



Never second best? A narrative perspective of the shaping and reconstruction of identity in twenty polio survivors

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by

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Narratives:

- Narratives are *cognitive processes*, a form of "meaning making" and make individual lives comprehensible as wholes. (Polkinghorne, 1988, p.18).
- *At the individual level*, narratives provides a framework for understanding the past events of one`s life, and for planning future actions.
- But it can also provide a *mutual consciousness* that groups can use to increase power seen in different liberation movements.



Background and aims of the study

- In 1994, The National Society for Polio Survivors in Norway and their Professional Board, conducted a survey where 1444 polio survivors participated.
- Among other published results, Schanke et al. (1999) found that those feeling psychologically harmed by the early treatment (27%), reported significantly more current symptoms and distress than the others.
- The present study aims to deepen the understanding of the kinds of problems experienced and the ways people cope with them.
- This presentation is based on an article from 2004 (Journal of Disability Research, 6: 89-110.)



Method

- ***Procedure for selection:***

Former polio patients who felt harmed by the early treatment they had received were recruited from the Polio Unit at Sunnaas Hospital, by announcement in the Norwegian Polio Newsletter and at a meeting of the Oslo Polio Society. 20 persons were selected, 8 men and 12 women.

- ***Participants:***

- between 60 to 41 years.
- age at onset of polio from 1-12 years.
- hospitalized from 1week to 14 yrs during childhood.
- 3 were single, the rest living with partners.
- 15 had disability pension, 5 worked full/ part - time.



The qualitative research interview

- A life story interview is a formative *dialogical process*.
- The life story interview is based on my clinical experience with polio survivors since 1989.
- The interviews lasted from 2 to 4 hours, transcribed verbatim about 1000 pages to be analysed.



Results

- The analysis is divided into three life stages:
 - Childhood and youth
 - The mainstream period as adults
 - The time when the late effects of polio occurred



Childhood and youth.

- The persons recollect and describe the fact they contracted polio as a "blow" or an "alienation" from their former identity as a "normal child". All, but one who can remember the acute phase describe becoming somewhat "*different*", "*changed*" or "*separated*" from the "tribe", family or friends.
- Many felt their parents had lost the normal child and that they had to do their best not to make it worse by hiding their own despair: "I brought grief upon my family because I got disabled."
- A woman exposed to ten years of daily training and seven corrective operations says: "I trained to make my parents happy, but it led nowhere. I remained in the wheelchair. ...I was not seen as a human being all these years. The polio case took it all."



Childhood and youth, cont.

- Both men and women describe vividly episodes when fear and crying were met with warnings and anger from the hospital staff, illustrating that emotional distress was defined as *non-compliant behaviour*.
- Only a few had parents with them during or part of their hospital stays. For others, visiting was so rare, that parents felt like strangers when they came to take them home. A woman living in a hospital for 3 yrs found "substitute parents".
- Being alone also during extensive surgical operations and corrective treatments, several describe how they learned as children to take the most *serious responsibility* for their own lives.



Childhood and youth, cont.

- In order to counterbalance the emotional neglect and oppression experienced, many made strong and successful efforts in exerting *secondary control*, i.e. *making comparisons to the "worst polio cases" saying "it could have been so much worse", and being grateful because treatment improved function.*
- Many recollect the feeling of inhabiting *a dual world*;
- Their internal one as a "polio case", *feeling emotionally alone and different* and
- The external one; *behaving as non-disabled* and *adjusting* to the social demands by focusing on compensatory skills in order to make up for shortcomings.



Childhood and youth, cont.

- In order to cope and avoid the position of the disabled associated with inferiority, they put a strain on themselves: "I was pushing my limits to show that I was as good as all the others , or even better."
- Gender roles are seen:
- The girls mostly adapted by being "*hardworking*", "*clever*" and "*nice*".
- The hardworking bright boys also became *leaders*. In addition, most of the boys developed a physical talent for fighting back.



The late effects of polio: repersonalizing polio as an illness and restoring the subjects voice

- Before the development of late effects, polio was a cultural taboo not spoken of. Most of the subjects had hardly met others with whom they could identify.
- Those admitted to hospital due to the late effects felt somewhat relieved that their own perception of current physical decline was *medically confirmed*. "I am not lazy, or a psychiatric case, I suffer from the late effects of polio."
- Meeting others gave rise to a *mutual consciousness and understanding*: "They know what it's all about and have the same experiences. It could have been yourself".
- "Coming out" gave rise to a narrative as polio survivor and re-established a sense of continuity in life: "It was so good to be admitted to the hospital and tell that one had contracted polio... One was finally allowed to."



The late effects of polio, cont.

- *For several, hidden memories were coming back from the early years of hospitalization, where the childhood demands could be normalized and their validity challenged or reformulated. "It felt healing to receive the human warmth that I really missed when I was a child at the hospital."*
- *Some started writing and publishing their polio histories to the public and professionals. Others told their stories in order to give voice to fellow men.*
- *For many, especially the women, the official acceptance of their polio and sharing of private life stories, offered new tools for understanding leading to increased self-acceptance and autonomy. "In one way I am more disabled due to the late effects, but on the other hand I feel so much better."*
- *The men react less emotionally, describing a process of self-examination: "I have questioned myself", or "I have had the time to reflect about my life story in a new way."*



Narratives as meaning making, a way to reach personal reconciliation

- In line with narrative thinking, the persons describe their lives in ways that take care of their respectability contributing *to reconciliation*.
- Acceptance is part of the *Judeo-Christian tradition*, and acceptance of what cannot be changed part of the value of perseverance (Becker, 1997).
- All of the subjects said that life had been "demanding" or for some "a fight", but many also underline polio as a challenge one had to cope with.
- Many describe thankfulness for having a "happy", "rich" and "privileged" life.



Narratives as meaning making, cont.

- The persons do not underestimate the sorrow and sadness, but at the same time underline the personal *growth*, or that the polio has strenghtened qualities such as willpower, courage, self-reliance, empathy, the ability for reflection and dealing with problems.



Discussion

- In childhood, the subjects tried hard to *fulfil expectations and comply to medical regimes.*
- At hindsight, they express sound indignation and sorrow to the emotional neglect they were exposed to, but also appreciate part of the treatment.



Discussion, cont

- According to Becker (1997) *discontinuities in life force individuals to reconstruct their biographies.*
- The late effects of polio served as a *turning point* challenging old values and contributing to mutual understanding and consciousness among poliosurvivors who were now "coming out".
- On the one hand this felt as a relief, on the other the physical decline are seriously affecting their daily life.



Discussion, cont.

- The subjects recollect actively coping to overcome problems.
- This is in line with the theories of human **resilience** (Kobasa, 1979, Antonovsky, 1986, Lifton, 1992, Bonanno et al, 2002, 2007, 2010).



Final comments

- Upcoming research on resilience place the experiences of poliosurvivors in a broader perspective.
- The article by Masten from 2001 called «Ordinary magic» highlights that adaptation to adversities are not exceptions, but rather normal parts of human coping strategies.
- Several studies on human resilience confirm that this hold true (Bonanno et al (2007), Quale and Schanke 2010, Bonanno et al (2010)).



**Thank you for your attention.
I also thank members of the National
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their participation.**



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