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Impact of a Parent's Neurodegenerative Disease and Care on the Daily Life of Children

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Abstract

The purpose of the study described in this chapter was to explore children's and parents' views of how a neurodegenerative disease in a parent influences the daily life of the child. Focus groups were carried out with nine families of children, adolescents and parents with and without Parkinson's disease, Multiple Sclerosis (MS) and Huntington's disease. Each group met twice over a period of 4 weeks. Data were transcribed and analysed using qualitative content analysis. The results explored the meaning of the two categories: consequences in daily life and influence of disease on children. These categories emerged out of the following subcategories: economy, responsibility, living with personal assistants, being and feeling, being different, activities and the symptoms of the disease. A parent's disease has an impact on the individual child who is affected emotionally and psychologically, and with regard to practical issues and basic needs. The parent's and the family's needs for support create a conflict between the child's rights for health, well-being and privacy and the needs and rights of the parent with the disease for high quality care. The negative impacts also relate to lack of information and knowledge about the disease and the family's need for economic support.

Keywords: neurodegenerative disease, child, parent, family, health, home environment, care, personal assistants

1. Introduction

According to the United Nation's Convention on the Rights of the Child (UNCRC) [1, 2], the child's best interests shall be of primary concern in all situations and actions relating

to children. When a parent is affected by a neurodegenerative disease such as Parkinson's disease, Multiple Sclerosis (MS) and Huntington's disease, it may be particularly difficult to ensure the rights of the child. These diseases affect different body functions. As a result, the parent's ability to engage in daily activities and tasks may be limited. As the disease progresses, the parent's personality may change and cognitive and communicative problems may further complicate everyday life and the parent's ability to maintain a healthy relationship with the child. Complex combinations of different symptoms, social factors and sometimes the long duration of the disease may be demanding for the child and the family. When a parent or other adults are affected by a disease or other serious difficulties such as drug abuse or violence, the whole family is influenced [3, 4]. Parental neurodegenerative illness may have a great impact on other family members' health and well-being. Approximately 17% of the children, aged 12–24, of parents with Parkinson's disease were classified as having a mild to moderate depression [5]. Having a parent with Parkinson's disease may have less negative impact than having a parent with MS [6]. The impact of parental MS on the child, in turn, depends on many factors including the family's social network [7]. The children of parents with MS were compared with their peers of similar age and gender whose parents had no physical illness, and the results showed that the children of parents with MS had greater emotional and behavioural problems [8]. Accordingly, children of parents with MS are at risk of developing mental health problems [9] and parental MS can have a negative impact on the child's social relationships as well as on his/her psychological well-being [10]. Similar results were found among children who grew up in a family where the parent was affected by Huntington's disease. These children could experience problems and were at risk of decreased psychological well-being [11].

Children of parents with a neurodegenerative disease may get extensively involved in domestic activities and may be expected to provide care for the parent who is ill. Children of parents with Huntington's disease have expressed changes in their family's everyday life. They sometimes have an adult role, could be expected to provide care for the parent [12] and could feel responsible for the family's functioning [13]. A recent survey showed that 7% of the 2424 responding adolescents in Sweden were involved in extensive care of a person close to them [14]. Health care professionals should acknowledge the impact of a neurodegenerative disease on families and support children and parents in finding strategies to cope with the situation [6]. Daily assistance for the affected parent is one kind of support that could be helpful for the entire family. In Sweden, where this study was conducted, the Act concerning Support and Service for Persons with Certain Functional Impairments [15] regulates the possibility for a person affected by a disease to get support in daily life. A person who has a neurodegenerative disease that affects his or her ability to manage activities related to basic daily needs has the right to be supported by personal assistants at home. The extent and type of support and care given is regulated by the law in relation to the person's needs and is assessed individually. When a family member receives assistance and care at home, the demands on the other family members may decrease. However, having other people than family members and friends at home may also intrude on the family's and the child's private life.

There is limited scientific documentation and a need for increased knowledge about the life situation of children in families affected by a neurodegenerative disease [16, 17]. Recognizing

the situation of the people around the patient is relevant [18] and the children's views are important for the development of policy and intervention [19]. On behalf of the National Board of Health and Welfare and in collaboration with the Swedish Family Care Competence Centre, a project aimed at surveying the health and well-being of children and adolescents who have a parent with a neurodegenerative disease was carried out. The perceptions of younger children and adolescents as well as of parents with and without a neurodegenerative disease were examined and used to formulate a model of how public and private networks and non-profit organizations could support the individual child and family [20].

The present study had the above-mentioned project as its starting point but deepened the analysis and concentrated on the impact of the disease on the children's everyday life. A child centred perspective is held throughout and the purpose of the study is to explore the views of both the children and the parents, of how a neurodegenerative disease in a parent influences the daily life of the child. The perceptions of the children and the parents are discussed with regard to the children's rights and needs. Implications for rehabilitation, family support and care of a parent at home are also discussed.

2. Method

2.1. Participants

The families were recruited during the summer and autumn of 2013. The recruitment was conducted by doctors, counsellors and nurses at hospitals and centres for persons with neurodegenerative diseases. Patient organizations were also involved in the recruitment. A convenient sample of nine families affected by Parkinson's disease, MS and Huntington's disease participated in the project. In total, there were 23 participants; 10 children, 6 parents with a neurodegenerative disease and 7 parents without a neurodegenerative disease. Three of the families were represented with all family members. Three families were represented with all children and one parent. Two of the families were represented by one parent but no children. In one family, both parents and one of three children participated.

The participants' age and gender (**Table 1**) were: (a) four younger children, aged 8–11 years, two boys and two girls, (b) six adolescents, aged 13–16 years, four girls and two boys, (c) six parents with a neurodegenerative disease, four mothers (aged 42–51 years) and two fathers

Participants	Boys Fathers	Girls Mothers
Children, aged 8–11 years	2	2
Children, aged 13–16 years	2	4
Parents with a neurodegenerative disease, aged 42–51 years	2	4
Parents without a neurodegenerative disease, aged 37–54 years	4	3

Table 1. Description of the participants.

(aged 42 and 45 years) and (d) seven parents without a neurodegenerative disease, three mothers (aged 37–54 years) and four fathers (aged 41–49 years).

2.2. Data collection

Children and parents with and without a neurodegenerative disease were interviewed by two researchers (first and fourth authors). The interviews were based on an interview guide with predetermined themes, directly related to the purpose of the project. The themes concerned the children's everyday life situation. The interviews were conducted as five focus groups [21, 22], and the composition of the groups was based on the assumption that people with similar experiences inspire each other in a conversation. In this study, the similarities of experiences concerned experiences of being in a specific age as a child, to have a neurodegenerative disease and to be a partner to a person with a neurodegenerative disease. Accordingly, the groups were as follows: (a) younger children (8–11 years), (b) adolescents (13–16 years), (c) parents with a neurodegenerative disease to younger children and adolescents, (d) parents without a neurodegenerative disease to younger children and (e) parents without a neurodegenerative disease to adolescents.

No participant was excluded due to problems with communication, but one of the participants was interviewed individually using Talking Mats [23] due to communication difficulties. Talking Mats helps people with cognitive and communicative difficulties to express their opinions and has been used by people who have Parkinson's disease and Huntington's disease [24, 25]. The person who used Talking Mats also participated in the focus group. The interviews with Talking Mats were conducted towards the end of each focus group session by one of the interviewers who is certified in using Talking Mats with people with disability. The interviews took place in another room than the focus groups and the purpose was to give the participant an extra chance to tell his/her views. The subject areas in the Talking Mats interviews were the same as in the focus groups but simplified and presented with visual support.

Each focus group met twice over a period of 4 weeks. After each session, the researchers talked about their experiences and about issues to bring up during the second focus group session. Each session was allocated to 3 hours, starting with refreshments and socializing. The average time for each session was 1:23:18 (hours:minutes:seconds), ranging from 1:03:52 to 1:36:20. The duration of the interviews with Talking Mats was 21 min and 58 s and 18 min and 53 s, respectively.

An interview guide including the following nine subject areas was used to stimulate discussion in each focus group: (a) the disease, (b) mental and physical health, (c) home, (d) school, (e) leisure time, (f) social network, (g) peers, (h) communication and (i) support functions. The interviewers (researchers) took turns being the main and the more passive leader in the focus groups. Both interviewers made sure that all participants had a voice in the group. The more passive leader made sure issues were followed up. In the first session, a whiteboard was used to summarize factors identified by the participants as different when a parent has a neurodegenerative disease. The same interviewer, in collaboration with the participants, wrote on the whiteboard in all focus groups. The participants had the last say regarding the views and

summary written on the board. All of the factors were reviewed and revised where necessary, i.e. a member check provided a possibility for the participants to correct data.

The participants were encouraged to discuss the subject areas in relation to the past, present and future time and it was the child that was of main concern. This meant that the younger children and adolescents talked about their own feelings and experiences and the parents talked about their views about the children's situation, i.e. the perspective was child centred [26, 27]. The children's feelings and dreams were discussed, as were theirs and the parents' thoughts about barriers and factors facilitating health, development and well-being. The younger children were asked to use crayons and paper to draw communication aids that they thought would make it easier for the parents with communication difficulties [28]. The drawings, and how the aids could support the communication, were discussed in the children's focus groups.

The focus group sessions were recorded with a digital voice recorder and a camera. The data on the whiteboard, and the children's drawings, were photographed. The Talking Mats interviews were recorded with a smartphone, and the mats were photographed. These photograph data were reviewed in the analysis.

One of the interviewers, a clinical psychologist, had follow-up telephone contact with all of the participants on two separate occasions. The purpose of the phone calls was to follow up the participants' emotional reactions to the focus groups. It was also an opportunity for the participants to ask questions. Data from the phone calls were not included in the analysis. The first call was made within 1 month after the focus groups and the second contact was taken after another 3–4 months. Ten months after the last focus group session was conducted the participants were invited to a meeting at which the study results were presented. The meeting was also an opportunity for the participants to express their views about the results.

2.3. Data analysis and presentation of findings

All recorded interview data were transcribed verbatim, and all drawings were saved as digital photos. The Talking Mats interviews were both audio recorded and saved as digital photos. All of the collected data became a unit of analysis according to the methodology of qualitative content analysis [29]. Each researcher individually chose meaning units from the unit of analysis, and coded and analysed these into subcategories. The subcategories were further analysed into categories. The researchers discussed their codes, subcategories and categories until consensus was reached in each step of the analysis. The analysis fulfilled the requirement of dependability and credibility because the researchers checked each other's analysis. The results were compared with the original data in each level of the abstraction to guarantee that trustworthiness was achieved [30]. In the results, categories related to the impact of the neurodegenerative disease on the children's daily life are treated. All main categories and subcategories are presented in Appendices 1 and 2.

2.4. Ethical considerations

The study was vetted and approved by the regional ethical review board. The voluntary nature of the study, as well as the right to withdraw from the study at any time without

explanation and personal consequences, was highlighted. Written and oral information was provided to all of the participants. All participants gave their oral assent to participate. The adults gave their written consent. Written consent for the children's participation in the study was given by their parents.

3. Results

The children's and parents' perceptions of the children's health and well-being were condensed into nine categories of which two—*Consequences in daily life* and *Influence of disease on children*—concerned the direct effects of the parent's disease on the children's daily life (Appendices 1 and 2). These were further explored. Ten subcategories of which three were common between the children and the parents (*Economy*, *Responsibility* and *Living with personal assistants*), three were unique for the children (*Being and feeling*, *Being different* and *Activities*) and one was unique for the parents (*The symptoms of the disease*) emerged. The ideas shared in all focus groups concerned the children; the children's own experiences and views and the parents' thoughts about the children's experiences and views. We will refer to younger children and adolescents as well as parents with and without a disease. The word 'children' alone, from here onwards, refers to both younger children and adolescents.

3.1. Economy

Both the children and the parents talk about the family's economy as a problem.

and we cannot afford to buy because we are one that provides for the family (parent without disease)

They cannot give the child the kind of things that other children get.

to feel that one may not have the same possibility to do these things that all the others can participate in and do (parent with disease)

The adolescents think of their family's economy as worse than the economy of other families and have experienced difficult times with regard to money.

when dad became ill then there was like I hardly had any clothes I had to use the same pair of jeans for three years (adolescent)

To lay aside money for travelling is difficult for the parent without disease. This means the children cannot see relatives and friends as often as they would like to and need. Economy is a sensitive issue and in order to avoid putting an extra burden on the parents the children work and earn their own money. One adolescent works for the parent who is ill.

one like feels a bit ashamed asking for money or anything (adolescent)

3.2. Responsibility

The parents believe that their children have larger responsibilities than children in families that are not affected by a neurodegenerative disease. The responsibilities relate to practical

duties but also imply that the children have to manage on their own in life situations where a parent, under other circumstances, would have been present. The children talk about having responsibilities for daily routines at home.

it meant I had to become more responsible at a young age (adolescent)

I am like ready to become a dad at age sixteen (adolescent)

Some have adult-like responsibilities for siblings without any real possibility to object.

not like that I could just ignore my little sister (adolescent)

Responsibility with regard to siblings is also talked about as something positive, leading to closer relationships within the family. Having large responsibilities as a child may affect the possibility to do child things, like playing.

I wasn't the kind that played a lot (adolescent)

Both the younger children and the adolescents talk about the burden of being responsible for telling others about the disease and give each other advice about how and whom to tell. One adolescent tried to get her parent to tell her friend about the disease. She arranged for this to happen naturally at a time when the parent usually took the medicine and was very disappointed when the parent hid the intake of the medicine by going in to the toilet.

so I tried to like get her to like tell but she like went to the toilet so that was also so oh no like why did you go to the toilet (adolescent)

The children are well aware of the changed parental roles and the greater demands on the parent without the disease.

dad has done a lot of things too one could say that he also has had a bit of the role of a mother (adolescent)

The children are concerned about easing the pressure on the parent who is not ill so that he or she remains healthy. Their concern is relevant.

because they know how mum is that she is ill and like that it is understandable that they nothing should happen to me (parent without disease)

Some of the parents without the neurodegenerative disease have been affected by other diseases.

now my mother is also ill (adolescent)

3.3. Living with personal assistants

Some parents have personal assistants by their side 7 days a week. This means that the child has to spend a considerable amount of time together with people that he or she has not chosen to be with. Having people at home almost all of the awake time is demanding and the issue was discussed in all focus groups.

since dad is sick we have assistants in our home who subs ... who do everything that dad should have done sometimes I think this is quite demanding (younger child)

The child needs to be aware, check where in the apartment or house the assistants are, and protect themselves by, for example, locking doors.

but really one is never alone (adolescent)

it is like difficult if one wants to take a shower or something like that and walks into the bathroom one always has to lock or something like that because one doesn't want them to come rushing into the room and like do things (younger child)

The children are also disturbed at night.

sort of very late at night when I am trying to fall asleep then the home care service comes and like wakes me up (younger child)

I have to try to fall asleep again when one is like sleeping deeply (younger child)

According to one of the parents, having personal assistants at home is the most difficult part of the disease.

but it (the presence of personal assistants) is actually the toughest of it all (parent without disease)

Having personal assistants at home influences the child's sense of being able to be and act as 'oneself', as well as the possibility to be alone. The size of the apartment or house is important as well as guidelines regulating where in the home the assistants are allowed to be. A small home makes the situation even more difficult and having space and areas where only family members are allowed is perceived as valuable.

so one can never avoid them we have the kitchen together and we have some parts of the house together of course they think it (i.e., the personal assistants) is a lot sometimes (parent without disease)

The fact that the family is involved in planning the assistance and the guidelines for its implementation, i.e. what the personal assistants should do and where they should be, is good but does not solve problems related to personal integrity. Having people at home, strangers from the beginning, who are paid to be there, triggers conventions about how to behave and makes the child feel uncomfortable.

to always be polite and not... like to never be able to just be in a bad mood and think that life is crappy but that you have to be polite to these people who are sitting in the kitchen smiling and being so nice (adolescent)

The personality of the assistant is important.

they think a lot about which (assistant) is good or bad (parent with disease)

The assistant should respect the family and know what to do and not to do with the child and the parent who is ill. The children use words such as compliance and natural when they describe the personality traits of a good assistant.

she knows when to leave she knows she is so nice and bloody good (adolescent)

she is so natural with us it is not like if she is like not like if she is employed (adolescent)

The way the assistants talk with the children about their presence in the children's home is also relevant and can make a big difference.

all the others talk about being staff and things like that but she (a "good" assistant) doesn't (adolescent)

It is unnatural when an assistant takes the role of a parent but at the same time the assistant needs to be updated about the child's activities. The assistant needs to be able to talk with the parent about where the child is without having to call and ask the child. Frequent phone calls from the assistants can be annoying, especially if the child already has informed the parents and the assistant about his or her activities after school.

as soon as we are not at home they call (adolescent)

also we have a calendar on which we write the whole week like that but they don't look there (adolescent)

Both the children and the parents talk about how the assistants manage communication. The assistants could support the interaction between the child and the parent who is ill but often they do not. Rather, the children's stories indicate that some assistants have difficulties in understanding the speech of the person they work with, i.e. the parent with the disease, and lack knowledge about strategies that would support the communication. The child is sometimes more competent than the assistants in understanding the parent.

really I think that we perhaps are a bit better at understanding than them (younger child)

The assistants' communicative style may also be burdensome for the child.

they start talking like this ... they sort of become a bit loud sometimes ... okay it is not like if they are screaming but they talk loud (younger child)

The children understand the parent's need for assistance.

the assistants have to be there she cannot sit by herself (adolescent)

Administering assistance takes a lot of time and energy for the family and the children get tired by the fact that there is so much talk about care at home. This is particularly so when family members, for example grandparents, work as assistants as well.

I said that to dad at my birthday that today you are not allowed to talk about the assistants at all (adolescent)

Spending time with family members only is appreciated.

those weekends you just long for (adolescent)

3.4. Being and feeling

The adolescents have many thoughts and feelings about the disease and describe symptoms of psychological unhealthiness.

I was depressed from thirteen to fifteen (adolescent)

so when I was twelve I thought about suicide (adolescent)

The younger children are also affected psychologically.

one gets a bit worried about dad (younger child)

3.5. Being different

A parent with a neurodegenerative disease is different. This makes the child different too. Not knowing anyone else who has a parent with a disease contributes to the feeling of being different.

I don't know anyone that lives that close like me who has a parent who is ill who has a disease (younger child)

Aids are evident outward signs that make the parent and the family look different and strange.

in the beginning when mum started to use a walker we should walk in town with mum on our own then I was a child and I thought she was embarrassing (adolescent)

Bringing friends home from school is difficult. The adapted home environment is a barrier.

in case I bring someone home... and our toilet is quite strange (younger child)

The children do not like the way other people observe and speculate about the parent who is ill.

one of our friends Berra he like stands there and looks at him for a few seconds (younger child)

A story about a parent leaving home in an ambulance is an example of how speculations can lead to rumours and affect the child negatively.

then some of our neighbours said the police got him and put him behind bars (adolescents)

3.6. Activities

Physical, psychological and psychiatric symptoms hinder the parent with the disease from participating in activities in the way the children would like.

but like he can't swim with me and do things (younger child)

she just sits there at home for the whole day (adolescent)

Activities with friends at home are also affected.

then dad becomes a bit angry when one like plays in the living room (younger child)

Family activities and holidays need to be planned in detail and yet everything could change in the last minute, like in this story about going to the swimming hall.

the MS was more difficult than usually the day we were going so we couldn't go (younger child)

3.7. The symptoms of the disease

The parents without the disease talk about how different symptoms such as tiredness, anxiety, aggression and lack of empathy in the parent with the disease affect the children. Psychiatric problems are the most challenging to manage.

it is when she is not feeling well psychologically and anxiety and things like that when that comes it of course... now she has good medicines so things are working better ... I don't know if they think the physical really is hindering (parent without disease)

Knowledge about the symptoms of the disease increases the children's understanding and gives them a possibility to gain control. The children get the knowledge from their parents. Yet, the parents are unsure about how much to tell.

my parents think it is awful they think we have been too open about it (parent without disease)

why should I talk about it with her make her worried I could feel (parent with disease)

4. Discussion and implications

The results are in line with existing research suggesting that a neurodegenerative disease in a parent affects the family and the children in particular [5, 10–13, 31, 32]. It is difficult to separate the needs of the children from the needs of other family members [33]. According to the parents and the children in this study, a parent's disease has a large impact on the everyday life of the child. Children are affected emotionally and psychologically with regard to practical issues and the fulfilment of basic needs.

One of the most obvious effects of a parent's disease on the child concerns the parent's need for support and care at home. The child is affected by the support their parent gets from people coming to their home. At the same time, as the present results also show, the families need this and other kinds of support. From a child perspective, paid external support such as personal assistance for a parent who is ill is both relieving and complicating. There is an evident conflict between the child's rights for well-being and privacy at home on the one hand and the needs and rights of the parent with the disease for high quality care on the other hand. The picture is that of a scalepan with external support in one of the bowls and the child's integrity in the other. Reaching a balance seems to be difficult. The aim of assistance is to support the person who is ill so that good health and living conditions are ensured [15]. This goal seems to be fulfilled, which could be relieving for the children who worry about both the parent who is ill and the parent without the disease. There is no evidence in the present data of children giving care by, for example, dressing or taking the parent who is ill to the toilet. Thus, it can be assumed that the support offered by the assistants is sufficient and prevents the children from becoming carers [14]. Well-functioning assistance for the parent who is ill also means reduced demands on the healthy parent and thus is positive for the child from this perspective as well. The responsibilities of the participating children, which are considerable according to the parents and the children, concern other issues such as having to do more practical work at home than is reasonable for a child, caring for siblings, worrying and being on their own in situations where a parent could have been involved.

Home is a central arena for the child's forming of identity and development, and therefore needs to be protected [1, 2]. A most noteworthy observation in this study concerns the lack of privacy for the children at home and the physical and mental space occupied by the disease. The children need free zones and the possibility to choose to be on their own and behave as

they wish, without having to conform to social rules and etiquette. These children are under emotional pressure and show signs of unhealthiness. Having strangers around in the house and being woken up during the night, because of a parent's need for care, not only reflects lack of privacy but is a threat to the child's health. A calm and safe environment with well-known people, during the day and the night, is a right of the child. The institutionalization of the home, which becomes a combination of hospital and work place, also seems to be difficult to handle for the child but is good for the parent who does not have to move away to get care. It is not only the size of the house and the fact that there is little room to be on one's own or to play with friends that matter but also being surrounded with people who are at work, different instruments, aids and environmental adaptations. Some assistants, more than others, make the children understand that assistants are not a part of the family. This is redundant information for the child who may prefer when assistants behave as if they were members of the family, albeit with respect for the integrity of the child. Put differently, the child does not have to be reminded about the parent's disease but rather needs supportive adults. That home turns into a work place is evident also with regard to the administration and implementation of care on behalf of the parent without the disease and other relatives. Some parents and grandparents are part time employed for the parent who is ill. Thus, there may be a mess of roles and relations for the child at home.

Developing and maintaining a relationship with a parent who has a progressive neurological disease and deteriorating psychological and communicative functions is important but difficult for the child. Maintaining a relationship with the child is also a right of the parent, but difficult because of the disease. Other adults play a beneficial role in this regard. The parent and the child may need support to plan activities to do together. Economical support could also be valuable for a family where one parent has a neurodegenerative disease. To reduce stress on both the parent and the child, the parent with the disease needs to be updated about the child's activities. The parent will be content knowing where the child is and the child will not be disturbed by frequent phone calls from home, as was the case for one of the children in this study. Supporting communication is an issue along the same line. The children are negatively affected by the parents' deteriorating ability to communicate and by how communication is managed by others. The parents may have difficulties speaking as well as understanding when other people speak. The children often understand their parents better than other people and feel uncomfortable by the way others talk with their parents. They also may get the role of interpreter, at home and in society. This is a heavy duty and not in line with their rights [1, 2].

Working in the home and giving care to a parent with a neurodegenerative disease is difficult [34]. Specific education about the disease and different ways to support communication is important [35, 36]. Carers and health professionals also need to be aware of the fact that the person they work with is a parent with needs and obligations towards a child. Educated people in the child's network could support the child's health and well-being. For example, by informing people around the child about the disease, the kind of observations and rumours spread by other people, as reported of by the children in this study, could be avoided. It should not be the responsibility of the child to inform others about the disease and specific symptoms. There is also a need for the children to learn more about the disease, how it can

fluctuate and how it will proceed. Increased knowledge about the disease and its sometimes unpredictable nature will increase the child's understanding of the parent's mood, activity level and behaviours and, as a result, his/her quality of life at home.

A child centred perspective will facilitate the child's well-being and development and implies listening to the wishes and needs of the child. These children are thoughtful and accommodative regarding their parents' needs. They understand and accept the situation, also because there is not much else for them to do. They carry out daily household tasks, care for siblings and work to earn their own money. Unnecessary burden on them should be avoided and they should not have to weigh their own needs against their parents'. Rather, adults in charge of the care need to consider how care can be given to the parent in a way that is minimally intrusive for the child. Taking the children's needs into account means asking them [27], given that their parent is ill, how would they like to organize their life at home? What is important for them in daily life? By asking the children about their situation and experiences, it will be possible to make life good for them at home and at the same time provide care for the parent.

Overall, the present findings point to the fact that children of families affected by a neurodegenerative disease need different kinds of support. Allowing the parent who is ill to attend a day care centre or a care home over the weekend, now and then, would give the child a temporary pause from the disease. Speech and language pathologists, social workers, psychologists and family nurses are other professionals, apart from personal assistants, who play important roles for the parent's rehabilitation as well as for the child and the family [37, 38].

5. Reflections about the study

Listening to the feelings and views of the children and the parents is important [19], and the present study is unique in involving children of different ages as well as parents with and without a disease. Children are not always willing to talk about their situation [19]. Both the children and the parents in this study expressed satisfaction about their participation in the larger project and 10 of the 23 participants came to the 10 months follow-up meeting. The meeting was an opportunity for the participants to get together with some of the other families and to reflect upon and give feedback on the findings and thus strengthened the credibility of the study. The participants attending the meeting agreed with and recognized the results as their own or the other focus group participants' views. The role of the health care system in supporting the children was discussed at the meeting, as was the important function of patient organizations.

Graneheim and Lundman [30] define transferability as the knowledge about whether the results can be transferred to other groups. This study describes the experiences of families living in Sweden and several of the participating families were recruited from patient-related non-profit organizations. Thus, there is a risk that the results are not transferable. However, the findings are in line with existing research [8–10] suggesting that the categories can be transferred to other families in western countries affected by a neurodegenerative disease. Furthermore, the findings should be treated in light of the fact that some of the families were

known by the interviewers who also were experienced in talking with families living with progressive neurological conditions. Background knowledge may strengthen an interviewer’s ability to ask relevant questions and to support the conversation in a group but may also make the interviewer to steer the conversation according to own interests and preferences.

6. Conclusions

A parent’s disease has an impact on the individual child who is affected emotionally and psychologically, with regard to practical issues, and with regard to the fulfilment of basic needs. For example, the need for care of the parent at home creates a conflict between the child’s rights for well-being and privacy and the needs and rights of the parent with the disease for good care. The presence of a personal assistant will influence the child’s need for privacy, sometimes up to 24 hours a day. However, the assistant is also a valuable and necessary support for the family and the parent who is ill and prevents the child from becoming a young carer. The negative impacts also concern the child’s lack of knowledge about the disease and economy. Professionals involved in the care and rehabilitation need thorough education and training in general care as well as in the symptoms, characteristics and consequences of specific diseases. In such training, the children’s situation should be a focus area. Research involving more families as well as studies focusing the experiences of health care professionals and others in society supporting these families are needed in order to plan and carry out meaningful education and training programs.

Appendices

Main categories	Subcategories
The disease	How the disease is noticed
	Knowledge about the disease
	Heredity
	The progression of the disease
	Medicine
Consequences in daily life	Being and feeling
	Being different
	Economy
	Activities
	Responsibility
	Personal assistants

Main categories	Subcategories
Social relations	Close family
	Close family network
	Future relations
To cope with the situation	Accepting the situation
	Adjusting own behaviour
	Practical support
	To get knowledge about the disease
	Talking with someone
	Meeting people who are in a similar situation
	The role and function of school
	Communication aids and strategies

Appendix 1. Younger children's and adolescents' perceptions of health and well-being.

Main categories	Subcategories
Influence of disease on children in daily life	The symptoms of the disease
	The presence of the assistants
	Responsibility for domestic activities
	The family's economy
Interaction	Activities for the parent with the disease and the children
	The parent with the disease needs support to communicate
	Relations within the family
The role of the parents	The parents' roles change as a result of the disease
	Caring about the children's present and future life
Network	Friends
	Organizations
	School
	Health care and nursing
Being and feeling	Psychological and physical unhealthiness
	Thoughts about the disease
	Physical activity

Appendix 2. Perceptions of the children's health and well-being by parents with and without a neurodegenerative disease.

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References

- [1] Hall D. Children, rights, and responsibilities. *Archives of Disease in Childhood*. 2005;**90**:171-173. DOI: 10.1136/ad.2004.053017
- [2] United Nations. Convention on the rights of the child document. 1989-1990. A/RES/44/25. Available from: www.ohchr.org/en/professionalinterest/pages/crc.aspx [Accessed: 27 January 2017]
- [3] Socialstyrelsen [The National Board of Health and Welfare]. Barn som anhöriga. Konsekvenser och behov när föräldrar har allvarliga svårigheter eller avlider [Children as relatives. Consequences and needs when parents have serious difficulties or die]. 2013. Available from: www.socialstyrelsen.se/publikationer2013/2013-6-6 [Accessed: 27 January 2017]
- [4] Storm Mowatt Haugland B, Ytterhus B, Dyregrov K. Barn som pårorende [Children as Relatives]. Oslo, Norway: Abstrakt förlag; 2012
- [5] Schrag A, Morley D, Quinn N, Jahanshahi M. Impact of Parkinson's disease on patients' adolescent and adult children. *Parkinsonism and Related Disorders*. 2004;**10**:391-397. DOI: 10.1016/j.parkreldis.2004.03.011
- [6] Jahanshahi M, Sheikh S. Long-term neurological illness in parents has a substantial impact on the lives of children. *British Journal of Neuroscience Nursing*. 2007;**3**:246-252. DOI: <http://dx.doi.org/10.12968/bjnn.2007.3.6.23708>
- [7] Rintell D, Melito R. "Her illness is a project we can work on together": Developing a collaborative family-centered intervention model for newly diagnosed multiple sclerosis. *International Journal of MS Care*. 2013;**15**:130-136. DOI: 10.7224/1537-2073.2012-022

- [8] Diareme S, Tsiantis J, Kolaitis G, Ferentinos S, Tsalamaniotis E, Paliokosta E, Romer G. Emotional and behavioural difficulties in children of parents with multiple sclerosis: A controlled study in Greece. *European Child & Adolescent Psychiatry*. 2006;**15**:309-318. DOI: 10.1007/s00787-006-0534-7
- [9] Steck B, Amsler F, Grether A, Dillier AS, Baldus C, Haagen M, Romer G. Mental health problems in children of somatically ill parents, e.g. multiple sclerosis. *European Child and Adolescent Psychiatry*. 2007;**16**:199-207. DOI: 10.1007/s00787-006-0589-5
- [10] Bogosian A, Moss-Morris R, Hadwin J. Psychosocial adjustment in children and adolescents with a parent with multiple sclerosis: A systematic review. *Clinical Rehabilitation*. 2010;**24**:789-801. DOI: 10.1177/0269215510367982
- [11] Forrest Keenan K, Miedzybrodzka Z, van Teijlingen E, McKee L, Simpson SA. Young people's experiences of growing up in a family affected by Huntington's disease. *Clinical Genetics*. 2007;**71**:120-129. DOI: 10.1111/j.1399-0004.2006.00702.x
- [12] Sparbel KJ, Driessnack M, Williams JK, Schutte DL, Tripp-Reimer T, McGonigal-Kenney M, Paulsen JS. Experiences of teens living in the shadow of Huntington Disease. *Journal of Genetic Counseling*. 2008;**17**:327-335. DOI: 10.1007/s10897-008-9151-6
- [13] Williams JK, Ayres L, Specht J, Sparbel K, Klimek ML. Caregiving by teens for family members with Huntington disease. *Journal of Family Nursing*. 2009;**15**:273-294. DOI: 10.1177/1074840709337126
- [14] Nordenfors M, Melander C, Daneback K. Unga omsorgsgivare - en kartläggning av ungdomar som ger stöd, vård och hjälp till en nära anhörig [Young carers—A survey of adolescents who support and give care to a close relative]. Nationellt kompetenscentrum anhöriga, Barn som anhöriga [The Family Care Competence Centre, Children as Relatives]. Kalmar, Sweden; 2014. Available from: http://www.anhoriga.se/Global/BSA/Dokument/Rapporter_kunskaps%c3%b6versikter/Nka_BSA_Rapport_2014-5_webb.pdf [Accessed: 28 January 2017]
- [15] Swedish Code of Statutes. Act concerning support and service for persons with certain functional impairments. SFS 1993:387. S 1993. Available from: <http://www.independentliving.org/docs3/englss.html> [Accessed: 27 January 2017]
- [16] Morley D, Selai C, Schrag A, Jahanshahi M, Thompson A. Adolescent and adult children of parents with Parkinson's disease: Incorporating their needs in clinical guidelines. *Parkinson's Disease*. 2011;**2011**:951874. DOI: 10.4061/2011/951874
- [17] Morley D, Jenkinson C. Furthering our understanding of the needs of adolescent children of parents with Parkinson's disease. *Adolescent Health, Medicine and Therapeutics*. 2013;**29**:75-77. DOI: 10.2147/AHMT.S47878
- [18] Bhimani R. Understanding the burden on caregivers of people with Parkinson's: A scoping review of the literature. *Rehabilitation Research and Practice*. 2014; Article ID 718527:1-8. DOI: 10.1155/2014/718527

- [19] Aldridge J. All work and no play? Understanding the needs of children with caring responsibilities. *Children and Society*. 2008;**22**:253-264. DOI: 10.1111/j.1099-0860.2007.00094.x
- [20] Ferm U, Jenholt Nolbris M, Jonsson A, Linnsand P, Nilsson S. Hälsa och välbefinnande hos barn och ungdomar som har en förälder med progredierande neurologisk sjukdom [Health and well-being in children and adolescents who have a parent with a progressive neurological disease]. Nationellt kompetenscentrum anhöriga, Barn som anhöriga [The Family Care Competence Centre, Children as Relatives]. Kalmar, Sweden; 2015. Available from: http://www.anhoriga.se/Global/BSA/Dokument/Rapporter_kunskaps%c3%b6versikter/BSA-rapport_2015-2.pdf [Accessed: 28 January 2017]
- [21] Creswell J W. *Qualitative Inquiry & Research Design*. 3rd ed. Thousand Oaks, CA, USA: SAGE Publications; 2013. p. 472. ISBN: 9781412995306
- [22] Wibeck V. *Fokusgrupper: Om fokuserade gruppintervjuer som undersökningsmetod* [Focus Groups: About Focused Group Interviews as a Method]. Lund, Sweden: Studentlitteratur; 2010. 178 p. ISBN 10: 914405856X
- [23] Cameron L, Murphy J. Obtaining consent to participate in research: The issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*. 2007;**36**:113-120. DOI: 10.1111/j.1468-3156.2006.00404
- [24] Ferm U, Bloch S, Saldert S. Negotiating disagreement in picture symbol supported decision making. *Journal of Interactional Research in Communication Disorders*. 2015;**6**:131-156. DOI: 10.1558/jircd.v7i1.27534
- [25] Ferm U, Sahlin A, Sundin L, Hartelius L. Using Talking Mats to support communication in persons with Huntington's disease. *International Journal of Language and Communication Disorders*. 2010;**45**:523-536. DOI: 10.3109/13682820903222809
- [26] Coyne I, Hallström I, Söderbäck M. Reframing the focus from a family-centred to a child-centred care approach for children's healthcare. *Journal of Child Health Care*. 2016;**20**:494-502. DOI: 10.1177/1367493516642744
- [27] Nilsson S, Bjorkman B, Almqvist A L, Almqvist L, Björk-Willén P, Donohue D, Hvit S. Children's voices—Differentiating a child perspective from a child's perspective. *Developmental Neurorehabilitation*. 2015;**18**:162-168. DOI: 10.3109/17518423.2013.801529
- [28] Druin A. Children as codesigners of new technologies: Valuing the imagination to transform what is possible. *New Directions for Youth Development*. 2010;**2010**:35-43. DOI: 10.1002/yd.373
- [29] Elo S, Kyngas H. The qualitative content analysis process. *Journal of Advanced Nursing*. 2008;**62**:107-115. DOI: 10.1111/j.1365-2648.2007.04569.x
- [30] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*. 2004;**24**: 105-112. DOI: 10.1016/j.nedt.2003.10.001

- [31] Bogosian A, Moss-Morris R, Bishop F, Hadwin J. How do adolescents adjust to their parent's multiple sclerosis? An interview study. *British Journal of Health Psychology*. 2011;**16**:430-444. DOI: 10.1348/135910710X521492
- [32] Williams JK, Driessnack M, Barnette JJ, Sparbel KJ, Leserman A, Thompson S, Paulsen JS. Strategies used by teens growing up in families with Huntington disease. *Journal of Pediatric Nursing*. 2013;**28**:464-469. DOI: 10.1016/j.pedn.2013.02.030
- [33] Wihstutz A. Working vulnerability: Agency of caring children and children's rights. *Childhood*. 2011;**18**:447-459. DOI: 10.1177/0907568210394878
- [34] Borreani C, Bianchi E, Pietrolongo E, Rossi I, Cilia S, Giuntoli M, Pe N. Unmet needs of people with severe multiple sclerosis and their carers: Qualitative findings for a home-based intervention. *PLoS One*. 2014;**9**:e109679. DOI: 10.1371/journal.pone.0109679
- [35] Morris MA, Dudgeon BJ, Yorkston K. A qualitative study of adult AAC users' experiences communicating with medical providers. *Disability and Rehabilitation: Assistive Technology*. 2013;**8**:472-481. DOI: 10.3109/17483107.2012.746398
- [36] Ghafari S, Khoshknab MF, Norouzi K, Mohamadi E. Spousal support as experienced by people with multiple sclerosis: A qualitative study. *The Journal of Neuroscience Nursing*. 2014;**46**:E15-24. DOI: 10.1097/JNN.0000000000000081
- [37] Bell JM. Knowledge translation in family nursing: gazing into the promised land. *Journal of Family Nursing*. 2014;**20**:3-12. DOI: 10.1177/1074840714521731
- [38] Benzein EG, Hagberg M, Saveman BI. 'Being appropriately unusual': A challenge for nurses in health-promoting conversations with families. *Nursing Inquiry*. 2008;**15**:106-115. DOI: 10.1111/j.1440-1800.2008.00401.x

