

Family caregivers' views on coordination of care in Huntington's disease: a qualitative study

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Background: Collaboration between family caregivers and health professionals in specialised hospitals or community-based primary healthcare systems can be challenging. During the course of severe chronic disease, several health professionals might be involved at a given time, and the patient's illness may be unpredictable or not well understood by some of those involved in the treatment and care. **Aim:** The aim of this study was to explore the experiences and expectations of family caregivers for persons with Huntington's disease concerning collaboration with healthcare professionals.

Methods: To shed light on collaboration from the perspectives of family caregivers, we conducted an explorative, qualitative interview study with 15 adult participants experienced from caring for family members in all stages of Huntington's disease. Data were analysed with systematic text condensation, a cross-case method for thematic analysis of qualitative data.

Results: We found that family caregivers approached health services hoping to understand the illness course and to share their concerns and stories with skilled and trustworthy professionals. Family caregivers felt their involvement in consultations and access to ongoing exchanges of knowledge were important factors in improved health services. They also felt that the clarity of roles and responsibilities was crucial to collaboration.

Conclusions: Family caregivers should be acknowledged for their competences and should be involved as contributors in partnerships with healthcare professionals. Our study suggests that building respectful partnerships with family caregivers and facilitating the mutual sharing of knowledge may improve the coordination of care. It is important to establish clarity of roles adjusted to caregivers' individual resources for managing responsibilities in the care process.

Keywords: family caregivers, health services, coordination of care, collaboration, chronic disease.

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Introduction

Huntington's disease (HD) is an incurable, genetic, neurodegenerative disease, with characteristic symptoms including cognitive impairment, involuntary movements and personality changes (1). The disease is autosomal dominant, with a 50% chance of transmission to offspring. The prevalence is 7–10 per 100 000, and the mean onset of symptoms is 30–50 years. Gradually, a patient's impairments can affect family members and keep them

from participating and functioning in everyday life (2, 3). Multidisciplinary care has been recommended for this problem (4). Research indicates that caregivers face challenges when communicating with health professionals and that knowledge about HD is often limited (5, 6). A patient gradually loses cognizance of his or her situation and the needs of others, which creates a huge challenge for health professionals and family members (1). Guidelines recommend a multidisciplinary approach in caregiving to patients with HD and that health professionals take active steps to involve family caregivers to improve the quality of health services to affected families (7).

Family members play important roles as caregivers in families affected by chronic illness, and the demand for family caregivers is expected to rise (8, 9). Collaboration between family caregivers and professionals is essential for

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the caregiver's support and may help them endure caregiving tasks; however, this collaboration may be challenging if the roles in the care process are unclear (10, 11). Research suggests that unrealistic expectations from health professionals may place an additional burden on caregivers (12) and that the communication between family caregivers and health professionals is not always optimal (13).

Coordination of the healthcare delivery and caregiving may take place through various mechanisms (14). The use of technology, the formatting of organisational structures and the characteristics of care tasks have been emphasised in the literature (15). However, recently, the technical requirements of the work and the quality of the communication in relationships between members of a patient's care team have been underscored (16). Relational coordination (RC) is a theoretical concept for the management of interdependencies between the people who perform the tasks (17). According to the theory, communication and relationships are crucial in relational interdependent work processes, as in caregiving, underlying more technical tasks (17). Three essential dimensions of relationships between involved partners are proposed as necessary preconditions for effective coordination: (i) shared knowledge, (ii) shared goals and (iii) mutual respect for one another's contributions. Preconditions for high-quality communication in relationships are frequency, timeliness, accuracy and a problem-solving orientation. In a relational coordinated care process, the qualities of communication and the dimensions of relationships are mutually reinforcing each other. All partners involved are believed to make a difference with their knowledge and dependencies.

In 2012, a coordination reform was launched in Norway to improve the coordination or integration of effective health care for people suffering from long-term conditions. One aim is to improve health services through better coordination of healthcare delivery, involving patients and their families (18, 19). The authors of this study have professional backgrounds in nursing and medicine and have experience in clinical practice in community health care, general practice, specialised medical hospital work and research in the field of communication, marginalisation and complex health conditions. These experiences motivated us to learn more about the coordination of care between family caregivers and professionals for patients with HD. We therefore conducted a study to explore the experiences and expectations of family caregivers for persons with HD concerning collaboration with healthcare professionals.

Methods

Participants and data collection

We wanted to conduct an explorative qualitative interview study (20). Participants were recruited with help

from specialised healthcare hospitals, community-based primary healthcare centres and a patients' organisation for HD in Norway. Elements of snowball effect resulted in contact with four participants recruited through membership of the patients' organisation. The sample consisted of 15 participants (12 women and three men) aged 20–67 years. Adults who cared for person(s) affected by HD without risk of the disease were requested. The participants represented experiences from all stages of HD and served as family caregivers for affected family member(s), such as spouses, siblings and children. Some of the participants had experiences from caregiving for several family members from two or more generations. The average duration of the caregiving experience was 11.6 years (Table 1). An interview guide was developed with input from health professionals experienced with HD and three experienced family caregivers. Semi-structured, 60- to 90-minute individual interviews were conducted by the first author in the period from October 2011 to February 2012. All interviews were digitally recorded and transcribed by the first author.

Data analysis

The transcribed manuscripts were analysed with systematic text condensation (STC), a cross-case method for thematic analysis of qualitative data (21). All three authors read the material obtained from the interviews and were involved in the analysis. The four steps in the analysis

Table 1 Characteristics of 15 family caregivers

	N (%)
Age in years	
20–29	1 (7)
30–39	0 (0)
40–49	6 (40)
50–59	4 (27)
≥ 60	4 (27)
Gender	
Female	12 (80)
Male	3 (20)
Family caregiver's position	
Spouse	10 (67)
Ex-spouse	1 (7)
Child of affected individual	4 (27)
Caring for multiple family members	
Yes	3 (20)
No	12 (80)
Family caregiver have children	
Yes	12 (80)
No	3 (20)
Contact with health services	
In community health care	15 (100)
In specialised hospital care	15 (100)

were followed: (i) all the material was read to obtain an overview of the data and got an impression of themes from family caregivers' encounters with health services, bracketing our preconceptions and identifying preliminary themes; (ii) meaning units were identified in the texts, representing aspects of participants' experiences related to our research question, followed by coding into code groups; (iii) to clarify different aspects within the code group, each code group was divided into 2–4 subgroups, from which condensates were developed and illustrative quotations were identified; and (iv) descriptions of participants' experiences based on the condensates were devised. The author group had ongoing, thorough discussions about the development of themes and the choices made regarding code groups, subgroups and the final categories of results throughout the process of analysis.

Results

Family caregivers tended to approach the health services hoping to understand the illness course and to share their concerns and stories with skilled and trustworthy healthcare professionals. Family caregivers believed their involvement in consultations with ongoing exchange of knowledge with competent, local healthcare professionals, familiar with their specific family situation, was critical for improved healthcare services. Family caregivers expressed unclear understanding of their expected contributions to the care process. Clarity of roles and responsibilities, especially in later stages of the care process, was believed to be crucial for collaboration. We will elaborate further on these findings below. Quotations have been assigned each participant's identity marker.

Sharing concerns with professionals

Family caregivers articulated a need for help to understand the illness, its course and consequences. Some family caregivers initially had very little knowledge of the illness, as it had not been discussed or was not part of the family history. Others had in-depth personal experiences with family members affected by HD. Some did not know what to expect, whereas others approached the health services with numerous specific worries about their futures and about the patients' health statuses. Some of them described how consultations with health professionals at an early stage of the illness trajectory had prepared them for the challenges ahead and made them foresee the impact the illness could have on their dual role as family member and caregiver. The genetic nature of the condition and that it could manifest in children and other relatives were common concerns.

In addition, family caregivers articulated a more general and basic need to establish trustful relationships with

health professionals through dialogue and counselling. They invested in relationships with the health professionals through sharing their stories, views and concerns, so that they would have someone to turn to if something happened or an urgent question emerged. Family caregivers' initial collaboration with health professionals was partly focused on understanding the present and the future and partly on building relationships for future help and support. A wife was informed about the disease in the late phase of family life and shared:

I have now an explanation to his behaviour and a name of the disease. I have spoken with the general practitioner, and if or when time comes, I will contact him again, and that will be fine. For our children it is too late, but we have concerns and hope for the future of our grandchildren.(B1)

Caregivers who were spouses, parents, children or siblings reported that they were not involved in the ways they wished. Being involved, such as being informed and invited to participate in consultations and meetings with health professionals, was crucial to these caregivers. The participants mentioned two reasons for this. First, the caregiver may have limited insight into the illness situation and need assistance in the forms of practical and emotional support. Participants claimed that they felt health professionals had been unintentionally misled by patients about the caregivers' and other family members' needs for support because the doctors were limited to the patients' accounts of the situation. Second, participants reported that they had their own needs as caregivers and wanted to contribute their understanding of symptoms, behavioural changes and challenges. One participant, a spouse of an affected husband and a mother of three, took several initiatives to be more involved and better heard. She was convinced that her presence in consultations could make a difference:

I had to push on to be with my husband at the meeting in the hospital. I had to be prepared to give our children some answers, and I had seen so much of the symptoms. But, I was not invited. They had forgotten to write it in the letter. But I wanted to be there, I had to push myself into it, I just had to be there. That day he wanted to take his own life and the follow-up from health professionals was poor.(E4)

Meeting competent and respectful professionals

Caregivers described the need for competent health professionals who were knowledgeable and skilled in treating HD, but who also understood how the illness could affect the family. This expectation was not always met. Although travelling to specialised centres was an option and something they were willing to do, the caregivers also underscored the value of competent local

professionals. Family caregivers articulated a persistent need for consultations with health professionals who were able to take notice of changes and understand the family as a whole. They also pointed to the importance of continuity in the contact with regular consultations. Seeing new health professionals who did not know the family's specific story was considered a burden. In addition, long intervals between consultations were considered a problem for the family caregivers:

In early stages, we had frequent consultations with a medical specialist at the hospital. He knew our history and we did not have to repeat our story every time. Now we have meeting only once a year. We need more often contact with a health professional who understand our situation.(D1)

Family caregivers reported meeting health professionals in different settings and arenas and described how coordination and communication within the health services were not always optimal. Some participants described positive experiences from their contact with individual health professionals, reporting that they received useful information or were guided to other health and social services for specific requests. At the same time, participants described difficulties in identifying how issues and needs should be disclosed to other professionals who were involved in providing care. One of the participants liked this type of experiences to being left alone and to find solutions without the help of health professionals, though these professionals knew the situation and could have been involved. A male participant, an experienced caregiver for his wife and daughter, reported being listened to, but later realising that his experiences and views had not been taken into account:

Health professionals who are responsible for services to my daughter seem to understand that I am experienced and they hear what I say, but all the time I have asked for someone who could take the responsibility, as a link between the health system and her. Sometimes they just send her a report from a meeting about decisions made for 4 months ahead. She cannot deal with appointments or understand agreements. Suddenly a decision was made about dust wiping. But there are other more important things she need. It is as if they do not listen to what I mean.(A2)

Clarity of roles and responsibilities

Family caregivers reported that roles and responsibilities between involved health professionals and caregivers were sometimes unclear, which made it difficult to the caregivers to know what was expected of them. A wife and mother of two children were confused because she expected someone in the community health system to

contact her after her husband had left the hospital. The communication routines of the system seemed to conflict with her needs for care and support:

I was told at the hospital that we would be contacted for further follow-up by health professionals in the community. Later, they contacted me and I was satisfied to learn that they kept their words. But it turned out not to be so easy. The health professional who called us said he was not supposed to be our contact and that we should be taken care of by another. Then there was summer holiday and nothing happened. So we don't know if a health professional from community health system or the hospital will be in charge.(C3)

The caregivers saw themselves as members of care groups for the patients. They shared that they sometimes had to take the lead in these groups to enforce change. One participant described a positive experience from taking the initiative to ask health professionals from the hospital to head a meeting in the community to share information about HD and to inform the local team about special considerations in the caring process. The caregiver described feeling relieved of the responsibility to inform others about the disease. Living close to the affected person in his or her everyday life, participants described feeling responsible to initiate increased healthcare services, which they felt should be initiated by health professionals. A woman who had cared for her mother for many years and now cares for an affected sister perceived a disconnection between her world of practical daily care and the care discussed in more formal multidisciplinary community health-group meetings:

I guess I am the one who have to take initiative and do something when my sister's need for care is changing. As an example, if she needs anything else in her house, I have to take care about it. A community nurse is coming once a time every second week, but my sister needs more help, at least once a week, in addition to a nurse taking care of medication. We have established a group with a medical doctor and health professionals from primary care. We have a meeting twice a year, listening to each other about my sister's needs. This has been good for something; I have started application for disability.(C1)

Discussion

Methodological considerations

The individual interview is appropriate for collecting data to explore individual experiences from life events and social phenomena (20, 22). We considered conducting focus group interviews (23) but wanted the opportunity to follow-up more closely with participants who shared experiences based on certain themes. Although

collaboration is an issue, health professionals were not interviewed. A one-sided perspective in understanding collaboration between multiple actors is a limitation, but a specific focus is the perspective of family caregivers, and we decided to focus on their experiences.

Researchers' gender, professional experiences and cultural background shape data collection and the research process (20). The interviewer had a nursing background, experienced from work in local communities and hospitals; this experience may have influenced the levels of attention paid to the interview content. For example, in the past, the interviewer worked with implementation of structures for individual care planning programs for persons affected by chronic conditions. The close involvement of the other two authors throughout the process increased our abilities to capture diverse nuances of family caregivers' experiences. We were familiar with the challenges related to symptoms and the changes of functions in HD, as well as the health system in Norway. This knowledge may have supported our understanding of the contexts within which the family caregivers lived their experiences and developed their expectations.

Our sample comprised 12 women and three men. Including a greater number of male participants may have enriched the data material, as participation in work life and responsibilities in the family may differ with gender. Different positions in the family and the caregiver's gender may trigger different needs and solutions for health services, which could affect collaboration (24, 25). Male participants in our study shared caregiving experiences from all stages of HD, including care for affected family members from two generations and contact with health services. The interview material on caregiver experiences was rich and diverse, and we consider our findings generalisable for family caregivers in families with HD in health systems with developed primary healthcare services. Findings in this study may also be generalisable for caregivers in families affected by other chronic diseases or conditions with regard to the acknowledgement of the caregiver role in partnerships to improve the coordination of care.

Knowledge sharing

Family caregivers reported seeking help from health professionals in order to understand disease progression and consequences. They also reported making efforts to share information they considered relevant for health professionals. Previous research has documented family caregivers' needs for information in families with HD (5, 26). HD is a rare disease, and the lack of knowledge and experience among health professionals may present challenges (6). Research suggests that the difficulties in gaining access to information, poor communication and lack of interaction between family caregivers and health professionals are also experienced by family caregivers in

better-known conditions, such as Parkinson's disease, other forms of dementia and in end-of-life care (27–29). Compared to caregivers in families with other chronic conditions, caregivers in HD may be in a more vulnerable and complex situation. The characteristics of HD may have significant impacts on multiple family members over time in early family life. The rarity of the disease, its symptom characteristics, time for onset and genetic component necessitate knowledge sharing in the early stages of the disease, which could play a significant role in future collaboration and management of symptoms.

Participants reported having desires to share their knowledge, but feeling uninvited to do so by health professionals. In another study, caregivers found that health professionals did not exchange knowledge with informal carers, citing reasons such as privacy and confidentiality (13). Knowledge sharing may promote a common understanding of the situation and the challenges at hand and may reveal knowledge that family caregivers do not want or need to share with health professionals. While most health professionals may have general knowledge about HD, the contexts for the illness course and family histories differ and may need individual care and support (30). Mutual dialogues may promote knowledge sharing in the form of RC, which can serve as a framework where new understanding of changes and challenges based on shared knowledge can become a precondition for shared goals and for revising functional goals in the care process (17). Participants underlined a need for continuity in relationships with health professionals. Sharing knowledge over time with continuity in relationships might prevent the power imbalances or tensions that can create barriers between caregivers and health professionals (13).

Multidisciplinary care services tailored to the needs of the HD-affected person require coordination of interdisciplinary collaboration (4, 31). In addition, healthcare professionals must consider the possible differences in the needs of the caregiver and the needs of the patient (32). Professionals from multiple healthcare-related disciplines as physiotherapists, occupational therapists or pedagogues may play important roles in the care team in addition to nurses and doctors. Our findings indicate that health professionals should encourage the family caregiver to participate in consultations and should then integrate the caregiver's knowledge as part of a common understanding. Routines and procedures for including family caregivers may present opportunities for flexible ongoing contact adjusted to the disease trajectory and care process. Continuity in relationships should be given priority in the coordination of the care course.

Fostering mutual respect in collaboration

Family caregivers expected respect from health professionals as competent partners in patient care. Our findings

also suggested that lack of communication and unclear expectations represented additional burdens for the caregiver. Our findings are in line with previous research suggesting that poor communication between caregivers and health professionals may lead to inappropriate care and place extra burdens on family caregivers (6). Lack of continuity in communication and coordination between partners was found to have negative impacts on patients and caregivers in another severe but more common neurological condition, Parkinson's disease (27). Research suggests that conflicts may arise between actors involved in care processes related to how they define each other's value of positions and knowledge. Family caregivers may challenge nurses as professionals because they are sceptical about releasing control (10). In a study of collaborative practice among health professionals, role understanding and communication were highlighted as two main competencies, while competencies such as a positive attitude and mutual trust were described as characteristics of individuals and not as competencies of collaboration (33). Ongoing mutual dialogues may increase understanding of role strains and the significance of shared knowledge (13). Mutual respect is aside shared knowledge an essential dimension of relationships in relational coordination. It involves an acceptance of the different but equivalent competencies and skills of the actors, which complement one another in collaboration. Mutual respect fosters receptivity to communication and contributes to the development of shared knowledge (34).

In our study, participants also reported poor communication related to infrequent meetings. Established routines for integration of caregivers' knowledge during the care course were not experienced as standard practice or as a guarantee for participants' experiences of being involved and acknowledged. Weinberg and co-workers applied the concept of RC in a study to assess coordination between health professionals and informal caregivers (35). Interaction along dimensions of quality and frequency of communication, as well as the supportiveness of relationships, was measured. The results suggested that relational coordination had a positive effect on caregivers' management of care and understanding of their roles. The frequency of meetings and accurate communication may not be standardised but must be adjusted to the illness course and family members' needs as caregivers.

RC may be helpful to improve coordination of care in HD, but the concept is in a relatively new stage of development, and further research on the strength of coordination in chronic conditions is needed (16). Further

research on how family caregivers may be involved in a coordinated care process with respect to their competences is also needed.

Conclusions

Our study suggests that family caregivers should be acknowledged for their competences and should be involved as contributors in partnerships with health professionals to improve the coordination of care. Involving family members and family caregivers from early stages of the disease may give health professionals more appropriate information and knowledge of the illness situation. The clarity of roles adjusted to each caregiver's resources for managing responsibilities is crucial. Unclear roles in collaboration might be experienced as an additional burden and debilitate coordination of the care process. Health professionals should bring competent knowledge of HD-specific characteristics to encounters with family caregivers and should emphasise continuity in contact for sharing knowledge throughout the care course.

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Author contributions

MR and JCF contributed to study design. MR collected the data. MR, KM and JCF were involved in data analysis and manuscript writing.

Ethical Approval

All participants received an information letter and were given oral information about the study before interviews took place. They all gave written consent for participation and were informed that their opinions or statements had no implications for the care process or healthcare delivery related to affected person or themselves. The study has been approved by the Regional Committee for Medical and Health Research Ethics (REC South-East B, ref. 2010/2072).

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