

Subjectivity of People with TBI

- Subjectivity: self and agency
 - How does cultural norms and expectations restrict and contribute self-knowledge and learning of an individual?
 - Strategies of TBI-people to cope with their injury
- Dialogue between diagnosis & experience
- Layered nature of TBI-person's subjectivity

Material of the Study

- Interviews of 24 (16 male, 8 female) TBI-people (writers, asking NGO, snowball)
- 3 to 4 interviews / each in ca. 1 year
- 22 to 62 y. old, injury at the age of 14 to 53
- Written narratives of 23 (12 female, 11 male) TBI-people > 9 also interviewed
- Finnish TBI organisation pub.: *Aivoitus*
- Analysis: phenomenological-hermeneutical

Changes caused by TBI

- Changes caused by TBI > subjectivity/self might become unknown or alien >
- Everyday life becomes challenging, stressful and tiresome
- Nochi: difficult to construct self-images
 - Memory blanks > identity
 - Perception of own abilities in relation to environment

Results of the study indicate...

- TBI causes disappearance of knowledge and disturbances in automation of function leading to...
- Fracture in subjectivity > need to reconstruct oneself according to norms
- Subjectivity becomes layered: pre-injured, post-injured, rehabilitating & norm subjects
 - > simultaneous and overlapping > complications to construct coherent subjectivity

Diagnosis vs. Experience

- Dysfunctions in abilities that are not perceivable > problems in understanding and explaining >
- Identification to diagnosis
- Using medical discourse > drifting apart from personal experience
- Talking both according to medical discourse and personal experience > 2 parallel realities: shared & unshared

Diagnosis vs. Experience

- Private & Public talk (Radley & Billig 1996): private to personal experience, public to legitimacy & understandability
- Nochi (1998): metaphors & neurological terms:

“My brain is short-circuited”

“The brain is shut down”

Diagnosis vs. Experience

“In primal state has been done several head CT-imaging, discovered in left frontal impression fracture as well as contusion haematoma” (Male 52 years.)

“It's good to have it on paper, that one knows why to feel so 'light'” (Male 52 years.)

“After getting home I began to cry while realising the finality of that diagnosis. One can heal from depression, not from a traumatic brain injury”. (Female 27 years.)

Diagnosis vs. Experience

- When a person uses medical concepts, she has more credibility
- Using medical discourse helps to understand oneself and to communicate with others > legitimacy

Simultaneous acceptance & resistance: "As a result of severe traumatic brain injury my initiative has been found to decrease and I had become quite a bit slower in my every activities. But nevertheless, I still presume that custodial practice of the hospital had it own negative effect in my life precisely in 'institutionalised' sense". (Female 53 years.)

Layered subjectivity

- Pre-injured subject

“I used to be a sprinter, I liked to dash [...] I had a trained body and so on.”(Male 22–23 years.)

“I had always been good in bustling and getting things done.” (Female 33–34 years.)

“There wasn't any room for anything else in my life besides that sport...I have maybe become lot more open person and I am not anymore so superficial guy.” (Male 22–23 years.)

“I have always been such a person that I, myself [had to do everything].” (Female 33–34 years.)

Layered subjectivity

- **Post-injured subject**

“Tiredness, problems in memory, stressing, concentration slackens, have strength only to nice things, doesn't have many lively hours during a day, pains, aches, can't tolerate alcohol. [...] I!, who am a regular visitor in big concerts, have panic disorders in crowds...crying, depression [...] I began to be nervous during, unconsciously, such things that weren't a big deal before. Having a morning assembly..in front of three hundred kids who sit in the auditorium [...] it wasn't anything before but now, before these occasions, was almost panicky feeling [...] I was like a worm, I felt dizzy and had no strength to do anything, and I have always been a doer.” (Female 33–34 years.)

Layered subjectivity

- Post-injured subject

“Changing from an athlete to such a- hemiplegia..to a disabled so, I couldn't really accept that change in me yet [...] I probably had it as one of the most severe symptoms, in that TBI, that dependency..that I can't really get anything done, I have a lot of things in my mind but it stays there.” (Male 22–23 years.)

Layered subjectivity

- Post-injured subject

“As a sportsman [a team sport] before the accident I had a kind of [laughs] plug in my ears, hidebound worldview, well...now, of course, I had become- that accident has a kind of...educated me, in its own way [...] maybe I understand a little bit more what is going on in the world.” (Male 22–23 years.)

“During these years I got new religious friends [...] Gradually one of my great dreams began to realise. We established this band [...] All these things maybe wouldn't have come to my life without the accident.” (Female 33–34 years.)

Layered subjectivity

- Rehabilitating (or desired) subject

“It hasn't been that last pressing, that I would've given everything [...] I probably have through physiotherapy been able to do bench press and all that kind of stuff. Slowly but surely the mobility is increasing [...] very bad balance but it has been progressed with the help of physiotherapy.” (Male 22–23 years.)

“I had a great will to rehabilitate. I learnt to walk: first to sit, 2 sec., standing, then walking with walking aid. I remember sweating in physiotherapy “doing exercises” [...] I had a hard willpower that I will, as soon as I can.” (Female 33–34 years.)

Layered subjectivity

- Norm subject

“When I think of people my age, my friends, some of them have had difficulties is accepting it or react to it [...] word: traumatic brain injury, has- horrible prejudices, and in addition to that, some paralysis, that you have other side paralysed, so **they might think** that he barely can walk or something like this...he is upside down, talks whatever.”
(Male 22–23 years.)

Layered subjectivity

- Norm subject

“Surely ***working age person*** in Finland- work is the most important thing for a human being [laughs] that I had a chance to go to work [...] That I have some place and mission [...] If you think of a ***normal person***, you go to work and then you have hobbies in addition to that, so that didn't come into question. This work is like a hobby at the same time [...] as if TBI wouldn't disturb me and I had to go there to ***normal life***, so those therapists too realised that I had to get there, that it is mentally a good thing for me.” (Female 33–34 years.)

Studies of Masahiro Nochi

Nochi has theorised TBI-person's experiences as "loss of self" in their interpretations to the relationship of their past and present (1998), as *void* in their understanding of self in the past and present (1997) as well as divided their self-narratives in coping with TBI into five categories: 1) "the self better than others", 2) "the grown self", 3) "the recovering self", 4) "self living here and now" and 5) "the protesting self" (2000).

References

- *Male 52 years: injured at the age of 37 in traffic accident, writer.
- *Female 27 years: injured at the age of 18 in traffic accident, writer.
- *Female 53 years: injured at the age of 43 in traffic accident, writer.
- *Male 22–23 years old: injured at the age of 19 in traffic accident, interviewee.
- *Female 33–34 years old: injured at the age of 23 in traffic accident, interviewee, writer.

References

- *Nochi, Masahiro (1997). Dealing with the 'Void': traumatic brain injury as a story. *Disability & Society* Vol. 12, No. 4, 533–555.
- *Nochi, Masahiro (1998). "Loss of self in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine* Vol. 46, No 7, 869–878.
- *Nochi, Masahiro (2000). Reconstructing self-narratives in coping with traumatic brain Injury. *Social Science & Medicine* 51, 1795–1804.
- *Radley, Alan & Billig, Michael (1996). Accounts of health and illness: Dilemmas and representations. *Sociology of Health & Illness*, 18 (2), 220–240.