

Caregiver roles in families affected by Huntington's disease: a qualitative interview study

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Aim: The objective of this study was to explore family caregivers' experiences with the impact of Huntington's disease (HD) on the family structure and roles in the family.

Methodology: We interviewed 15 family caregivers in families affected by HD, based on a semi-structured interview guide. The participants were recruited through hospital departments and a lay organisation for HD in Norway. Data from the interviews were analysed with systematic text condensation.

Results: Huntington's disease could have a substantial impact on the family system, the shape of roles among family members and the hierarchical order between spouses, partners, and parents and children. The relationship between spouses and partners changed during the course of the disease. A reciprocal relationship was

difficult to maintain, as the role as carer overshadowed other roles. Children of an affected parent could compensate for impairments by taking on adult responsibilities, and in some families, a child had the role as main caregiver. The increasing need for care could cause conflicts between the role as family member and family caregiver. The burden of care within the family could fragment and isolate the family.

Conclusions: Huntington's disease has a major impact on family systems. Caregiver roles are shaped by impairments in the affected family member and corresponding dynamic adoption and change in roles within the family. Making assessments of the family structure and roles, professionals may understand more about how to care for and support individuals in their role as family members and caregivers in different stages of the disease and family life cycle.

Keywords: caregiver role, family caregiver, family dynamics, Huntington's disease, chronic disease.

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Introduction

Huntington's disease (HD) is an autosomal dominant neurodegenerative disease with a prevalence of 5–10 per 100,000 (1). A child of a gene carrier has a 50% risk of inheriting the HD gene. The clinical symptoms usually start when the carrier is 35–55 years, but there is significant variation in age of onset. The disease develops in five stages over decades, and symptoms appear as characteristic involuntary movements, behavioural changes and decrease in cognitive function. At present, there is no cure for HD, but much can be performed to alleviate

symptoms (1). HD causes increasing impairments and need for care. Patients will often be in a long-term nursing home in the latest stage of the disease, but relatives and family members have important roles as family caregivers in earlier stages.

Huntington's disease affects families in several ways. As the afflicted family member gradually loses functions, the conditions for family life change with concerns for the future, and an allocation of daily tasks between family members. When caregivers learn that HD is a hereditary condition, the question of children being at risk will arise. The diagnosis may thus serve as an explanation for a spouse, parent or grandparent's strange behaviour, but also represents new challenges for the future.

During the different phases of HD, family caregivers in affected families experience practical care burdens, decreased social contact, financial problems and psychosocial challenges (2–4). The need for health services of

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family caregivers in families affected by HD seems to differ from the needs of caregivers to patients with other severe progressive diseases, such as multiple sclerosis and Parkinson's disease (5). The differences are related to lower quality of life, a complexity of genetic questions and lack of knowledge about HD in the society and in the health services (6, 7). The role as family caregiver unfolds in the family as complementary to role as family member. According to the role theory, a person might experience being overloaded by expectations of too many roles at the same time. An individual might experience role conflicts when roles are difficult to combine or fulfil (8, 9).

Family system theory can be relevant for understanding family aspects of HD. Wright & Leahey (10) have developed a theoretical model or concept for assessment, intervention and care in families with chronic diseases. The model is based on system theories, conceptualising the family unit as a system, in perpetual change. A family unit is composed by the persons who feel socially related to each other, not necessarily biologically. Family constellations may change over time, but the role of family caregiver still unfolds within the unit, and it may be explored using perspectives from family theory.

A family system consists of a small group of inter-related and interdependent elements and is characterised by hierarchies, subsystems and boundaries (10–12). Boundaries might be helpful for a family unit in its protection of values and community; at the same time, there is need of a certain permeability as a corrective and stimulation in the unit's communication with the environment. A traditional family unit may go through a life cycle that develops in stages with characteristic events such as childhood, adolescences, adults leaving home, time to retire and for some grandchildren. Family members continuously interact in relational bonds that represent subsystems, such as the relation between mother and child, the relation between siblings or the relation between spouses. To maintain balance in the process of family life, roles are adjusted when a family system face challenges (10), and one family member's illness may thus have an impact on the whole family system. Family life develops in phases and the dynamics in the family system shapes and regulates family members' expectations to their different role functions. A better understanding of how HD affects family systems and how family caregivers experience and perceive their role could be useful for adequate support of families affected by HD (13, 14).

The authors of this article are trained in nursing and medicine and have clinical and research experience from community health care, general practice and specialised medical hospital work. We are familiar with some of the specific challenges HD patients and other marginal patient groups are facing. We wanted to conduct a study to explore family caregivers' experiences with the impact

of HD on the family structure, dynamics and roles in the family.

Methods

Design and participants

We have conducted a qualitative interview study and recruited 15 individuals with experiences as a caregiver in a family affected by HD. Participants were recruited through hospital departments and a lay organisation for HD in Norway. Participants included three men and twelve women aged from 20–67 years. The sample consisted of caregivers who had experiences from caring for affected parents, spouses, siblings or children in all five stages of HD (Table 1).

Interviews

Data were obtained from semi-structured interviews with participants. The interviews were conducted by the first author (MR) in October 2011–February 2012. Participants were interviewed once. Each interview lasted 60–90 minutes. The interviews took place where it was suitable for participants, such as in their homes, in offices, at hotels or other places. A thematic interview guide had been developed based on input from HD specialists at a hospital department, patients and family caregivers. A group of three family caregivers, all spouses of affected husbands, were consulted about factors of importance for the interview situation. The interviews centred on participants' experiences as family caregiver, perceived needs, coping strategies and experiences with the health service. Emerging themes and hypotheses were explored in interviews with subsequent participants. The material was digitally recorded and later transcribed verbatim by the first author.

Analysis

We used systematic text condensation (STC), a method for cross-case thematic analysis of qualitative data (15).

Table 1 Characteristics of participants (N = 15)

<i>Age in years</i>	<i>Gender</i>	<i>Relationships of caregivers</i>	<i>Have children</i>
20–29	1 Female	12 Spouse	8 Yes 12
30–39	0 Male	3 Spouse/parent	2 No 3
40–49	6	Ex-spouse	1
50–59	4	Daughter/sibling	1
60+	4	Son	1
		Son/sibling	1
		Daughter	1

Average years of caring experiences: 11.6 years.

In this project, the method involved the following: (i) reading all the material to obtain an overall impression and bracketing previous preconceptions; (ii) identifying meaning units, representing different aspects of participants' experiences from their role as family caregivers and coding for these; (iii) condensing the contents of each of the coded groups; and (iv) summarising the contents of each code group to generalise descriptions and concepts concerning family caregiving related to HD. All authors read the material. The complexity of the way the participants experienced their role as caregiver, and the influence of family dynamics was thoroughly discussed. All authors participated in the further elaboration of themes and interpretation of findings.

Results

We found that HD could have a substantial impact on the family system, the shape of roles among family members and the hierarchical order between spouses, partners, and parents and children. The relationship between spouses and partners changed during the course of the disease. A reciprocal relationship was difficult to maintain, as the role as carer overshadowed other roles. Children of an affected parent could compensate for impairments by taking on adult responsibilities, and in some families, a child had the role as main caregiver. The increasing need for care could cause conflicts between the role as family member and family caregiver. The burden of care within the family could fragment and isolate the family. We elaborated these findings below.

Transitions of family members' roles and changes in relationships

All participants of an affected spouse or partner experienced that their relationship gradually changed during the course of the disease and as the need of care increased. They said that it was difficult to maintain a balance in their reciprocal relationship, and this loss of partnership was difficult, as pointed out by a woman with an affected husband:

What hurts me most is that you lose the one you loved. A complete different person is sitting in the dining room today, another person than the one who was my husband years ago. That is sad for me. I am more like a caring person now, not his spouse and loved one as I was. (participant C2)

Partners and spouses experienced that they had lost their equal partner and that the disease had brought 'a new child' in the family. They told about conflicting responsibilities and new role functions concerning caring for their partner and raising their children, practical tasks and work. Sometimes, they had to protect the youngest children against uncontrolled behaviour from the affected

parent, such as unexpected aggression or rude verbal statements. They had to make efforts to ensure that the youngest children were not alone with the affected parent during the day. Some participants also described conflicts about the family economy, as their partner was no longer able to share the responsibility due to cognitive decline. For partners who worked part-time, it was not easy to increase workload because of the need of care at home. Some partners received payments by the welfare system as paid family caregiver, thus reducing the need for professional home-based care. While a role as paid caregiver could help maintain a balance in the family system, it could, however, also result in lower income and social isolation.

Participants who had taken care of siblings with HD described it as the end of a mutual friendship, replaced by a complex relation based on a sibling's need of care and functions in a role of caregiving. Important bonds between siblings gradually broke down as the symptoms progressed. One participant had cared for her affected mother for years, while a friendship between the two sisters gradually changed when her sister developed symptoms:

Yes, there is a lot of frustration because me and my sister were best friends, super friends, sharing everything, clothes, boyfriends, and excitements, and now she is not here, and in this process I have not been able to establish friendship of my own. (participant C1)

In addition to losing a good friend and a supportive companionship, the continuous care process prevented her from establishing a social life friendship outside the family.

Family caretakers must adjust to mixed feelings

Some of the participants who had grown up in a family with one parent severely affected of HD described taking on a caregiver role early in their lives. Their childhood and adolescence were filled by adult responsibilities and tasks adults usually do. Compensating for their parent's impairment, they took care of younger siblings, followed them to school and day care, did the laundry and made food, as portrayed by a woman who cared for her affected mother:

I could not tell about it to my father. I isolated myself from others, and in dark times, after I had put smaller siblings to bed, their schoolbags were packed, food for the next day made ready and the house cleaned up, I had ten minutes for myself. (participant E1)

Typically, teenagers would try to conceal the difficult situation by not disclosing their challenges to anyone, while at the same time, they felt a lack of support from adults or other family members. They felt desolate in

dealing with difficult challenges, such as medication issues and a parent's suicidal behaviour. Family caregivers in our sample experienced mixed feelings in the caregiver role as sense of duty and guilt for not being affected. For some, it resulted in bad conscience and devotion. Some of the participants described that the role of caregiver and responsibilities could cause emotional conflicts among family members, as underlined by one of them:

Our son moved out early, but our daughter who stayed at home was like a chopping block for her HD affected mother. When something went wrong she was always the one to blame. She must have suffered a lot. (participant A2)

The family network becomes vulnerable and fragmented

In some families, the disease led to stronger boundaries between the family unit, other relatives and the social world. The family network was fragmented and the family became isolated. Changes in family structure and fragmentation made families more vulnerable with a lack of family members to rely on when support was needed. It seemed difficult to reconnect with relatives after longer periods without contact. A man's story illustrates the complexity:

I was 8 years old when my parents divorced. Dad was always angry and we did not know of HD. I lived with my mother and three elderly siblings a couple of years, and then they moved out. I remember when dad came visiting us, we were afraid and thought he was an alcoholic. [...] We did not have contact with other relatives, just a little with an aunt. My mother never told me about grandparents. I know nothing about them. We got a message when my dad died in a psychiatric institution. Two of my siblings later got married and had children. We did not have much contact. All my siblings died within 15 years of HD. I seldom see the kids and have no contact with the spouses. Now I live alone and help my mother when she needs it. (participant C3)

Families affected by HD early in the family life cycle seemed to undergo more complex changes, as the disease conflicted with the question of raising and other responsibilities. The impact on family structures seemed less severe and the participants seemed more relaxed about changes in roles and family relations in families with late onset of the disease.

Discussion

Validity, transferability and reflexivity

Participants in our study were recruited through hospital departments and a patients' organisation. Our sample

consisted of people who were willing to be interviewed about their experiences, and there may be experiences that we might have failed to illuminate. We have not elicited the experiences of relatives who did not take on a caregiver role. Our sample represents a variety of experiences with caregiving in different stages of the disease, making our results transferable to caregivers in various families affected by HD. Three researchers with different backgrounds as health professionals have been involved in interpreting the data, which we consider a methodological strength.

Age of onset and phases in family life

Our study demonstrates how HD challenges the stability in the family system, by changing family positions, role functions and tightens some families' boundaries. The impact of the disease may be very different from family to family, because HD develops in phases over years, and symptoms and impairments may vary. The disease enters into family life cycle at different stages and will have different impact on the family system. Family caregivers experience particular difficulties when HD occurs in an early stage of family life and if the disease coincides with parental obligations for children and adolescents. In our study, this stage of family life seems to be a peak period for complex role expectations and responsibilities between family members. This is also a period of less social contact, while increased social support might be helpful. When the onset of HD occurs later in family life, the disease does not seem to have the same impact on the parental subsystem in the family, as in the case of an early onset. However, also in later stages of family life, we found that caregivers experienced complex feelings of anxiousness and anger for the future of their children and grandchildren at risk. This is probably one of the major specific challenges experienced by caregivers in families with HD. Caregivers in families with other severe and chronic neurological diseases also experience burdens and strains (16), but concerns for next generation's health, and the history of caregiving for affected parent is present only when the disease is hereditary.

Caregiving for persons with dementia can be very demanding and lasts over long term. Onset of dementia may appear early (17), but normally occurs in a late stage of family life with different consequences for the role of caregiver. It is difficult to compare caring experiences, but one important difference between the diagnosis of dementia and HD is the heredity. Adult children of parents with dementia may have different resources for support as caregiver because they are not at risk, and they do not need to be anxious for the future of their siblings. Several of our informants had experiences of caring for two or more family members. Some of them cared for a spouse and an adult child in the same period,

describing a sort of a 'who is next' situation. Dementia, like Alzheimer disease, is more common and well known than HD, so the threshold for adapted and organised health services and understanding is probably lower. This highlights the unique complexity of the caregiver role related to HD and the need of research of comprehensible interventions on individual level.

Children and teenagers as caregivers

Huntington's disease affects parental functions, because the ability to fill the parental role is decreasing during the course of the disease (18, 19). We found that children and teenagers felt that their own needs were put aside to give priority to caregiving of an affected parent. A child in a parent's role is called 'parentification' (20–22) and is a way a family and a child may adapt to a challenging situation. Parentification may suppress a child's own needs and may be destructive if a child, for a longer period of time, has to manage tasks, emotional issues and responsibilities for which they are immature (22). The problem of parentification is recognised among families affected by different diagnoses and social conditions, as cancer (23, 24) and substance abuse care (20). Multiple sclerosis is a severe chronic disease with similarities to HD. A recent study from Iceland (25) describes findings among young caregivers of a parent affected by multiple sclerosis with onset in an early family life, similar to ours. Experiences of being overloaded and immature for adult's responsibilities, putting their own needs of care aside, add to the burden of suffering. For health professionals, this might be a message of the importance of assessing the possible impact on each family member. The same study (25) documents a positive development for young caregivers later in life. Increasing social activity and support combined with less care seemed to be helpful for family caregivers entering a new life situation. Some of our participants struggled with lack of family and social support when another family member was developing HD and needed care. Our participants, who were caregivers as a child or teenager, also described relational conflicts later in life. Emotional responsibilities in addition to practical tasks are highlighted as the most risky type of burden because there is less openness about it (26). Some of our participants described their situation as frustrating, due to the silence of their family HD history and lack of competence in the environment. A recent study concluded that growing up in a family with one parent affected of HD appears to affect a child's adult psychological attachment (27). If one parent is affected and the other parent leaves the family, the children will be even more vulnerable for extensive caregiver burdens and neglect of their own need of care. Health professionals aim to work patient centred, but do not always adopt a family perspective or use methods to uncover a family situation (4). Spouses and partners experience burdens of care (6, 16,

28), but healthcare professionals also need to be aware that children and teenagers may have the role as main caregiver in the family.

Our study suggests that the situation of children and teenagers in families affected by HD deserves increased attention and that a family system perspective may be helpful in the management of patients and families affected by HD. Health systems are supposed to support and educate family members who are caregivers, to contribute with appropriate care and to enable caregivers to stay healthy. More knowledge about appropriate interventions, such as counselling and practical support to family members and the family caregiver, is needed, to prevent family disruption in certain vulnerable phases.

What does this study add to previous knowledge?

We are not the first to describe the heavy burdens of care that family caregivers in families affected by HD experience (2, 4, 13) and that children and teens experience burdens growing up in families with HD (19). Our study adds novel insights about the significance of the context and circumstances in which the caregiver role unfolds. In a family perspective, where experiences of family history and the context of family life become frameworks for understanding, our study highlights that the caregiver role might be experienced differently and have different consequences in families, even if practical burdens seems to have similarities. Therefore, supporting a family caregiver also should include the need of support as individual family member. Our study pinpoints the similarities of care burden and need for caregiver support in HD and other diseases and highlights particular challenges in HD: the complexity of genetics, the onset of the disease in relation to stages in family life and a general lack of knowledge about HD.

Conclusion

Huntington's disease has a major impact on the family system. Caregiver roles are shaped by impairments in the affected family member and corresponding dynamic adoption and change in roles within the family system. Health professionals should make assessments of the family structure and roles, to understand and reveal possible role conflicts or changes in family life. As the disease and the family life cycle progress, there will be a need for flexible care and support adapted to the individuals in their role as family member and family caregiver.

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Author contributions

Merete Røthing and Jan C. Frich designed the study. Merete Røthing conducted the interviews. Jan C. Frich and Kirsti Malterud have been involved as supervisors, and all three authors read the data material and were involved in the analysing process and discussions. All authors have read and approved this manuscript.

Ethical approval

The study has been approved by the Regional Committee for Medical and Health Research Ethics (REC South-East B, ref. 2010/2072). All participants were given written and oral information about the study and signed an informed consent form.

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