods may be realized


Thank you!

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