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Rethinking FQoL: The Dynamic Interplay Between Individual and Family Quality of Life

Femke Boelsma*, Irene Caubo-Damen*, Alice Schippers*,†, Menco Dane*, and Tineke A. Abma*
*VU University Medical Centre, Amsterdam; and †Disability Studies in the Netherlands, Amersfoort, the Netherlands

Abstract

Family quality of life (FQoL) is an emerging concept to understand and improve the well-being and quality of life (QoL) of families. While there has been a lot of effort to conceptualize life domains of families and measurement tools are devised, few studies concentrate on an in-depth understanding of FQoL. The specific aim of the current study is to understand the relation between individual QoL and FQoL, by studying families with a child/children with intellectual and developmental disabilities (ID/DD) in the Netherlands. This can contribute to a stable foundation of the concept of FQoL. Methods: An explorative case study design was used, in which the parents, sibling, and child with ID voiced their thoughts on their FQoL. The presented case has been analysed through thematic and narrative analysis. A father and a mother with a child with an intellectual disability have joined the research team as co-researchers. The relational dynamics found within the family illuminated an interactive pattern in which the son with ID acted as an Emperor, creating a Golden Cage for other family members and Umbilical Ties among them. The family portrait shows that FQoL is a dynamic and relational concept. By making strict distinctions between individual QoL and FQoL, the dynamics between family members and the way they work alone and/or together to ensure the well-being of the family and its members can easily be overlooked. In addition to the common-sense notion that FQoL and QoL support each other, conflicts and tensions can occur.

Keywords: family quality of life, intellectual disability, qualitative research, quality of life

Introduction

For most of us, our family is the first social network we belong to. In families, children are raised, cultural practises are being transferred, and a moral consciousness is formed. Whether a family is formed by blood or choice, the thing most families have in common are the social and emotional ties between the family members which bound them together. It is therefore not surprising that in the field of quality of life (QoL) research (see Cummins, 1997, for an overview), there is increasingly attention for family quality of life (FQoL), as an expansion of the concept of (individual) QoL (Turnbull & Turnbull, 2002). There has been a substantial amount of studies on QoL and its indicators and domains (Brown, Brown, & Bayer, 1994; Felce, 1997; Felce & Perry, 1995; WHOQOL Group, 1998), which has led to a consensus document formed by a team of international scholars (IASSID SIRG-QOL, 2000; Schalock et al., 2002). These domains are: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (IASSID SIRG-QOL, 2000; Schalock et al., 2002). These were complemented by Poston et al. (2003) with the FQoL domains: daily family life, parenting, family interactions, financial well-being (Poston et al., 2003). Two leading FQoL instruments have been developed: The Family Quality of Life Survey-2006 (Brown et al., 2006) and the Beach Center Family Quality of Life Scale (Beach Center on Disability, 2005; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006).

The FQoL studies originate mostly from the intellectual and developmental disabilities (ID/DD) field, and the development of the FQoL construct is seen as especially relevant to this field because the family becomes more and more important for caring and supporting a family member with ID/DD (Brown et al., 2006). When a child with ID/DD is born in a family, it will impact the family life. The way family members deal with their special family is informed by their social world (Seligman & Darling, 2009). Despite the fact that we, the authors, wholeheartedly support the trend toward studying FQoL, research on families can be slightly problematic, as the family comprises individual family members and "the family" is not a tangible "person" (Bourdieu, 1996). The family is a product of human interaction, including the capacity to meaningfully redirect social processes (Berger & Luckmann, 1971). The family is rather an interacting "unit" in which all family members influence each other (Seligman & Darling, 2009). Patterns of interactions and relationships, stories and rituals develop and reconstruct a dynamic family life. In this article we follow the definition of Poston et al. (2003) who define family as: "People who think of themselves as part of the

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Correspondence: Femke Boelsma, MSc, Department of Medical Humanities, VU University Medical Centre, De Boelelaan 1089a, 1081 HV, Amsterdam, The Netherlands; E-mail: femke.boelsma@vumc.nl

family, whether related by blood or marriage or not, and who support and care for each other on a regular basis" (p. 319).

We depart from the notion that interactions are vital in understanding the QoL of family members and the collective unit. As Minuchin (1974) claims: "human experience has two elements: a sense of belonging and a sense of being separate" (p. 47) and Handel (1991) describes this as: "the family's task is to provide a means for the individual members to be both separate and connected" (p. 247). This illustrates our point that both individual and collective senses of well-being are in a dynamic way present in a family and its members. It is therefore difficult to separate these to gain a full understanding of the family life and the experiences and needs of all family members.

Scholars from the FQoL field acknowledge that the individual and family level interact, and that individual QoL is an integral part of FQoL (Chiu et al., 2013; Zuna, Brown, & Brown, 2014; Zuna, Summers, Turnbull, Hu, & Xu, 2010). Zuna et al. (2010) define FQoL as: "a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level interact" (p. 262). These insights have also formed the base for the family–centred approaches and family-centred support (Davies & Gavidia-Payne, 2009).

The dynamic nature of the FQoL concept, and how the individual and family levels are intertwined, has received less attention and seems difficult to translate into an instrument. The Satisfaction with Family Life scale measures the satisfaction with family life from the perspectives of all the different individual members, in five broadly formulated items (Zabriskie & Ward, 2013). While this gives an individual perspective on satisfaction with family life, it does not include the individual satisfaction with one's life, in relation to the family life. It seems that measuring either individual or family QoL leads to a kind of dichotomy, between the individual member and the collective unit of the family. Also, when measuring FQoL, it is usually the perspective of the main caregiver (usually the mother) that is being measured, and there is a need to include the other family members more explicitly, as family members may differ in their perceptions of FQoL (Zuna et al., 2014). More knowledge about the interactions between the individual and family level is needed to contribute to a sound theoretical foundation of the FQoL concept. This theoretical foundation is currently lacking, as a review of the literature showed (Hu, Summers, Turnbull, & Zuna, 2011). In our study, we therefore aim to contribute to a better theoretical understanding of the FQoL concept and have chosen to study the dynamics between the family members and their QoL and FQoL. For this aim we have chosen qualitative methods, more specifically we chose a naturalistic case study design (Abma & Stake, 2014; Lincoln & Guba, 1985; Stake, 2013) as this approach is best suited to study the family as a dynamic and complex unit which is influenced by a particular context.

Case studies concentrate on the experiential knowledge that can be gained from unique, bounded contexts. Also, research on families with children with ID/DD usually focus on one target group: parents, siblings, or the person with ID/DD. A case study approach allows for cross-comparison within a family and provides a deep understanding of the families, their internal dynamic and the relations between the different family members. In this article, we will use a case study to show the dynamic characteristics of FQoL.

Methods

As mentioned in the introduction, for this study we have chosen a case-study design in which qualitative methods were used.

The Case

The Porter family[1] is a family of four: mother Anne (64 years), father Henk (61 years), daughter Noor (23 years), and son Tim (21 years). They have a couple of cats and a dog. Anne, Henk, and Tim live in a small village in the east of the Netherlands, in a house where they have been living for a long time. Noor is a college student and in recent years she has been living in her own apartment. Tim has an unknown condition which causes an ID and autistic-related behavior. Anne and Henk have always worked full-time while raising their children, and have now been retired for a couple of years. Tim has been to schools for special education, which were not fully equipped to teach him, according to his parents. Noor was a wilful girl when she was younger and has been difficult to handle during a few times in her childhood. Henk and Anne always had enough financial means to support their family. Various people were involved in family life when the children were growing up: there were people on the payroll who tended the children and others who helped out with the household chores. The extended family of Anne and Henk are not very involved with the Porter family.

Data Collection

To gain an understanding of the personal experiences and multiple perspectives we used semi structured interviews with all the family members. The mother and father were interviewed twice alone (respectively, 3 and 1.5 h), and two times together (total 3.5 h). The son and daughter were interviewed once (respectively, 1 and 1.5 h). The interviews took place in the home of the family members, usually at the kitchen table. The researcher made sure that she had seen Tim a couple of times before (during the interviews of the parents) so that he was already familiar with her before they had a talk together for the interview. During their interview, the researcher adjusted the questions so that they were clear enough, she drew a mind-map (a drawing of words and connected stripes between them that illustrates the connections and relations between words and concepts) during the interview to check whether she understood what was important to Tim, and also a map of the people around him, so that they had a visual aid during the talk.

The topics of the interviews were inspired by a literature search and FQoL theory and included information about the family members (hobbies, jobs, social contacts), daily family life (activities, daily structures), family relations between the family members, contact with other people (i.e., friends, extended

[1]The names and some details have been altered to ensure anonymity.

family, colleagues, and neighbours), important factors for individual and family life, family needs, support network, personal goals, and needs (conflicting and converging) interests of family members. All the interviews were recorded after consent and transcribed. All family members were informed about the goals of the research and signed an informed consent. The Medical Ethics Review committee of the VU University Medical Centre declared that the Medical Research Involving Human Subjects Act did not apply to this study.

The research team included a father of an adult son with an ID [MD] and a mother with a son with a disability [IC-D] who were involved in making the topic lists and analysing the interviews. The main researcher was female, with a background in cultural anthropology. She was in her late twenties and had worked with young people, and people with an ID before. Besides the topics for the research, there was room for small talk, which helped establish rapport with the family members.

Analysis

The principles of inductive thematic analysis were used to analyse the case study (Braun & Clarke, 2006). The work of Lawrence-Lightfoot and Davis (Lawrence-Lightfoot & Davis, 1997) about "portraiture" was used as inspiration to analyze a story line out of the narratives of the family. This means that the researchers extracted and coded all topics from the interviews and field notes. Then, clusters of codes and overarching themes were identified (Braun & Clarke, 2006). After this inductive analysis the researcher [FB] looked for metaphors in the story of the family members (Lawrence-Lightfoot & Davis, 1997; Van Hove et al., 2009), which were in line with the major themes that were found in the first analysis. One researcher [FB] coded the data, and two parents/co-researchers [IC-D & MD] read the data to familiarize themselves with it. In a meeting, the interpretation of the clusters, themes, and matching metaphors were talked through among the research team in which discrepancies and similarities in interpretation were checked. After this meeting, consensus was reached.

Quality Procedures

During the interviews there was room for elaborate examples and stories, to enable a "thick description" including meaning and context (Abma & Stake, 2001, 2014). Thick descriptions provide readers with a "vicarious experience" of the studied case and enable readers to make a "naturalistic generalization" (Abma & Stake, 2001, 2014). To increase the validity, a summary of the interviews was made of around two/three pages which was send to the individual family members. They were asked to check whether this summary provided a true picture of the conversations that they had with the researcher. This is also known as a member check (Lincoln & Guba, 1985; Mays & Pope, 2000). As mentioned above, multiple researchers checked the data and the interpretations, to reduce personal bias, also known as inter-rater reliability (Hsieh & Shannon, 2005).

Findings

The dynamics between the family members will have smaller moments of interaction that impact the daily lives of the family members, and there are also bigger dynamic flows that will resonate throughout the overall family lifeline. If we imagine the narrative of the family as a book, we find that the description of the daily realities of the main characters in the various chapters will inform the bigger storylines.

In this section, we first present the three main metaphors that we found through our analyses and which describe the various storylines: The Emperor, Golden Cage, and Umbilical Ties. After this, we will illustrate the plot of the Porter story and show how FQoL is a relational concept in which individual QoL is intertwined and interconnected.

The Emperor. The Porter family life seems to revolve around the life of son Tim. Tim is currently employed through a social workplace. He has a few colleagues, and some of them he describes as being a friend, and others more as acquaintances. Besides work he does not have a lot of other friends. Tim's need for daily structure has a big impact on the family life. Anne, Henk, and Noor call him the "emperor of the family." Noor explains: "We always call him emperor of the family, because he has such an influence, still. On everything that you want to do, holiday, it is always: dinner at certain times, he needs structure and always needs to know what you are going to do." Henk endorses this: "You have no choice, you just need to follow his structure, then he is feeling well. And if he is feeling well, then so is everybody else. But he always comes first. And that is miserable and it drives Anne and me sometimes completely mad, but you just have no choice."

When we depict an emperor, we might imagine a generously adorned gentleman who is being adored by "his" people and serves as a prime example of virtuousness and character. That is not so much the case in the Porter family, but the hegemony that Tim has over the rest of the family is noticeable. Tim may not be surrounded by overwhelming material prosperity like the emperor we just depicted. The treasures he receives are more immaterial in nature as we will see in the rest of the paragraph: love, attention, dedication, and above all, power. Tim's routines are like laws in the life of the Porters. He needs a lot of structure and routine that have become part of the family rituals, as Henk explains: "Just all days in the week the same, and all weeks in a year the same, and he is happy. So no Saturday or Sunday, no Easter, no Christmas. . . that would be the best."

The needs of Tim always come first, because in the end that is and was beneficial for the whole family, as Noor told us: "If Tim is not doing ok, he will become very compulsive, and then everything has to be even more structured and organized, and things may escalade. So if he is doing ok, so is the rest. That is why we were always making sure he was doing all right, because then the family could function better." For Noor, this was not always easy, because her brother's needs always came first, and while that was normal for her, it sometimes made her angry: "Sometimes I thought, why does it need to be that way, angry at the world, but not really on how things were done because that was in everybody's interest. [. . .] He can be very pushy and that is difficult

and that is why. I don't blame my parents, but I have often been placed second, just because there was no other way. He needed that attention, and I didn't."

Noor had several periods in her childhood during which she started to argue and fight with her parents. One of the first periods was when she was in primary school, and her mother described that Noor was misbehaving so badly that she did not know what to do anymore. Another time when Noor started to act out on her parents was in puberty, which put quite a strain on the family. Henk recalls: "Well, that period of puberty was. The whole atmosphere in the house was disastrous, when you have such a teenager in the house. That was a very turbulent time." Having Tim as the emperor in the house, Noor felt left alone and neglected at times. Tim's need for structure controlled the family, and it made Noor rebel, which in turn also had a big impact on the relationship with her parents and the family well-being.

It is quite clear that all family members strive to please Tim, but not vice versa. He does not seem very attentive toward his parents. Anne describes that when they come home after being a night away, Tim is very happy to see them, hugs them and then goes back to his room without asking how their trip went or if they would like a cup of coffee: "But then we hear him singing in his room, and then he is completely happy. He does not need us all the time, but he just needs to know we are home."

Golden Cage. Anne and Henk feel that the dynamic in house has changed due to the children getting older. While they experienced their lives as quite satisfactory when the children were young, this has changed when the children became adults. Noor is now living in her own apartment away from home, and Tim is now an adult who has his own say in things and does not always listen to his parents anymore. When Noor moved out of the house, so did a major part of her support to the family. Noor feels guilty about this: "In the beginning when I just moved out, I went home a lot because I felt guilty, that I sort of left my parents alone. I used to watch Tim for an evening, so that they could go out or whatever. Now they cannot do that so much anymore, because I am no longer available."

Anne feels as if she and Henk are living in a golden cage, as they have the financial means to do things, but they feel as if they cannot go anywhere: "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. If we talk about QoL, then I think that we give Tim an enormous amount of QoL, and he feels that too. But it is a question whether Henk and I have that too."

The social life of Henk and Anne has become smaller by the years. Some people could not handle a child with a disability and they cut off contact with the family in the first years after Tim was born. But also in the last years, with Tim becoming older and older, it is more difficult to explain to other people why, for example, Anne and Henk cannot stay very long at a birthday party, and why they bring Tim along. Henk says: "When we were younger we experienced this less, but now I think that because of Tim, if you don't look out, you will become socially isolated. Because you think it is better not to go somewhere, and just do the things here, and then you have peace and quiet. [. . .]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 and Anne have tried to find protected living arrangements for Tim, but they have been scared off by some very disturbing experiences of other parents. Anne says in this regard: "I think that the care arrangements are now insufficient, and that is not acceptable to me. For me he needs to feel like a 7,5 or 8 out of 10. And knowing that the care is not acceptable the way it is now, and you need to accept that his life is a 6, well, that is something that I cannot deal with. But I am also honest enough to say that Tim's life is now probably a 9. Well, my life isn't. It is close to a 5."

Henk and Anne show strong feelings of obligations and dedication toward Tim which contributes to their golden cage. For example, Anne and Henk would like to go out by themselves sometimes to get some time alone. But if they tell Tim they want to go out, he wants to go with him, as Anne explains: "And we do not want him to go with us. And that just does not work. And I do not want to lie to him and say we are doing something else."

The family dynamics have changed when Tim grew older and became a young adult. Anne says: "I do everything every day to make sure he is all right but it used to be symbiotic, but now it has become parasitic." Henk reacts by saying: "Now it is at the expense of everything else." When the children were young, their well-being usually meant the well-being of all family members, but in current family life, the feeling of reciprocity has been lost. The QoL of the members within the family is becoming unbalanced and causes the parents to feel caged in.

Umbilical Ties. Anne and Henk have always tried to make their children happy and Anne still has, as Henk calls it "umbilical ties" to Tim. Anne says in this regard: "What I find very important is that your child is happy, and that you are able to coach and raise your child, and give him the tools to be a happy person and to live a happy life. That is very important."

With Noor studying and living somewhere else, she is becoming an independent adult and is slowly cutting loose from the umbilical cord that used to tie her together with her family. She explains that this was not so easy to do, because she feels partly responsible for the care for Tim. She has, in her own way, also a umbilical tie with Tim, because she adopts the parental role, for example, when Tim is sleeping over at her apartment: "If my brother is coming over, I really have to care for him, it has always been that way. But I do not feel like I am replacing my parents, but we do have a different relationship than two healthy siblings."

Unlike Noor, Tim still needs his parents' support, and they train him to become more independent and teach him things he needs to know if he wants to live on his own or in a group without his parents. Tim says: "I have learned things, we are working on that now." Especially for Anne it is difficult to give Tim more freedom to live his life, and even to make mistakes. She feels Tim needs constant training and practice: "You need to give him the challenge, and you need to keep training his skills. You need to

stay alert." Henk replies laughing: "Do you hear what you say?" It is a process of letting Tim go, and that does not always come easy.

Plot

FQoL is formed by the daily occurrences, circumstances, interactions, and experiences of the family members. Within the family, the individual stories are connected and formed in an interactive manner. Anne illustrates this as following: "We found throughout our own development that it is nice, the QoL of people with a disability, but the QoL of the people around them is at least as important, because you need to do it together." Henk describes it as: "When our own QoL is not ok, 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."

If one of the family members is not feeling well, this will impact the rest of the family. Henk illustrates this by telling how Anne was drowning in her own sorrow after the birth and problems with Tim: "Anne and I thought that Anne needed to get back to work. Just sitting here being sad, makes you unhappy. And that makes the rest of the family unhappy too."

In "The Emperor" we saw that Anne, Henk, and Noor believe that if the structures of Tim are being followed and he is feeling good, so is everybody else in the family, as Henk explains: "You follow his structure, and then he is feeling well. If he is feeling well, so is everybody else." Noor said in this regard: "Something that was always very important: if Tim is doing good, then so is the rest of the family."

At the same time, we see that even if the family follows Tim's routines, it does not make them very happy, and it contributes to them feeling in a Golden Cage in the later part of family life. In the previous paragraphs, we noticed that Tim is the dominant character in this story, even if he is not aware of it himself. All family members work together to make him as happy as possible, because they believe that this in turn benefits all family members. However, in "Golden Cage" we saw that this is changing when Tim is getting older and becoming a young adult.

Perhaps, as a result of the dedication of his parents, Tim rates his own life a 10 out of 10: "because everything is going good now, and I feel good, and I feel good about myself." His mother on the other hand rates her life a 5 out of 10.

Besides the difficulties and struggles in family life as described above, all family members perceive the family as being very close and connected. Tim says that he always had a good connection with his parents and sister: "They help me with everything, to learn and they do a lot for me. They help me a lot." When he describes the people around him, the most important persons for him are: "my parents, sister and the dog."

Henk and Anne acknowledge that having a child with a disability has changed them in a positive way too: "In the course of life you discover that you have certain qualities, that other people do not have, and that feels very good. We are very good at raising children." Henk continues: "Yes, I am very proud of that. We are a great team, both very good at it." Noor says that because of Tim, she sees the world in a different perspective: "It is a different perspective. You see other things than others. For example, the place where Tim works, those are things which you never would have seen. I might have seen some things in the world differently."

Discussion

This case study highlights the dynamic and relational dimension of FQoL. Especially in a family, people live in close proximity to one another, and the lives of the different family members are closely connected together. Our case study, as well as other studies, show that there can be ties of love, power, care, responsibility, and moral obligations between the family members (Lindemann Nelson & Lindemann Nelson, 1995; McPhail, 1996; Turnbull & Ruef, 1996). Studies from the field of family systems theory have also acknowledged these interactive patterns and interdependency between the family members, especially on an emotional level of family life, and have a clear psychological focus on dynamics in the family and strategies to improve family life (Brown, 1999; Fingerman & Bermann, 2000). This implies that if families are mentally and physically well, this will benefit every family member (Odom, Yoder, & Hill, 1988; Rosenbaum, King, Law, King, & Evans, 1998).

A common-sense notion which was also dominant in the Porter family was that if the person with a disability is feeling well, all family members will feel well. To a certain extent this was indeed the case; the son with a disability needed structure and this prevented him from compulsive behavior. Yet, when the son grew older, conflicts and tensions arose, the family members experienced the structure as limiting their own well-being. This was especially the case for the mother who scored her own well-being a 5 while her son received a 9 or 10. Here we see that there was no reciprocity between the son on the one hand and his parents and his sister on the other hand.

One of our findings is that the son with ID had a dominant position in the family and had a big impact on the QoL of the other members. That need not always to be the child with ID; one can imagine that the father, mother, or other children can also have a significant (negative or positive) impact on the well-being of another family member, and the family as a whole.

Researchers from several countries used the Family Quality of Life Survey-2006 or Family Quality Of Life Scale to measure the FQoL of families with a child with a disability (Ajuwon & Brown, 2012; Hu, Wang, & Fei, 2012; Steel, Poppe, Vandevelde, Van Hove, & Claes, 2011). Results from, for example, Australia, Canada, South Korea, and Taiwan found that family relations and spiritual beliefs are generally scored highly, while support from others scored low. The countries differed in scores on the domain health and careers, which scored lower in South Korea and Taiwan (Brown, Hong, Shearer, Wang, & Wang, 2010). Measuring individual or family domains can be insightful, however, we feel that by making strict distinctions between individual QoL and FQoL (i.e., by creating domains and indicators) we can fail to see the dynamics between family members and the way they work alone and/or together to ensure the well-being of the family and its members. Our case study shows that an overall FQoL score might be misleading as it can vary and diverge individually and over time. Also, we noticed in our case study that in particular the parents as main caregivers scored relatively low for their own well-being compared to other family members. This leads us to

the conclusion that the perspective of the main caregivers cannot be used as a proxy for the whole family. This has been noticed in the literature as well (Zuna et al., 2014). The "Golden Cage" that has been described in this article has similarities with studies on the experiences of parents with a child with autism, who describe themselves as "living on a world of their own" and feeling isolated from a "normal" life (Gray, 1993, 1997; Woodgate, Ateah, & Secco, 2008). Different from these studies is that the Porter family has felt being in a golden cage only in later part of family life, when the children were grown and not so much during the years that the children were younger.

Over time, interactions and relational patterns within a family can change which is inextricably connected with their FQoL, as we saw in the Porter family. In the current phase of this family's life, a converging process seemed to happen: some family members left the family, and ties to people in the outer circles (such as nannys, schoolmates, and colleagues) tended to weaken. As the world of the family was getting smaller, the interdependence of the remaining family members increased. Also other scholars have indicated that the experiences of family members can change over time. These studies often focus on experiences of parents and siblings with an adult child/sibling with ID. For example, a study on parents with adult (40+) children (Jokinen & Brown, 2005) showed that older parents are concerned about the health of all family members, and the role of siblings. A study by Seltzer, Begun, Seltzer, and Krauss (1991) found that mothers who had help from siblings who supported in the help of their adult brother with ID had better well-being than mothers who had no such support. If a family member with ID moves out, it could partly resolve the "Golden Cage" of parents. Werner, Edwards, and Baum (2009) found that if a family member with ID moves out, this had both positive and negative effects on the FQoL. Family members did experience more freedom to pursue personal goals and also felt the relationships between the individual members improved. However, these experiences were accompanied by feelings of worry and guilt (Werner et al., 2009). Daughter Noor experienced similar feelings when she was the one moving out of the family house: on the one hand, she experienced more freedom, and on the other hand she felt guilty because she was no longer able to help with looking after her brother.

One last important finding is that caring for children, and especially a child with ID, imposes a moral appeal on and creates moral dilemmas for the parents which can be quite complex and contradictory. In the case study, we saw that Tim put a strong implicit moral appeal on his parents to care for him. The moral value to care for him, conflicted with the moral value to care for themselves. The concept of "mature care" (Gilligan, 1982; Pettersen, 2008, 2012) might be useful when contemplating these moral dilemmas. The mature care concept portrays care as a relational and dialogical interaction that takes place in a given cultural, professional, and political context and challenges the traditional view of care as something provided to a care-recipient. A focus on mature care may prevent the caregiver, for example the mother, from becoming so absorbed in the person that needs care that the obligations and needs someone has toward themselves and others are neglected. The care responsibilities that are taken up have to be realistic within the actual context. Therefore, caring, understood as mature care, is demanding work for all, as it requires (self-)reflection and awareness about one's own boundaries as well as the others' (Hem & Pettersen, 2011).

Theories on family ethics can be insightful to further develop thoughts on the complex moral web of family loyalties, obligations, and responsibilities (Lindemann Nelson & Lindemann Nelson, 1995). Families are considered as social institutions with their own specific backgrounds, habits, and features, possessing own moral logics and responsibilities. Hilde Lindemann (2007, 2014) has illuminated a gap of knowledge in traditional medical ethics and argues that the "moral logic" of traditional medical ethics does not correspond with the moral narratives within families of patients.

Limitations

Including all family members and their perspectives in studying FQoL provides valuable knowledge in understanding the dynamic, relational, and interdependent nature of FQoL. However, while we have talked with all family members, the data gathered from the child with ID was less substantial than the other family members and that remains a challenge for studies. Further, we acknowledge that this case study provides findings that are particular and context-bound (Stake, 2013) although some argue that these findings can also have a more universal meaning (Lawrence-Lightfoot & Davis, 1997; Simons, 2015). Through "thick descriptions" of the context and meaning readers can gain a "vicarious experience" of the case and generalize the findings to other contexts than the studied context (Abma & Stake, 2001, 2014).

Implications

The findings of this case study have some implications for FQoL theory. First, we agree with Zuna and others (2014) that there is a need for a broader perspective on FQoL, which includes the perspectives of all family members and not just the main caregiver (Zuna et al., 2014) which will help in acknowledging the various experiences of the different family members on family life. Relevant research has been done on siblings and QoL which suggests that also children in the family are very well able to reflect on their QoL and their family life (Moyson & Roeyers, 2011, 2012). Therefore, we would like to endorse the proposition of Zuna et al. to implement a family-based support framework in the provision and evaluation of care, and to include the perspective and experiences of all family members. This also could provide an opportunity to combine individual QoL domains with the FQoL domains.

Second, an important finding is that the FQoL of a family, and the individual QoL of its members, can change quite significantly over time. In this case study, family life was good when the children were younger, but when the children grew older and the social support became smaller, the QoL of the parents decreased. These dynamics indicate that more research is needed about the FQoL of families in various stages in their family life and in life transition phases, as they move from children being born, children growing up, children becoming adults, children moving

out. Also, this is an important finding for family care workers in working together with the family in various stages of their family life.

Last, we found that moral dilemmas can be part of family life, because of family loyalties, obligations, and responsibilities. Professional who support families should be aware of these moral considerations of family members and their impact on the way family life is organized and experienced.

Conclusion

In short, we learned from this case study that it is important to reflect on the dynamic nature of the FQoL concept. The QoL of the various family members and the FQoL can change over time, and it is useful to keep this lifelong aspect of caring for a child with an ID/DD in mind when studying FQoL. Also, we argued that an overall score of a family may be misleading as it does not acknowledge the diverging experiences of the family members when it comes to the quality of their individual and their family life. Last, we think that efforts should be made to include the perspectives of more than one family member in measuring FQoL, so that it can be a useful concept for the evaluation of family based support.

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