



Teaching empathy: Photos as narrative tools in clinical care for brain injury patients

Teaching Narrative and Teaching Through Narrative



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Glossary

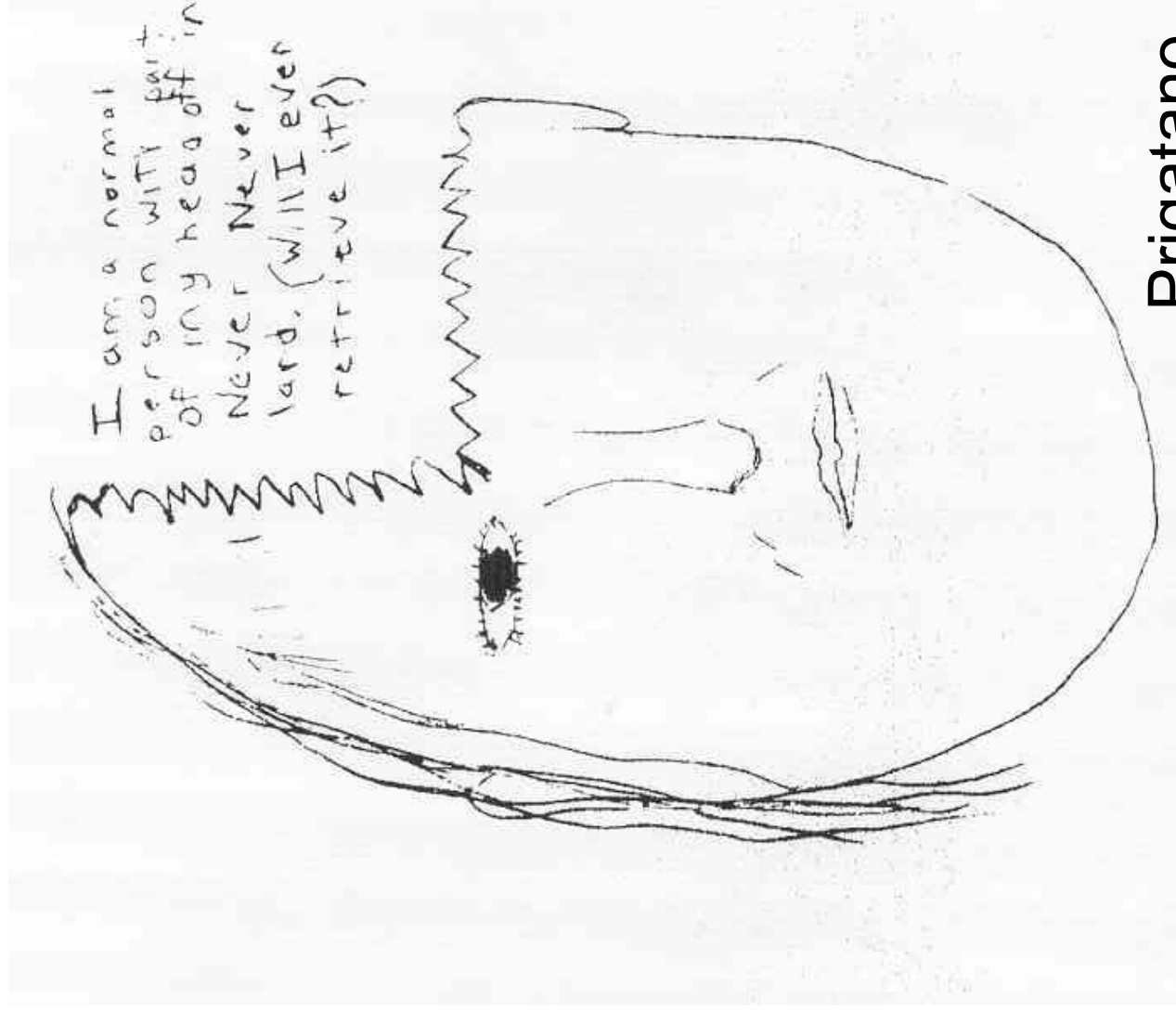
Acquired Brain Injury (ABI): An injury to the brain that occurs after birth and results in deterioration of brain function

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

**Clinicians
have long
advocated
for gaining
an insider
perspective
on patients'
experiences**



Prigatano, 1989



With brain injury, **patients do most of their healing work at home**, increasing the urgency to understand their daily lives

Yet **brain injury patients experience lack of recognition and support** and must contend with misdiagnosis, negative attitudes, lack of respect, and feelings of powerlessness (Jumisko, Lexell, and Soderberg, 2005; Nochi, 1998; Sherry, 2006)

Providers may focus on the empirical knowledge they bring and feel challenged in comprehending their patients' self-perceptions and health decision making (Rich, Patashnick, and Chalfen, 2002).

Physicians may not have the capacity to recognize what their patients are going through or have empathy for their suffering (Charon, 2001).

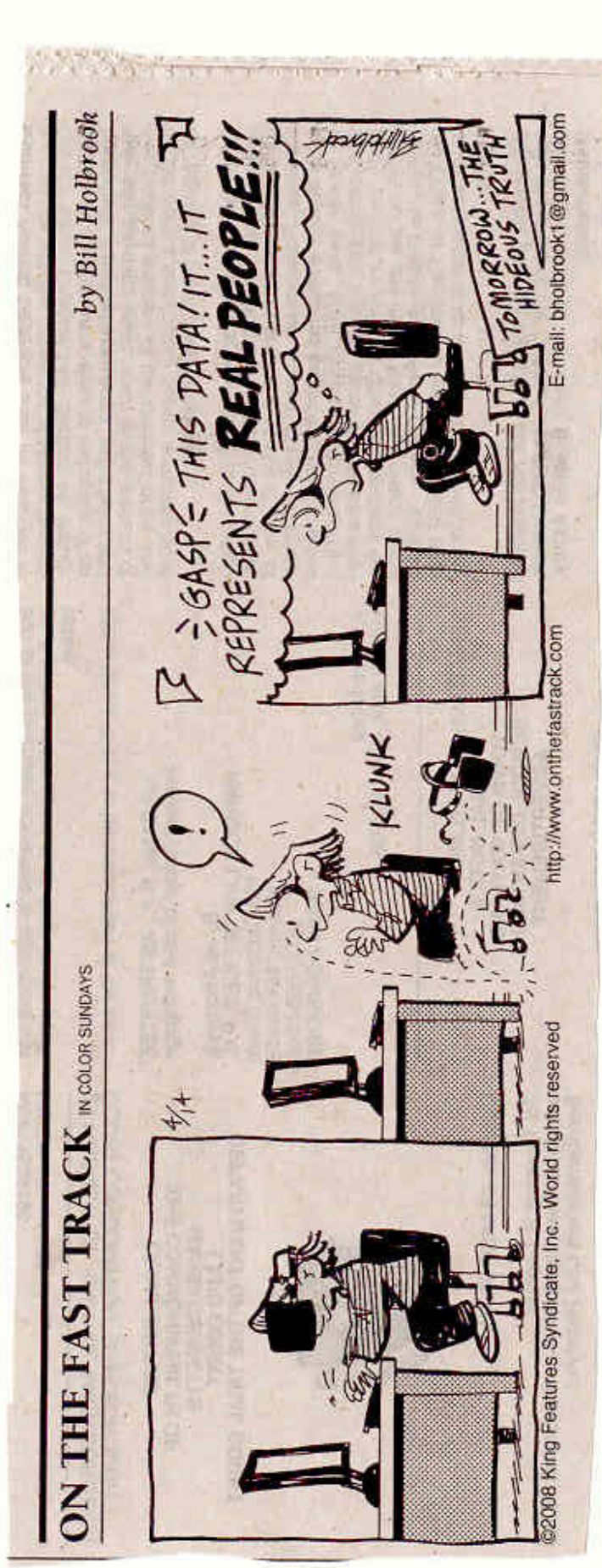


What is empathy?

- Broadly defined, **empathy is the ability to understand another's perspective, stand in their shoes, or see through their eyes.**
- a personality trait and a momentary emotion
- emotional and cognitive aspects (Eslinger, 1997):
- ✓ cognitive empathy: thinking with patients or participants instead of thinking about them (Frank, 2004).
- ✓ emotional empathy: the vicarious sharing of an emotional state with another person
- Together, **emotional and cognitive aspects of empathy engender what Charon (2006) calls 'bearing witness to sickness'** (p. 179) or both thinking and feeling with a patient.



A Social Justice Issue



One way to develop empathy for lived experience with health and illness is to create ‘discursive spaces’ (Katz and Shotter, 1996; Radley, 2009) by putting cameras in the hands of patients and talking with them about their photographs.



This Study

- A primary study purpose was to ‘understand a larger world of suffering beyond the consultation room’ (Katz and Shotter, 1996: 924).
- Patients were asked to use their cameras to show their point of view on living with brain injury and the things that help or slow down their recovery, and to discuss their photographs with me.
- 14 individual with brain injury participated



Photo-elicitation (Harper, 2002)

Taking photos:

- Unlocks subjectivity, perspective, and emotion (Harper, 2003; Collier, 1957)
- Surfaces information that might otherwise remain submerged (Frith & Harcourt, 2007; Radley & Taylor, 2003)

For individuals with brain injury:

- Can improve communication when brain processing speed is slowed and short-term memory issues get in the way (McCullagh and Feinstein, 2005)
- Provides patients with something to talk about and a way to remember



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

(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?
- I focused on his feelings of frustration and confusion – important and understudied topics in brain injury research



Structural Analysis (excerpt 1)

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*.

**A purposeful
work of
illness**

**His photo
symbolizes
the confusion
in his brain**



Structural Analysis (continued)

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 hm hmm

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.

**Disorder
created by
others
prevents
him from
fulfilling a
family role**



Structural Analysis (continued)

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. *hm hmm*

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 *hm hmm*.

Coda: These are appropriate pictures

These are appropriate pictures.

These are all the chaos

He places the blame squarely on himself and his brain

His photos bridged the gulf between us



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

His photos performed his abilities – to reflect and touch both heart and mind

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...”



“This is brain damage”



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



An Expanded Story

Again, the women in his life prevented him from fulfilling a family role

He did not express anger – rather, takes ownership of the “art” created in his lawn

His repetitive efforts – to cook, to clean, to do yard work – despite the confusion in his brain, reminded me of Sisyphus

Upon reflection, I could admire his heroic efforts and have empathy for his frustration in watching the stone roll down the hill again



Discussion

I have come to realize that Subject D was performing a multiplicity of selves:

- **Someone with power** – to contest my analysis
- **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

It was unfair of me to ask him to take photos of his life with brain injury and then say he was dominated by the frustration and confusion of his injury!



Perhaps I felt strongly about Subject D in part because I felt strongly about my prior work in international development

My anguish at failing to prevent violence in that context affected my ability to listen, observe, and understand



Discussion/Conclusions

- Using the camera brings the environment and ‘real lives’ into health policy and practice
- 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)
- With my analysis, 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 and our patients or participants, the healing potential of visual methods may be realized





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Thank you!

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