



Storylines from a qualitative study on family quality of life

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The research

- Multiple case studies
- Families with one (or more) children with an intellectual disability/development disability
- Qualitative research: semi-structured interviews and part. observation
- Aim of our research:

Understanding FQoL and the dynamics between individual and family QoL

“The human experience has two elements: a sense of belonging and a sense of being separate” (Minuchin 1974, p. 47)

Themes

- Family dynamics & relational quality of life
- Lifelong
- Community and society

Illustrated by a case using metaphors: the Emperor, Symbiotic v.s. Parasitic, Golden Cage, Umbilical Ties, Outside world.

“[...]Metaphors capture the reader’s attention, call up powerful associations, and resonate through the rest of the piece. These metaphors, well chosen (actually they are often heard first- and repeatedly- in the actors’ observations and reflections) serve as overarching themes and rich undercurrents that resound throughout the portrait. The metaphors act as symbols pointing to larger phenomena that will emerge as significant and be developed more fully later on in the narrative.” (Lawrence-Lightfoot & Davis 1997, p 55).

The case

The Porter family:

- Mother Anne (64), father Henk (61) daughter Noor (23) and son Tim (21).
- The family lives in a small village in the Netherlands.
- Tim has an unspecified condition which causes an intellectual disability and autistic related behaviour.
- Noor is studying in college.
- The extended family is not very involved in the family life.

Family dynamics

'The Emperor'

- Daily structure of Tim is dominating family life, needs of Tim come first

"If Tim is not doing o.k., he will become very compulsive, and then everything has to be even more structured and organized, and things may escalate. So if he is doing o.k., so is the rest. That is why we were always making sure he was doing all right, because then the family could function better." (Noor)

- Also other family members at times impacted the whole family dynamics: Noor acting out, Anne feeling unhappy staying at home, Henk's midlifecrisis.

Relational quality of life

‘Symbiotic v.s. parasitic’

- Quality of life of family members connected

“When our own quality of life is not o.k., we are not able to look after our boy. At that time, we hadn’t realized that, but as Tim is getting older, we see that more clearly.” (Henk)

- Quality of life of family members is different

“If we talk about quality of life, then I think that we give Tim an enormous amount of quality of life, and he feels that too. But it is a question whether Henk and I have that too. It used to be symbiotic, but now it is parasitic” (Anne)

Lifelong (1)

'Golden Cage'

- Social life of parents has become smaller
- Family life in a lifelong perspective

"We always say that we have now reached a certain age, in which we live in a golden cage. We love travelling and doing things, well, that is not possible. That has to do with Tim. And we find that very difficult." (Anne)

[...]It has to do with his age, when Tim was young, we could go on a holiday and have someone else look after him and Noor for two weeks. When he got older, that group of people got smaller and smaller. We now have no one to ask." (Henk)

Lifelong (2)

‘Umbilical Ties’ (Navelcord connection)

- Strong ties connecting the family members, and especially Anne and Tim
- Letting go is difficult

“You need to give him the challenge, and you need to keep training his skills. You need to stay alert.” (Anne)

“I have learned things [to live independent red.], we are working on that now.” (Tim)

Community & society(1)

'Outside world'

- People find it hard to understand

"People think they get it, but they don't." (Henk)

- Societal expectations and being 'normal'

"We have often said to each other: if only we had a child with Down Syndrome, than at least it would have been visible to the outside world. Then it is clear: the society will adjust their expectations when they see someone with Down syndrome." (Anne)

Community & society(2)

- The informal support network is small

“Many people have abandoned us, but we also created a group of people with who we are very closely connected” (Anne)

Conclusion

- Ties of love, power, care, responsibility and moral obligations between the family members.
- Moral appeal on the parents.
- Interaction and relational patterns within a family change over time, and so does their FQoL.