

# Experiences of Ambulatory Patients With Huntington's Disease With Case Management

## *A Qualitative Study*

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### ABSTRACT

**Purpose/Objectives:** Huntington's disease (HD) requires high-quality care to reduce disruption of the patient system, prevent crisis situations, and prevent early admission in a nursing home. In the Netherlands, case management has been available for the last 9 years for people with HD. However, there is a notable gap in understanding experiences and beliefs of HD patients regarding case managers' care, guidance, and support for quality of life. To improve the international quality of care for people with HD, insight in experiences of ambulatory HD patients with the care, guidance, and support received from a case manager HD (CMHD) is crucial.

**Primary Practice Setting:** Ambulatory care.

**Findings/Conclusions:** Ambulatory patients with HD highly appreciate and value the role and support of the CMHD. This was reflected in four themes: (1) the CMHD as a person, with commitment, sympathy, and reliability as central concepts; (2) the CMHD as a professional, with the key roles of coordinator, point of contact, expert, and supporter; (3) impact of the CMHD on quality of life, with support of coping with decline and monitoring the home situation as important subthemes; and (4) support of the CMHD for family members, with providing help and giving attention as subthemes. This insight into patients' experiences of the CMHD's role adds value to the improvement of the international quality of care for people with HD.

**Implications for Case Management Practice:** Commitment, expertise, support for both family members and patients, and bond of trust from the CMHD are experienced as very valuable. These qualitative findings from a patient's perspective add significantly to the body of knowledge on CMHD's role and practices as "spider at the center of the web."

**Key words:** ambulatory HD patients, case management, Huntington's disease, patient experience, qualitative research

Huntington's disease (HD) is an autosomal dominant and neurodegenerative disease, characterized by cognitive, motor, and psychiatric disturbances (e.g., chorea, dystonia, depressive moods, anxiety, lack of initiative, irritability, suicidal ideations), which have a significant impact on the life of the patient, their partners, and children (Domaradzki, 2015; McColgan & Tabrizi, 2018; Mühlbäck et al., 2023). Usually, symptoms of HD start at the age of 35–40 years, with early symptoms often presenting before clinical diagnosis. At present, there is no cure for HD or treatment to delay progression of the disease, and death occurs 15–17 years after onset (Domaradzki, 2015).

The complex and devastating nature of HD requires high-quality care to reduce disruption to the

patient's family system, prevent crisis situations, and/or early admission to a nursing home. For patients with dementia, a strongly promoted and widely used intervention for organizing and coordinating care at the level of the individual is case management. Its aim is to provide long-term care in the community as

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an alternative to early admission to a care home or hospital (Reilly et al., 2015). Case management can be defined as a “collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost-effective outcomes” (Case Management Society of America [CMSA], 2016; Schiller et al., 2021).

Case management in dementia care is international and commonly known; yet, for people with HD it is far less common, with the Netherlands among the few countries where case management for HD is developed. In the Netherlands about 1,700 people are diagnosed with HD (Veenhuizen et al., 2018). In the vision of the Dutch national care program, HD is unique in advocating that case management should be available to everyone with HD (Huntington Netwerk Nederland, 2015). Case managers, united in seven Huntington Centers of Expertise, support and coordinate care for ambulatory patients with HD in their living environment. The case manager with a HD specialty (CMHD) has expertise about the disease and knowledge about the different phases the patient goes through. The patients’ quality of life (QoL) is central to the care and guidance offered by the CMHD. The CMHD is a confidant for the patient and the relatives, coordinates the care and therapy that is needed, and is responsible for the implementation of the treatment plan. In other words, the CMHD is a “spider at the center of the web” that connects the health care around the patient. The CMHD offers psychosocial assistance to teach the patient to deal with the disease and stimulates self-management. During the progression of HD, the needs for care are often complex and variable, which impacts the care and support provided by CMHD. For example, the demands for care can shift from advice on the use of supporting devices or dialogue with an employer toward the use of home care support or the decision

on admission in a nursing home, in which case the involvement of the CMHD ends. Involvement of the CMHD is “demand-driven,” which means that the contact frequency with CMHD may differ depending on the care needs of the patient. Appointments are scheduled in consultation with the CMHD and can be arranged on a regular basis or upon request, whereas remote contact can be by means of email, WhatsApp, or phone.

As far as the authors know, no scientific research has been conducted on the experience of patients with case management HD.

Studies by Backhouse et al. (2017) and Reilly et al. (2015) on case management for people with dementia suggest that case management may contribute to a reduction of, and improved satisfaction with, the delivered care. In addition to communication and collaboration with professionals, the presence of a single point of contact, facilitating continuity of care, emerged as a highly valued key component.

Although case management for HD in the Netherlands has been available for the last 9 years, experiences and beliefs of HD patients with case management and the implications of case managers’ care, guidance, and support for QoL have not been examined before. Therefore, the aim of this study was to gain insight in experiences of ambulatory HD patients with the care, guidance, and support provided by a CMHD.

## METHODS

### Design and Setting

A qualitative design was used to explore in-depth experiences and views of HD patients (Polit & Beck, 2020). To enable participants to not only reflect on their experiences but also take into account the possible cognitive problems caused by HD, we conducted semistructured interviews. This ensured that both specific topics were covered and participants were encouraged to talk freely using their own words.

Interviews took place within Atlant, a HD Centre of Expertise in Apeldoorn, the Netherlands, which provides inpatient care and care for ambulatory patients. In case of ambulatory care, patients receive care through day treatment, the outpatient clinic, and case management.

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## Sampling and Selection Procedure

At the time of this study, 105 patients with HD of Atlant received case management provided by three case managers, each with a case load of 35 patients. Selection took place in two steps. First, we included Dutch-speaking adults with clinically diagnosed HD, who received case management for at least 1 year and with no severe cognitive problems. This led to 74 potential participants out of whom a purposive sample (Polit & Beck, 2020) was selected. To enhance transferability of the data, we aimed maximum variation regarding gender, age, and years of receiving case management. As a second step, for an equal distribution among the three case managers, six patients per case manager were selected. Candidate participants were invited by a researcher and received an information sheet containing details of the study. After 2 weeks, they were contacted by telephone by the researcher, who provided further information and answered any remaining questions. Participants signed an informed consent form before being interviewed.

## Data Collection

Data were collected by individual semistructured interviews, between July 2020 and July 2021. The interviews were guided by an interview guide, developed by the researcher, nurse, and research supervisor who has extensive experience in qualitative research. This guide was based on a literature review regarding experiences and effects of case management for patients with chronic diseases; topics such as QoL and psychosocial support were addressed (Askerud & Conder, 2017; Bleich et al., 2015; Joo & Liu, 2018; Latour et al., 2007; Sutherland & Hayter, 2009). To enhance credibility, the guide was peer reviewed by an experienced CMHD. Each interview started with the same open-ended question: "What are your experiences with your case manager?" After which the following topics were addressed:

- Shared Decision-Making
- Quality of Life
- Practical Support
- Social and Emotional Support

The iterative process allowed us to refine the interview guide during the study period, which led to more specific questions enhancing the exploration of

experiences to the fullest. With due observance to the COVID-19 measures, interviews were held at the participants' homes, the day treatment center, or online. All interviews lasted approximately 60 min and were audio-recorded.

## Data Analysis

Data were analyzed using Thematic Analysis (Polit & Beck, 2020; Verhoeven, 2020). After conducting eight interviews, the interviewer started with the data analysis by full transcription and coding of the interviews. The research supervisor reviewed the analysis of three randomly chosen interviews and discussed with the interviewer the codes and subthemes. Through discussion between the researcher and another peer research supervisor, consensus was reached about the preliminary themes and subthemes. Data analysis of the following six interviews initially took place between the interviewer and the research supervisor. They refined and reformulated the identified codes and subthemes. The final data analysis was performed by the research supervisor and the case manager. They discussed the emerged codes, subthemes, and themes, and reached consensus about the final themes and subthemes.

Data saturation was reached after 13 interviews. An extra interview did not reveal deviating data or additional findings. All participants were invited for a member check by completing a questionnaire. In this questionnaire, the findings were presented to them in a general overview table containing quotes, emerged subthemes, and themes. The response did not lead to any changes. Computer software Excel version 2016 was used to manage the data.

Two senior researchers helped supervise the project and assisted in reviewing and revising this article.

## Ethical Considerations

The study was assessed by the Medical Ethics Review Committee of VU University Medical Center (2020.0603), which concluded that it did not fall within the remit of the Dutch Medical Research Involving Human Subjects Act (WMO). This exempted this study protocol from further review, which is applicable only to medical scientific research involving human subjects who have behavior imposed or are

subjected to actions (that infringe upon psychological or physical integrity).

RESULTS

Participants

Fourteen persons with HD were interviewed: eight men and six women. Six of these interviews were held at the participant’s home, four at the day center, and four online. The mean age of the participants was 59.6 years (range: 40–76 years). Years of received case management varied from 2.5 to 9 years. See Table 1.

Themes

Analysis of the interviews revealed four themes, composed of 11 subthemes, capturing the experiences and views of HD patients with the CMHD (Table 2). The themes encompass the following:

- 1. The CMHD as a Person
- 2. The CMHD as a Professional
- 3. Impact of CMHD on QoL
- 4. Support of CMHD for Family Members

Theme 1: The CMHD as a Person

Within this theme, three subthemes were identified: the CMHD as a person who is committed, sympathetic, and reliable.

Participants appreciated the CMHD’s commitment, which is described in terms of their initiative to reach out to them. This becomes apparent in

TABLE 2  
Thematic Map on Themes and Subthemes

Themes	Subthemes
1. The CMHD as a person	<ul style="list-style-type: none"><li>• Committed</li><li>• Sympathetic</li><li>• Reliable</li></ul>
2. The CMHD as a professional	<ul style="list-style-type: none"><li>• Coordinator</li><li>• Point of contact</li><li>• Expert</li><li>• Supporter</li></ul>
3. Impact of CMHD on quality of life	<ul style="list-style-type: none"><li>• Support in coping with decline</li><li>• Monitoring home situation</li></ul>
4. Support of CMHD for family members	<ul style="list-style-type: none"><li>• Providing help</li><li>• Giving attention</li></ul>

Note. CMHD = case manager HD.

spontaneous contact and personal attention, which extends also to their private life according to the participants.

Frequently, participants described the CMHD as a sympathetic person. Other qualities of the CMHD appreciated by the participants were being nice, pleasant, approachable, interested, clear, and understanding.

A type of warmth, involvement. The approach doesn’t have to be so business-like where I’m concerned. (ID13)

Most of the interviewees experienced the CMHD as a reliable person whom they trust; for example, they stated to “click” with her, felt a bond of trust, and that they are willing to openly share their concerns with the CMHD. In addition, some participants told that the CMHD does what she promises and is client-centered.

It makes me feel very calm [...] that’s all okay and I have faith in it, I don’t know, probably because of the way she presents herself. (ID12)

Theme 2: The CMHD as Professional

Within this second theme, four subthemes were identified: the CMHD as a coordinator, point of contact, expert, and supporter.

Participants expressed their satisfaction with the way the CMHD coordinates and collaborates with other professional care givers, such as the general practitioner, to provide care and assistance at their home.

She’s also been here once with someone from the district team. (ID11)

CMHDs are viewed as important contacts and are generally valued for their easy access. Whenever the patients need help, the CMHD can be reached by

TABLE 1  
Participants’ Characteristics

ID	Gender	Age (Years)	Marital Status	Years of Case Management HD Received
1	Female	76	Living together	3.7
2	Female	55	Living alone	9.3
3	Female	59	Living together	5.0
4	Female	63	Living together	5.5
5	Male	66	Living together	2.5
6	Female	55	Living together	3.8
7	Female	42	Living together	2.9
8	Male	59	Living together	2.4
9	Male	40	Living together	1.7
10	Male	60	Living together	5.4
11	Male	74	Living alone	2.5
12	Female	72	Living alone	6.3
13	Female	64	Living together	2.8
14	Male	50	Living together	2.9

Note. HD = Huntington’s disease.



telephone, app, or email. In most cases, the CMHD will contact them shortly and respond as quickly as possible, even outside office hours.

I like it that she's, like, easily accessible and, yes, if need be, I can also apply for a meeting or telephone call or an email ... she's always, like, pretty good in replying to those. (ID7)

Moreover, participants highly valued that both frequency and the way of contact are tailored to everyone's personal needs.

These experiences increase the feeling of safety and create a sense of closeness with their CMHD as a point of contact.

Most participants highly valued and appreciated the CMHD's expertise. This was exemplified by the participants acknowledging the CMHD's profound understanding and knowledge of HD, indicating their sense of being truly understood. In addition, CMHD's experience with multiple individuals with HD equips them with valuable insights into specific situations, enabling them to readily offer guidance or support in comparable situations, whether it be at patients' homes or workplaces.

That's partly because she knows the clinical picture and therefore understands it. I could tell anyone around here, but no one understands. But my case manager does, so that already makes a big difference. (ID2)

Participants also value the suggestions made by their CMHD, such as considering temporary admission to a nursing home or utilizing the day care center. Also highly appreciated is the guidance and support in case of challenges with employers, social security, or benefits administrations.

Look, it's nice that you're nice, but I also find her to be competent. (ID13)

Furthermore, participants experience the CMHD as one who has an overview of the availability of engaged and suitable professionals to solve specific problems, when needed. The CMHD is also perceived as someone who takes decisive action in implementing interventions when the situation requires it, such as arranging for home care services.

In addition to being viewed as a coordinator, relevant point of contact, and expert, the CMHD represents someone who offers mental support. Participants think that it is reassuring to be able to rely upon their CMHD whenever they need help or support. They highly appreciate being able to talk about everything and ask the CMHD what is problematic for them. Metaphorically speaking, participants describe the CMHD as *a pillar, a warrior, and as*

*Metaphorically speaking, participants describe the CMHD as a pillar, a warrior, and as back support.*

*back support.* Participants also positively valued the personal attention of the CMHD to their social life. Apart from feeling seen and heard by the CMHD, it means a lot to them to have the CMHD's respects for their autonomy, while simultaneously providing advice and support to both them as patients and their partners.

And you're not forced into things or such that you've got to go and do certain things or whatever, you're kind of free in what to do, and I really like it this way. (ID8)

Participants expressed that they also highly valued the support provided by their CMHD in case of important choices such as reporting sick and disability benefits or making use of the day care center. They experience their CMHD as someone who understands and backs up their decisions, listens, looks beyond the "sick person," shows respect, and sees one in its full value.

### *Theme 3: Impact of CMHD on QoL*

Arising from the way the participants experienced the CMHD both as a person and a professional, participants expressed the impact that the CMHD has on their QoL. Subthemes within this third theme are support in coping with decline and monitoring the home situation.

Many participants feel supported by their CMHD when talking about their disease, their future with HD, and the upcoming decline related to HD. Even thoughts and wishes about euthanasia can be discussed with their CMHD, which felt good in terms of being able to do something or making future arrangements in time and in line with their personal wishes and in consultation with the CMHD. Someone shared that talking with the CMHD stimulates one to change perspectives, which helps to cope with decline. Furthermore, communication with and support of the CMHD bring peace of mind and calm, where there used to be stress and tension.

I wouldn't really know what I don't like about it. That's what I say, she just counsels us. That means that there's a lot of peace and quiet here. (ID9)

Participants expressed that they felt being seen as a full-fledged person and not as a person with limitations by their CMHD. This acknowledgment helps in

coping with HD both in general and in terms of the decline associated with the disease.

The CMHD provides practical tips and advice on resources and support options such as personal alarms, assistance with showering, and of the arrangement of adjustments in their house. This enhanced the interviewees' hope of being able to live longer at home. Next to that, these kinds of solutions contributed to a feeling of less dependency on their partner and the possibility to be able to do fun activities again. The participants also highly appreciated the CMHD's focus on the overall home situation and family life.

Not how things are going with me alone but also how things are going with our family life. At one point, that didn't go with the flow either. (ID8)

All these aspects and contributions of the CMHD improved the experienced QoL of participants.

#### **Theme 4: Support of CMHD for Family Members**

Almost all participants experienced the support of CMHDs for their family members. This finding led to two subthemes: providing help to family members and giving attention to family members.

In addition to the support for themselves, the participants also described the help provided by the CMHD for their family members. Multiple participants expressed how their family positively experienced this support. CMHDs provide suggestions such as peer support groups or temporary admission of the client to a specific Huntington ward in a nursing home.

It's already all about me [...] And such things, those practical matters, yes, it's also very important for my husband when she's paid him a brief visit again. He says that. I think he feels really well supported when she's there. (ID3)

Participants also acknowledged that both themselves and their spouse experience improved coping with HD due to the facilitated open discussions initiated by the CMHD.

In most cases, the spouse is present during the visits of the CMHD. At any given time, support and attention provided for their spouses by the CMHD are highly valued by interviewees. Attention for family member's needs, wishes, or uncertainties regarding the future is appreciated. Some participants feel that it can be valuable for their children to be in contact with the CMHD, because this might contribute to deal with the disease, decline, or situation better.

My wife and the children too, because they've also been present a few times ... how we can cope with it all this way. (ID8)

## **DISCUSSION**

The aim of this study was to gain insight in experiences of ambulatory HD patients with the care, guidance, and support provided by a CMHD. The findings of this explorative study demonstrate that patients highly appreciate and value the role and support of the CMHD. This was reflected in four themes:

1. The CMHD as a person, with commitment, sympathy, and reliability as central concepts.
2. The CMHD as professional, with the key roles of coordinator, point of contact, expert, and supporter.
3. Impact of the CMHD on QoL, with support of coping with decline and monitoring the home situation as important subthemes.
4. Support of the CMHD for family members, with providing help and giving attention as subthemes.

Overall, our findings show similarities with findings in the study by Verkade et al. (2010). They conducted a Delphi study among care professionals to identify the essential components of case management for people with dementia as well as the preconditions for an effective delivery of case management services. They also found that coordination of care, additional support, and counseling for the family members and level of expertise are essential components of case management. Our study on patients with HD demonstrates that these components are also valued by patients themselves.

In our first theme, participants expressed high value of the CMHD as a person. They appreciated the commitment of the CMHD, and the experienced reliability of the CMHD created an openness to share sensitive topics. Similar characteristics, among which are interpersonal skills, empathy, and a positive therapeutic relationship, are described as important for a case manager's role in a review of CM programs for dementia (Schiller et al., 2021). The common ground of all of these characteristics, and perhaps the base of the high value CMs as persons receive, is that they all potentially contribute to what may be by participants called a "bond of trust" (Schiller et al., 2021).

Our second theme reflects relevant roles the CMHD fulfills as professionals. These findings are in line with those found in a review on the experience of the CM by patients with other chronic illness such as dementia, diabetes, or heart disease (Joo & Liu, 2018). In this review, the patients reported to overall appreciate the CM in facilitating access to health care resources and coordinating between health care professionals. Participants in the studies reviewed by Joo and Liu (2018) also experienced the role of the CM as very useful in connecting them with services

more quickly and easily than traditional health care providers. Similarly, patients with HD in our study experience their CMHD as a central point of contact and coordinator, who engages professionals around the client when needed. Furthermore, participants in our study highly valued the expertise of the CMHDs. Their insight and knowledge regarding the disease made them felt understood. These findings are in line with the position paper of Mühlbäck et al. (2023) on multidisciplinary treatment and care in HD. They depict that the key to the value of case management is “the consistent presence of the CMHD with knowledge of the disease, the individual and the system of the individual.”

CMHDs have an impact on the QoL of HD patients. Our findings with regard to our third theme suggest that the support of the CMHD brings peace of mind and calm. These findings are in line with the results from Bakker et al. (2015) and Gowing et al. (2016). Bakker et al. (2015) performed a qualitative study on the perspectives of patients with amyotrophic lateral sclerosis, sometimes called “Lou Gehrig’s disease,” and their spousal caregivers and professionals. Amyotrophic lateral sclerosis is a progressive disease that also impacts motor functioning and manifests at a relatively young age as is the case with HD. The qualitative study by Gowing et al. (2016) explored perspectives of frail patients receiving community case management. In both studies, the CM was valued for his or her role in fulfilling their care needs, and participants felt comfortable in receiving interventions by the CM. Next to other aspects, the participants felt emotionally supported by the CM and described their relationship with the CMs as close. As one caregiver said, “I felt calmer with a CM than without. I felt reassured that everything was taken good care of” (Bakker et al., 2015, p. 184).

Although there are many similarities in our findings and the findings by the review of Joo et al. (2018) and Schiller et al. (2021), compared with dementia, HD is a progressive disease that generally manifests at a younger age. This may create some nuances and differences. Issues that patients with HD have to deal with, such as the heredity of the disease, children still living at home, and (un)employment, emerged in the interviews as important topics of discussion in contact between the patients and their CMHD. This was also evident in our fourth theme, which highlighted the support provided by the CMHD to family members. Considering the hereditary nature of HD, it necessitates the CMHD to pay special attention, as multiple family members are likely to be HD patients themselves. These issues require a high versatility of skills and possibly additional skills for CMHDs in comparison with other case managers in other diseases. The support of the CMHD for family members

is recognized in our study from the perspective of the patient with HD. Nevertheless, it would be interesting to also explore the view and experiences of family members of HD patients regarding the support provided by the CMHD and assess potential differences and similarities between patients and family members.

## Strengths and Limitations

The strength of this study is the emphasis on the patients’ perspective especially by interviewing HD patients themselves. An equal distribution among the three case managers of the participants and a variation of the selected patients regarding age, gender, and living situation contributed to a representative sample, which makes transferability of findings to other CMHDs plausible. Yet, a limitation is that our findings are limited to the situation in the Netherlands, which may hinder the generalization to a wider international context. However, given the positive outcome of our study regarding CMHD, other countries that do not have a CM for patients with HD can benefit from implementing a CMHD in their care. Although the interviews revealed many positive aspects about CMHDs, during the interviews less attention was given to points for improvement for case management HD. Further research could address this more explicitly in the topic list.

## CONCLUSION

To our knowledge, this is the first study exploring in depth how ambulatory patients with HD experience and value the care and support by a CMHD. Despite the potential limitations, the qualitative findings from a patient’s perspective importantly add to the body of knowledge on CMHD’s role and practices as “spider at the center of the web.”

Case management was highly appreciated and valued by ambulatory HD patients. Commitment, expertise, support also for the family members, and bond of trust from the CMHD are experienced as very valuable. This newly gained insight into patients’ experiences of the CMHD’s role is of added value to improve the international quality of care for people with HD.

## Implications for Case Management Practice

Commitment, expertise, support for both family members and patients, and bonds of trust from the CMHD are experienced as very valuable. These qualitative findings from a patient’s perspective add significantly to the body of knowledge on CMHD’s role and practices as “spider at the center of the web.”

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