Using Narrative Analysis of a Patient’s Photographs and Interview Text to Understand Living with Traumatic Brain Injury from the Patient’s Perspective

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Today

• What is TBI?
• This study
• Three approaches to narrative analysis
  – Looking at the details
  – Structuring the discourse
  – Plotting the sequence
• Discussion
TBI overview

• An injury to the brain caused by an external force
• Can cause headaches, weakness, fatigue, memory loss
• Invisible to patient, family, friends, doctors
• 1.4 new injuries each year in U.S
• 80 to 90,000 new disabilities
Narrative Analysis

For this study, narrative is defined three ways:
(1) Individual images taken by respondent
(2) Interview text generated in discussion
(3) Series of photographs and their related interview text
This study

• One respondent
• Cognitive level at least 7 out of 10
• We met three times
• She took photographs of living with TBI and facilitators and barriers to recovery
• We spoke for 4.5 hours, the last 2 hours specifically about her photos
Two research questions

• What is the lived experience of people who have a traumatic brain injury?
• What are facilitators and barriers to recovery from the perspective of someone who has a TBI?
Three NA approaches

- Looking at the details of a single photograph (Becker, 1986)
- Interpreting the discourse structure of an interview excerpt (Gee, 1991)
- Grouping a series of photos and text into 3 plot categories: problem, action, and resolution (Mishler, 2004)
First approach:
Looking at the details

“Every part of the photographic image carries some information that contributes to its total content” (Becker, 1986, p. 231)
2nd Approach: Structuring the discourse

• Illuminates a structure that reveals themes and perspective of person speaking
• Bonds the analysis closely to the actual words used
• Allows for transparency about co-creation of data
LF: I thought that kind of depicted it, you know, the challenge right there, that
photo. um, there’s a lot of unsaid things there, but I mean as you look at that,
you know, to live your life with that kind of connection, or lack of connection,
lack of connection. yup.

LL: when you say lack of connection, do you mean connection to the past? to
the person…

LF: oh, I mean lack of connection in terms of my brain. um, that, it was kind of
like um, uh, (laughs) when you, you know, have a thought, that you didn’t
know what it was going to.. latch on to. it was kind of like living in the middle
of nowhere, um, there was no sense of connection. um, uh, and uh, to your
environment, to other people, um, it was as though you were just born anew,
um, uh. yes there were things you knew how to do, it wasn’t like you were a
newborn, (laughs) but in a sense you were. so um, everything was new, and
um, life without connection, um, hard to explain, you know, hard to articulate,
and um, and I I basically laughed through every day. There was this
laughter that just went on, constantly, uh, you know, just this giddiness,
laughter, um, again, living at that crest of the wave, and when you are living
at the crest of the wave, to maintain that level of um of uh, that level, … um..
it was just as though you had lost the connection with reality? um, to some
degree? or reality as you knew it? and you know it all had to like be
reestablished, or, the connections, over time, is how I see it now, in in
hindsight. um, for me I think it was more, you know, the passage of time uh..
and you know, doing, you know, taking small steps, uh… and things were
just kind of re-knitting .. themselves, you know, just you know, in the
healing…
Living without Connection

Part 1: Why I took this picture

Stanza 1: That’s how I felt
1. This picture here there’s no connection;
2. And that’s why I took it because that’s how I felt,
3. I felt as though right after my accident, that there was no connection;
4. And there were so many missing links, as I tried to begin living again.

Stanza 2: I thought that kind of depicted it
5. And so I thought that that was a good, that again is a very good beginning,
6. Because this is probably where I was starting out, was with this kind of, this type of …
7. *Sounds challenging, yuh!*
8. And I thought that kind of depicted it, the challenge right there, that photo.

Coda: A lot of unsaid things there
9. There’s a lot of unsaid things there, but I mean as you look at that,
10. To live your life with that kind of connection, or lack of connection, lack of connection, yup.
Part 2: Everything was new

Stanza 3: It was like living in the middle of nowhere
*When you say lack of connection, do you mean connection to the past, to the person…*
9. Oh, I mean lack of connection in terms of my brain;
10. It was kind of like when you have a thought,
11. That you didn’t know what it was going to latch on to;
12. It was kind of like living in the middle of nowhere.

Stanza 4: It was as though you were just born anew
13. There was no sense of connection, to your environment, to other people;
14. It was as though you were just born anew;
15. Yes there were things you knew how to do, it wasn’t like you were a newborn,
16. But in a sense you were.

Coda: Hard to explain
17. Everything was new,
18. And life without connection, hard to explain, hard to articulate.

Stanza 5: I basically laughed through every day
19. I basically laughed through every day.
20. There was this laughter that just went on, constantly,
21. Just this giddiness, laughter, living at that crest of the wave.
22. And when you are living at the crest of the wave, it was just as though you had lost the connection with reality? to some degree? Or reality as you knew it?
Part 3: How I see it now, in hindsight

Stanza 6: It all had to like be reestablished
23. It all had to like be reestablished, the connections, over time,
24. Is how I see it now, in hindsight;
25. For me I think it was more, the passage of time and taking small steps;
26. And things were just kind of re-knitting themselves, just, in the healing.

Stanza 7: I had so many gaps in my brain
27. And I also thought of just now,
28. This lack of connection, when I said with the brain;
29. It was as though I had so many gaps in my brain,
30. That there was like not a connection any longer.

Stanza 8: I would bump up against that
29. So it was a synapse? Almost like,
30. And I would bump up against that,
31. Minute by minute it seemed;
32. But so you just throw it out.

Stanza 9: My reaction was this laughter
33. It was as though my reaction to all that,
34. Because I was in that lucky one to two percent,
35. My reaction was this laughter, reverie state,
36. As opposed to the awful frustration, or what could have been.

Coda: A perfect way to sum it all up
37. So, when I saw that I said well,
38. That seemed like a perfect way to sum it all up.
Part 4: The only way I can make any sense out of it

Stanza 9: Are you really, truly connecting
39. No longer like that,
40. But in that reverie state, you even feel as though, are you really, truly connecting with the other person, when you’re with them;
41. Because you’re in this, euphoric state, and they just seemed somehow,
42. It was almost like we were in a hollow, some kind of a hollow, or a vacuum.

Stanza 10: That’s what I meant
43. So, that’s what I meant I guess,
44. I couldn’t feel really connected, in lots of ways;
45. And the way I released it I guess was through all that laughter;
46. It’s the only way I can make any sense out of it.
Living without Connection

Part 1: Why I took this picture
Stanza 1: That’s how I felt
Stanza 2: I thought that kind of depicted it
Coda: A lot of unsaid things there

Part 2: Everything was new
Stanza 3: It was like living in the middle of nowhere
Stanza 4: It was as though you were just born anew
Coda: Hard to explain
Stanza 5: I basically laughed through every day

Part 3: How I see it now in hindsight
Stanza 6: It all had to like be reestablished
Stanza 7: I had so many gaps in my brain
Stanza 8: My reaction was this laughter
Coda: A perfect way to sum it all up

Part 4: I couldn’t feel really connected, in lots of ways
Stanza 9: Are you really, truly connecting
Stanza 10: That’s what I meant
3\textsuperscript{rd} approach: Plotting the sequence

- The basic story parts
- A longer story
- Researcher as editor
- Co-creation is not transparent
- 15 out of 27 photos
- The analysis transformed the sequence
- Last photo in each group leads to the next
Problem

…that’s how I felt…right after my accident, that there was no connection and there were so many missing links as I tried to begin living again…it was kind of like living in the middle of nowhere…When I saw that, well, that seemed like a perfect way to sum it all up, you know
...this is a burnt cake, and it symbolizes my forgetfulness...now there is a joke in my house, where if I ever were to open up a restaurant, it would be called the well done café, because I tend to like to make everything well done...but this is pushing it...so that is my well done cake ... and to have a sense of humor about this whole thing is critical
Action

My forgetfulness is such that...if I really wanted to remember something, I would have to...place it right in the middle of the floor, and otherwise, it would most likely be forgotten. Lists, you know, lists just wouldn’t work....I was trying to remember to take a picture that day.
I have a lifelong characteristic, of...caring for others. And when it comes to myself I don’t do quite as much....I think what matters is...to the degree that we neglect ourselves. And I think there was a time in my life when I did it, to the point of neglecting myself. ...I’ve always taken other people, seriously,...at work, at home, everywhere. But now it may be time to truly take my situation seriously.
Resolution

...now this one here is again, another connection, but it...has nice, big..bulky connections, ... (and) it’s a whole picture... everything’s working, connected, and it’s behind the scenes...and those connections being made behind the scenes is what makes everything go. So that’s why I took that. It’s just, kind of simple, but yet it personifies a pretty big thing. A pretty big thing.
I wanted to take her [Janét’s] picture …where she would be happy and proud. The pride that you can see…as she stands there, is the pride that I feel in my accomplishments. And it’s very similar to the pride of a young child as she’s growing…she symbolizes for me the hope, for the future.
Discussion

• Each analysis tells a valid story
• Each is a partial telling
• Helps us recognize “the many facets of any given approach to the social world” (Janesick, 2005)
• Using 3 approaches may help us gain a deeper understanding of what the data can tell us