



A Way into Empathy: Seeing Life from a Brain Injury Patient's Perspective



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Outline

- **Background:** Inspiration, Glossary & Purposes
- **Methods:** Generating & Analyzing Data
- **Case Study:** Living with Frustration & Confusion
- **Brief Review** of 2 More Case Studies
- **Conceptualizations** of the 3 Cases
- **So What?** Conclusions & Implications



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

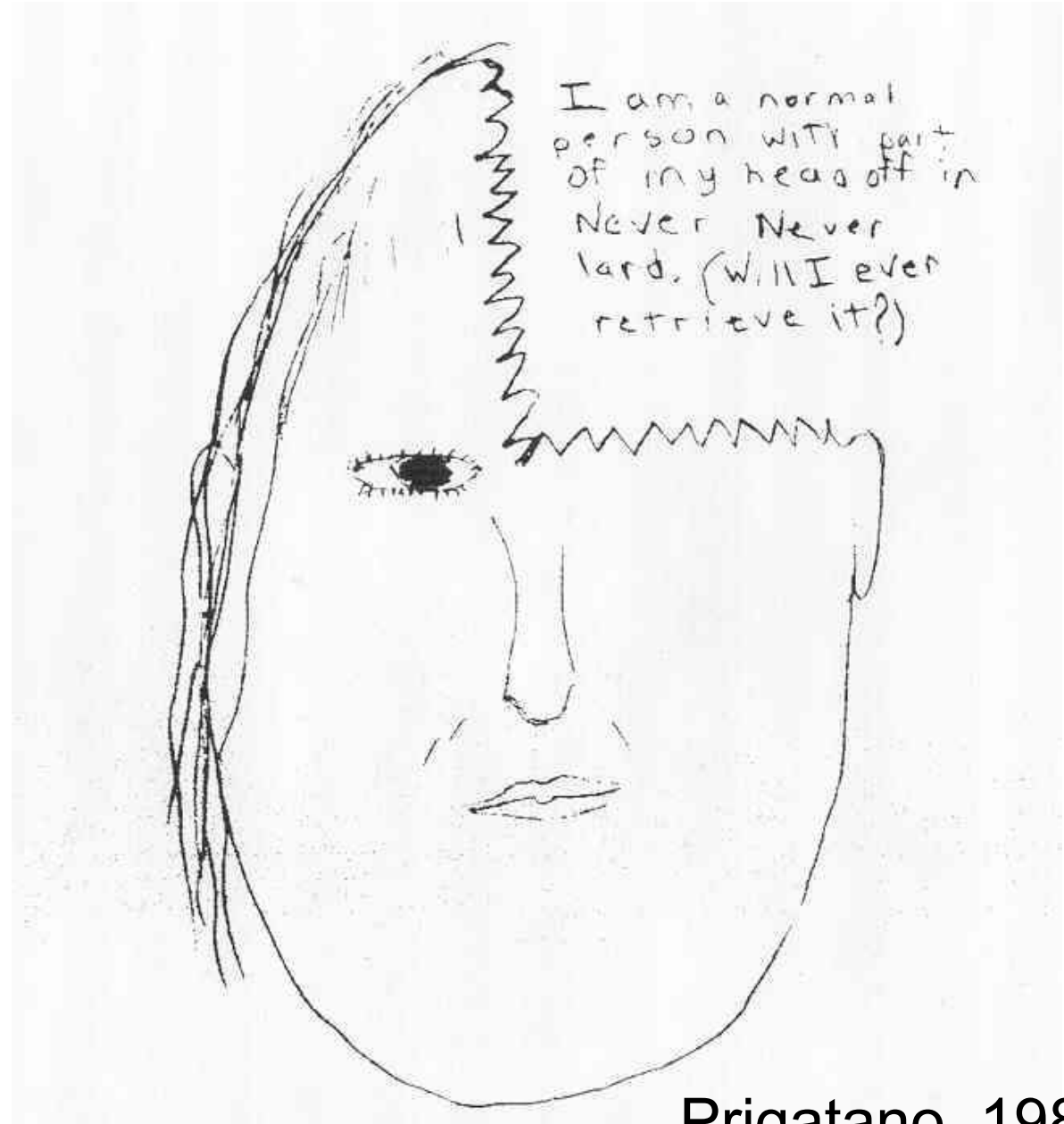
Lived experience: An understanding of the nature or meaning of our everyday experiences

Illness narrative: A story or account of events describing an individual's experience living with a chronic condition

Visual illness narrative: An illness narrative that includes visual images—photographs, video, or drawings, as well as text



Inspiration for This Study



Prigatano, 1989



Study Purposes

- 1) Gain an understanding of brain injury survivors' experiences living with their injury
- 2) Use visual research methods to promote researcher-participant dialogue about participant experience living with brain injury
- 3) Uncover new knowledge about personal, community, and health policy issues related to ABI



Procedures

Photo elicitation (Harper, 2002):

Inserting a photograph into the research interview to “understand the world as defined by the subject” (p. 757)

For this study, all photographs were taken by the participants, or subjects

The approach is called a “participatory visual method”



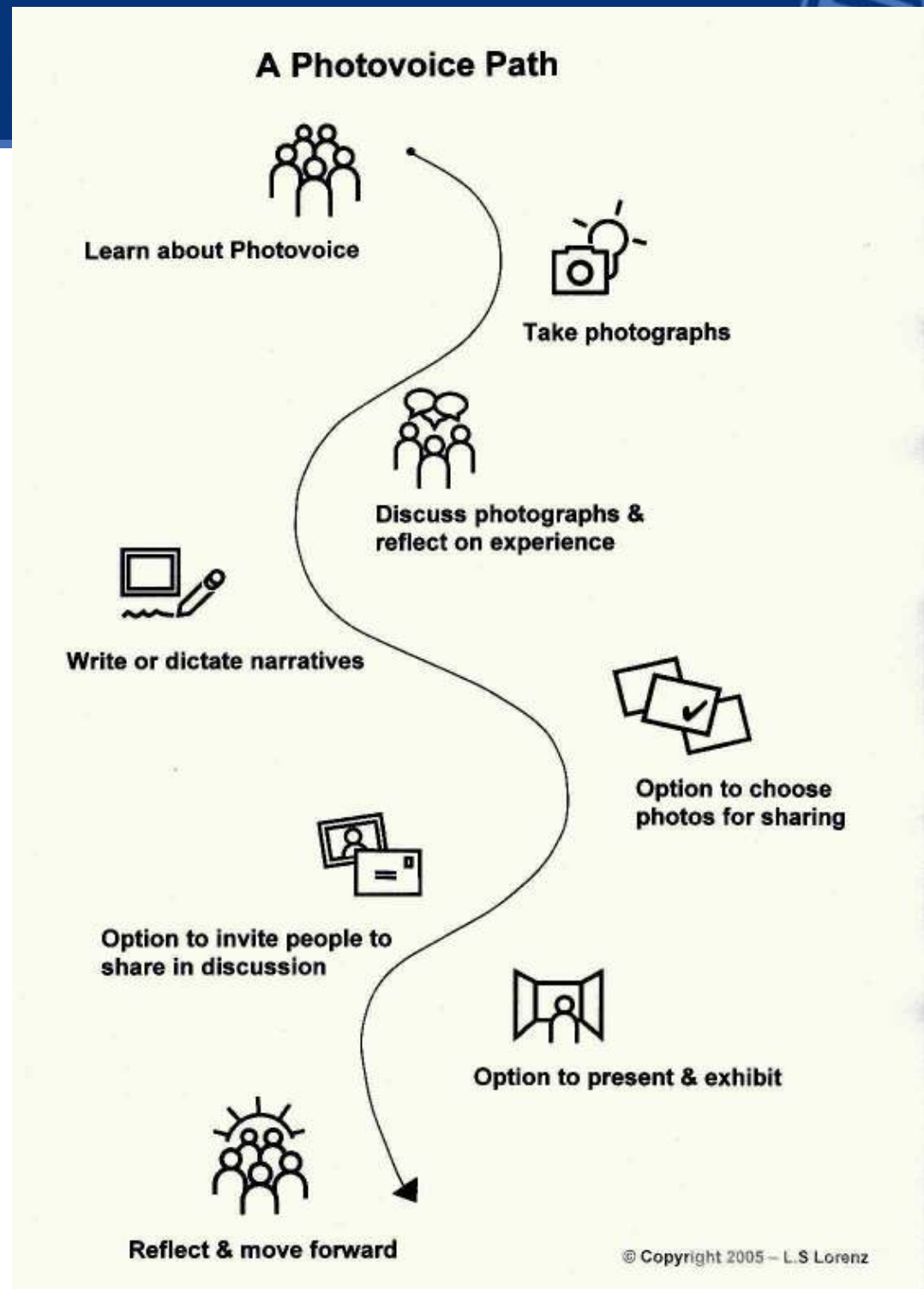
Selection, Recruitment, Consent

- Rick recruited people he thought were reflective and would provide rich data
- I met with them to explain the study: taking photographs and talking with me about their photos
- For some participants, a parent or partner was present in the informed consent interview
- All but one participant completed the study
- Participants signed a second consent form stipulating photo use
- They received a binder of their study photos, and a framed enlargement of one photo in appreciation for participation



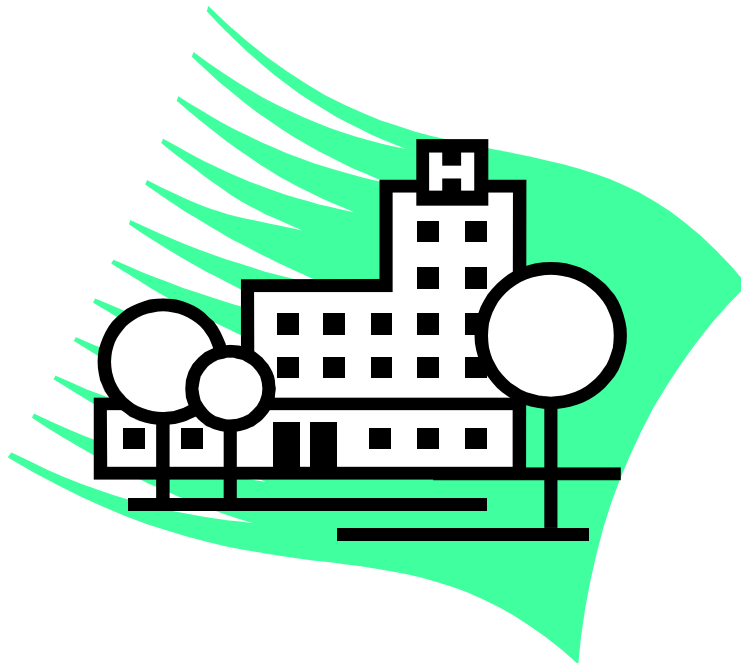
Photovoice Path

Example of an informed consent tool





Sample: 14 ABI Survivors



**6 TBI survivors
accessing outpatient
services at Spaulding**



**8 members of a brain
injury survivor support
group**



Photo-taking Assignment

- Participants were asked to use their camera to show their point of view on living with TBI and the things that help or slow down their recovery
- They used disposable cameras with 27 exposures each
- Photo content was emphasized over artistic quality



Visual Data

- 504 photos were taken, using 28 cameras
- Spaulding participants used 1 to 2 cameras each
- 10 people photographed challenges (69) and nature (48)
- 9 people photographed family and friends (58)
- 8 people photographed themselves (14)
- 7 people photographed metaphors (56), strategies (42), their home (48), or their car (19)
- 6 people photographed achievements (30) or took photos that were mistakes (10)
- 5 people photographed services or supports (26)
- Only three took photographs of a job or family role (6)
- Only two took photos depicting spirituality (8)



Sample Photo





Sample of Raw Interview Data

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, it freaks me out, everything is disorganized, you know, I can't find anything. (*hm hmm*) 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 hmm*).



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

- A white male in his late 50s who worked professionally until he fell down his basement stairs and hit his head
- He was in a coma for several weeks
- He has not been able to return to work and no longer drives on the highway
- He accessed outpatient services intermittently for over a year as his insurance coverage waxed and waned



Interview and Photo Process

- All interviews took place in his home
- He took no photos of people because he did not want to be identified as “brain damaged,” by gov’t agencies that might audit the study
- He used his study camera in one day—and immediately bought a second camera and shot a second roll of film
- 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

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 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 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 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



**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**



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Encompassing Darkness & Light

EXCERPT 1: Skylight
“There’s light in the dark”



I’m in a cave sometimes it seems
You can’t get in, you can’t get out
But...there’s light in the dark

EXCERPT 3: The Mural
“You can be grateful...or you can curse”



This is a mural at my son’s school
Promise and hope and creativity...fading into
darkness
Sometimes...it’s okay
Other times...it’s coming to get you
You can be grateful...or you can curse
Sometimes I wonder...how different things
might have been
One of these life things, you know?

EXCERPT 2: A Friend’s Floor
“I was trying to get the darkness and the 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

EXCERPT 4: The Chess Set
“This game I used to love...is just a mystery
now”



I was trying to show...I’m not able to play that
game anymore
I don’t know how to
The world is still playing...and my forces are
divided
I don’t know...what I’m supposed to be doing
I’m getting creamed

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**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

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



We as brain injured people put things in weird places

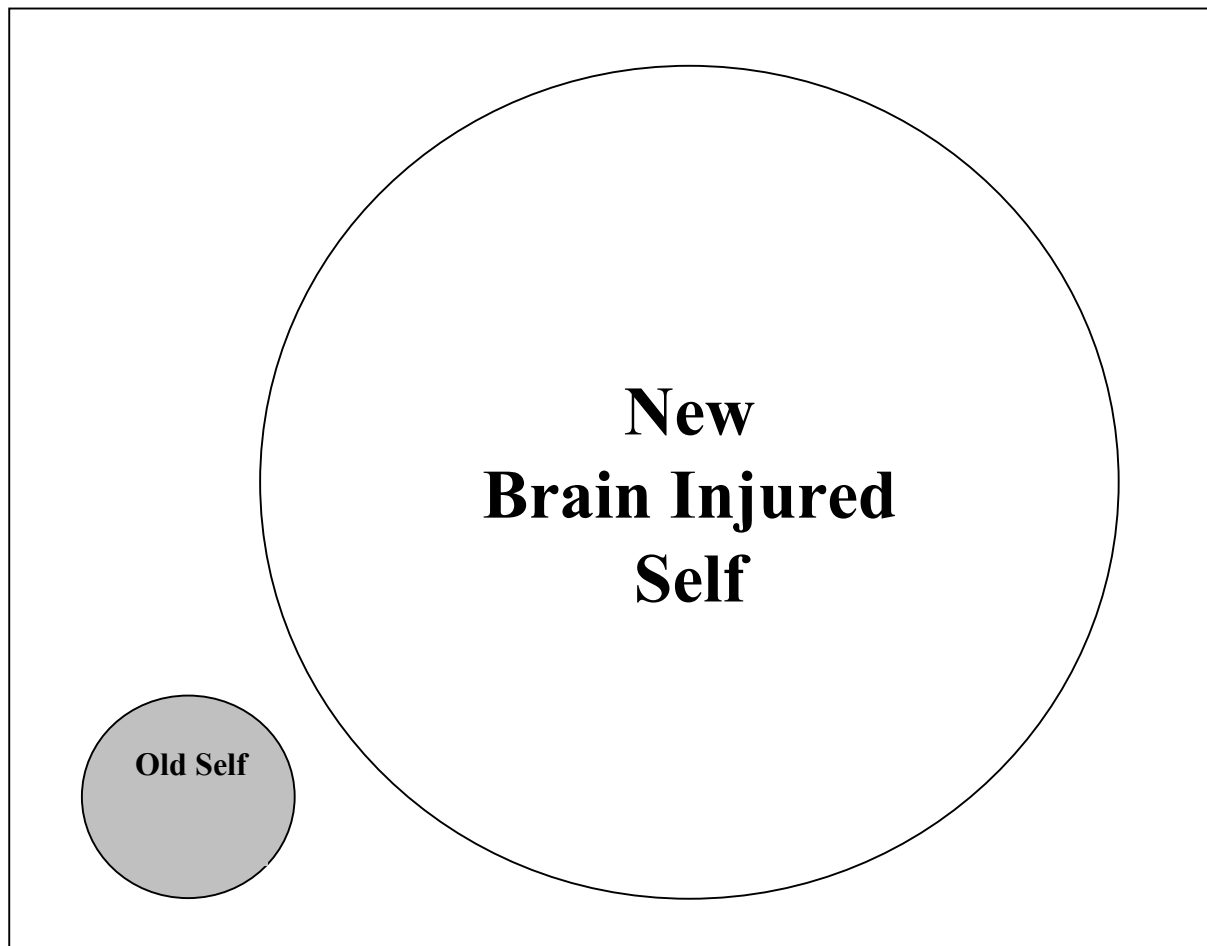
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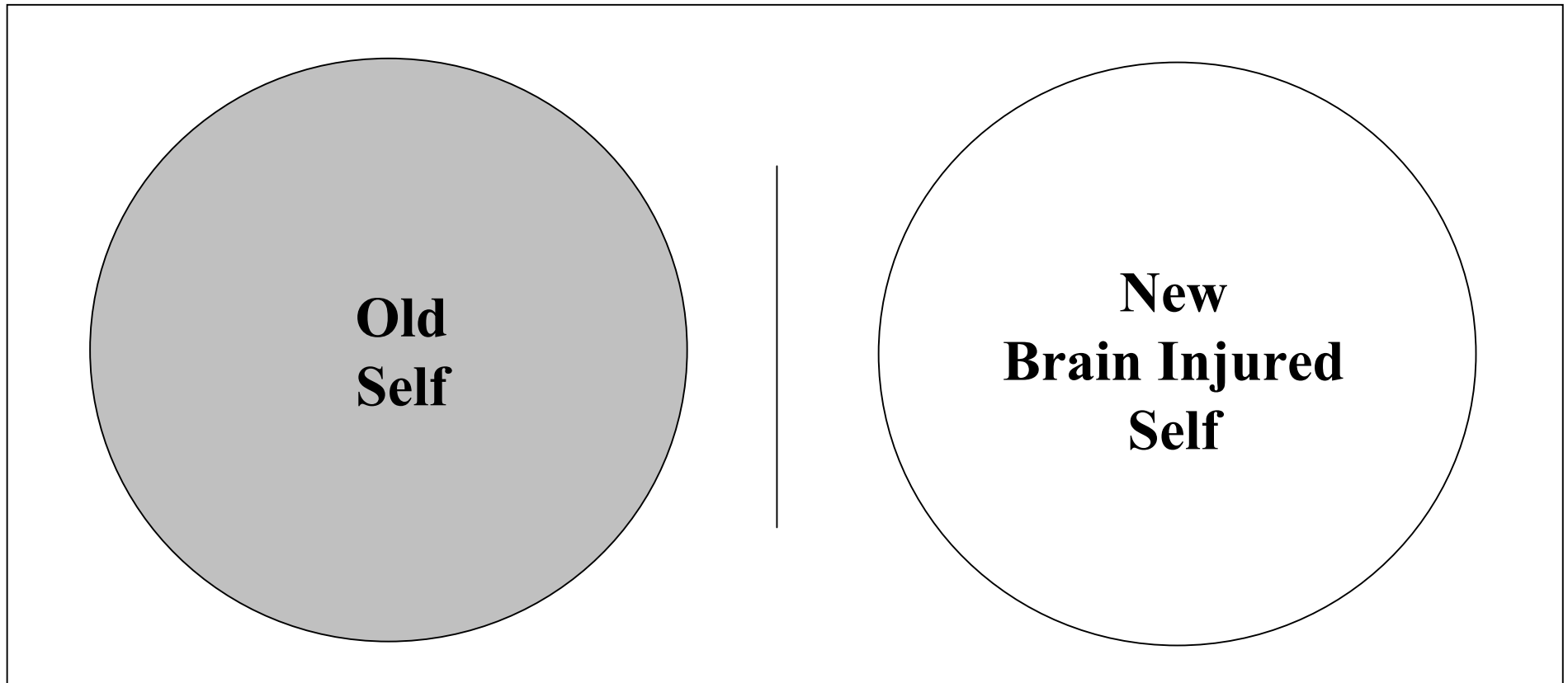


Brain Injured Self Dominates



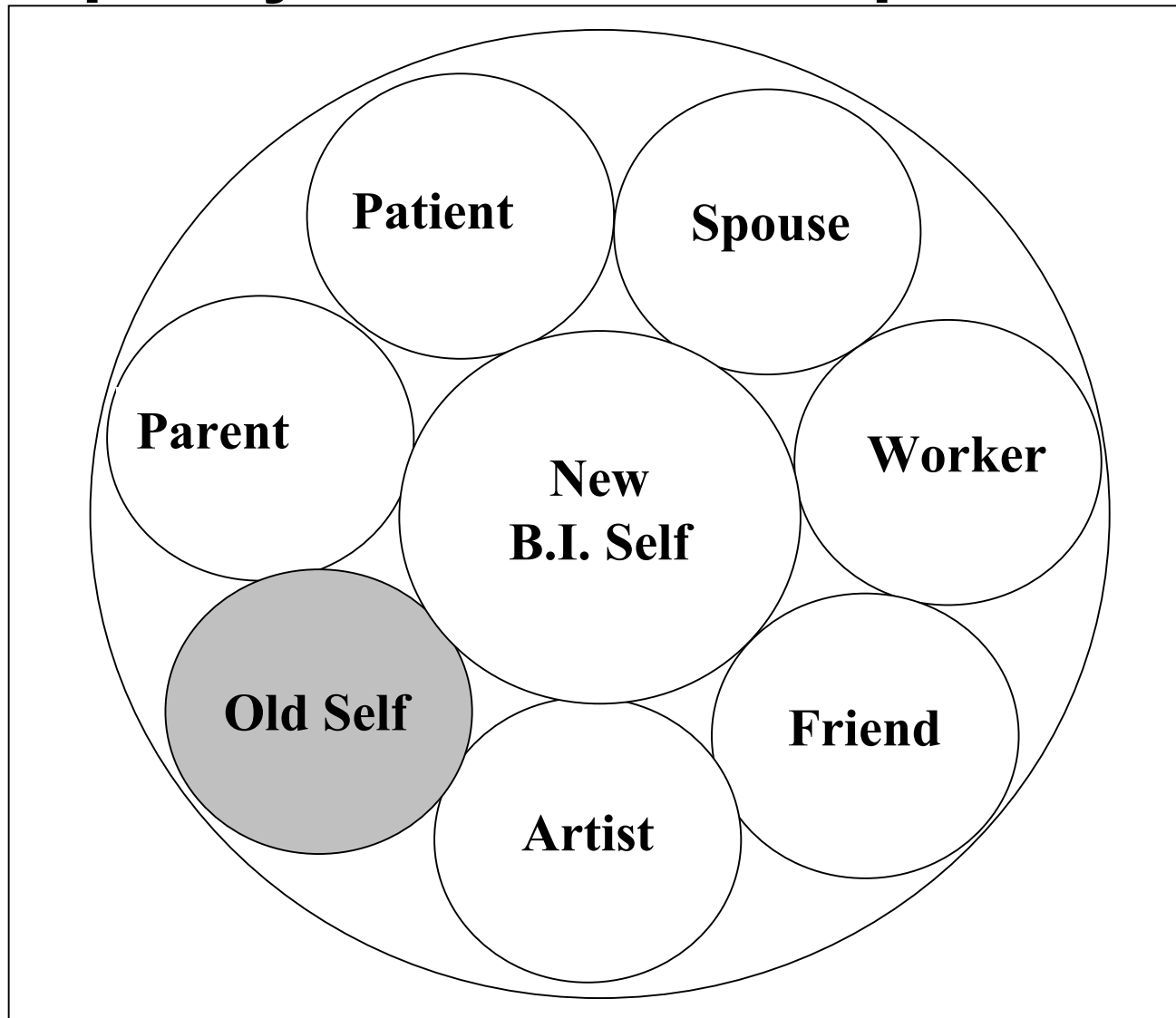


New Self and Old Self in Dialogue





A Multiplicity of Selves Accepts Each Other





Conclusions

- Disruption and a search for coherence
- Method contributed to meaning making and putting into perspective a life lived
- 3 valid stories, each is a partial telling
- Each story has many facets, revealed by using multiple methods of analysis
- Using several narrative analysis methods helps us to gain a deeper understanding of what the data can tell us



Policy Implications

- Dialogue: an underlying aspect of person-centered care and the therapeutic alliance
- Narrative inquiry methods: Encourage dialogue, mutual learning, and sharing of emotions—empathy
- Improving the therapeutic alliance can lead to better outcomes for ABI survivors
- Add visual methods to the arsenal of therapeutic and research methods—especially when seeking to elicit emotions and lived experience
- There is potential to transform visual illness narratives so they become visual healing narratives



Applying These Methods in Practice

- Different research is needed to explore the therapeutic potential of taking photos and talking about them
- Ask patients to be researchers of their own lives using visual methods
- Possible applications include: have participants draw pictures, cut out photos from magazines, bring in family snaps, take new photos using own cameras, or describe images that express their experience
- Ask them what their photos mean. Let them teach you—and in so doing, they may also teach themselves