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Support Need Among Patients with Huntington Disease in the Netherlands: Results of a Focus Group Study

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ABSTRACT

The course of Huntington's disease (HD) is progressive and relentless, but symptoms vary greatly, turning HD patients into a heterogeneous group of patients. Little is known about the support need of HD patients seen from their point of view and whether these needs are met. The aim was to describe the support needs of patients with Huntington's disease and the problems they experienced in order to better contribute to patient-centered care for these patients.

This was a qualitative study in which nine patients in Huntington's disease stages III-V participated in three focus group interviews. The interviews were video recorded and thematically analyzed. Four men and five women participated; ages ranged from 43 to 67 years. Six patients were living at home, four of whom visited a day care facility, and three patients were living in a nursing home.

The discussion in the focus groups centered on three types of support needs: healthcare related support need, practical support need and social support need. The underlying problems were uncontrolled movements, instability, lack of energy, sleep disturbance, memory loss, lack of concentration, angry outbursts, inability to control impulses and impending isolation, family issues, loss of friends and loss of employment.

Learning about the patients' perceptions of problems and their needs for care and support may help healthcare professionals better understand the complexity of Huntington's disease and find adequate client-centered care and interventions.

Keywords

Focus group study, Huntington's disease, Patients' perception, Support need.

Introduction

Huntington's disease (HD) is a hereditary progressive neurodegenerative disorder, characterized by motor, behavioral and cognitive symptoms [1]. The disease was first described by George Huntington [2] and is caused by expended cytosine-adenine-guanine-repeats on the HD gene [3].

The prevalence of HD in Western Europe and North America is approximately 3.60 and 7.33 per 100,000 individuals, respectively [4]. In the Netherlands, it is estimated that 1,700 people are affected and approximately 6,000–9,000 people are at hereditary risk of the disease [5]. HD is an autosomal dominant genetic disorder, so offspring have a 50% chance of inheriting the gene mutation. This genetic component may cause an enormous burden for family members [6]. Although onset of the disease is possible at any time between the ages of 1 and 80 years, in most patients post symptoms of HD start to show between 35 and 50 years of age, when career and family life are developing [7].

The first symptoms in patients are subtle changes in personality, cognition and motor control [1]. Family members and healthcare professionals who have little experience with HD may not link these symptoms to it. Therefore, it often takes some time before the HD diagnosis is finally made. Then delay in diagnosing may

cause delay in seeking help and finding appropriate support. In time, the most prominent symptoms of HD are motor symptoms, such as involuntary and uncontrolled movements (chorea), poor coordination, gait and balance problems, cognitive symptoms (e.g., impairment in organizing and planning), and behavioral symptoms (e.g., anxiety, disruptions of aggressive behavior, obsessions, compulsions and delusions) [8-10].

Moreover, the ability to speak (dysarthria) and comprehend language deteriorates in line with the general disease progression [11].

HD affects the everyday lives of HD patients [12]. Ho, Hocaoglu and the European Huntington's Disease Network Quality of Life Working Group [13] described the impact of HD from the patients' perspectives, throughout the full illness trajectory from preclinical to end-stage HD. Patients raised issues and concerns regarding physical problems such as changes in balance and walking, and social and emotional issues such as independence and self-confidence. Issues and concerns regarding physical functioning were increasing strongly over time [13]. The course of HD is progressive and relentless, but symptoms vary greatly, turning HD patients into a heterogeneous group of patients.

Care for HD patients is often fragmented because of the variety of neurological and psychiatric symptoms associated with cognitive decline. Although a multidisciplinary approach is needed [14], nurses may play a pivotal role in recognizing and identifying the future problems of HD patients. Specialized nurses often play the role of case manager on a multidisciplinary team [15]. However, there is a distinct absence of guidelines to guide nurses and other healthcare professionals in their work.

In addition, little is known about support needs from the HD patients' point of view and whether those needs are met. Better understanding of the disease and the HD patient as a person will help patients and their families, nurses and other healthcare professionals in making choices about how the disease should be managed.

Study aim

The aim of this study was to describe HD patients' needs for support regarding the problems they experience and to recognize/identify their patterns of support need. In addition, the results may provide more tailored and personalized care and may contribute to patient-centered care for HD patients.

Methods

Study design

A descriptive, qualitative design using focus group interviews was adopted. Three focus group interviews were conducted with HD patients to identify their support need regarding the problems they experienced. Our main aim was to gain a better understanding of the HD patient as a person and their perceptions of the problems they experience and their needs for support. Each focus group interview took approximately 1.5 hours.

Recruitment

Purposive sampling was used to invite Dutch-speaking HD patients to participate in the focus group interviews. They fell into one of three categories: 1) living at home, 2) living at home and visiting a day care facility, or 3) living in a specialized HD nursing home; these categories were labeled stage III, stage IV and stage V, respectively, as described by Shoulsen [16] (Table 1).

Early Stage	The person is diagnosed as having HD and can function fully both at home and work.
Early Intermediate Stage	The person remains employable but at a lower capacity. They can still manage their daily affairs despite some difficulties.
Late Intermediate Stage	The person can no longer work and/or manage household responsibilities. They need considerable help or supervision to handle daily financial affairs.
Early Advanced Stage	The person is no longer independent in daily activities but can still live at home supported by their family or professional carers.
Advanced Stage	The person with HD requires complete support in daily activities and professional nursing care is usually needed.

Table 1: A compilation of the stages of Huntington's disease as described by Shoulson (1980).

To recruit patients living at home, the Dutch Huntington Association placed an invitation on their website and randomly sent letters to 50 patients living in the region near the HD specialized nursing home where the focus group interviews would be conducted. The team managers also invited ten patients living in the HD nursing home and 16 patients visiting the day care facility. Those patients received an invitation letter and were asked to participate. Patients were included if they were willing and able to communicate in a small group.

Data collection procedure

The topic list (Table 2) for the focus group interviews was developed using related literature and the research team's experiences. The topic list had been peer reviewed with research colleague's and the team managers of the HD specialized nursing home in order to check its appropriateness. Using open-ended questions, participants were encouraged to describe and discuss their experiences regarding 1) the consequences and impact of HD on their daily life, 2) how they cope with the disease and 3) what kind of support they need. The focus group interviews were conducted by MA (an experienced moderator, senior researcher and third author) and WG (researcher and second author) observed the interviews. The focus group interviews were video recorded.

Topic list
What are the most important consequences of HD and your treatment?
What impacts have the disease and treatment had on your daily life (e.g., physical, cognitive and psychosocial consequences)?
Which consequences are difficult to cope with?
How do you cope with this?
What kind of support do you have?
What could others, including healthcare professionals, do for you?

Table 2: Topic list for focus group interviews.

Data analysis

The focus group interviews were thematically analyzed by one investigator (WG) using Observer XT Software [17]. Observer XT is a package for analyzing video interactions. Observational data can be collected, reviewed and edited with synchronized display of the corresponding video images. The support needs and experienced problems were labeled, defined and categorized into themes and sub-themes. For example, one theme was 'healthcare-related support need'; its sub-themes were 'physical support related to treatment and care', 'information related to disease and heredity' and 'emotional support.'

To increase validity and reach consensus, BvG (see acknowledgement) also coded quotes from one patient in each category. BvG and WG discussed their findings until consensus was reached. Finally, the findings were discussed again and validated by WG and EV [senior researcher and first author].

Ethical considerations

The ethical committee CMO Arnhem-Nijmegen, the Netherlands approved the study and declared that it does not fall under the Medical Research Involving Human Subjects Act (WMO), the Dutch Medical Ethical Law. An information sheet assured all patients that they would remain anonymous and that researchers would maintain strict confidentiality guidelines. Participants' written informed consent was obtained.

Results

Nine HD patients participated in the three different focus group interviews: 1) two patients were living at home (stage III), 2) four were living at home and visiting a day care facility (stage IV) and 3) three were living at a nursing home (stage V). Four men and five women participated; their ages ranged from 43 to 67 years. The patients were known to have had HD for 1 to 15 years. The patients' characteristics are shown in Table 3.

	Gender	Age	Living situation	Years with known HD	Marital status	Child-ren	HD Stage* (I-V)
R1	Male	67	Nursing home	15	Married	Yes	V
R2	Male	43	Nursing home	6	Single	No	V
R3	Female	59	Nursing home	12	Married	No	V
R4	Female	46	At home and day care	8	Divorced	Yes	IV
R5	Male	49	At home and day care	2	Married	Yes	IV
R6	Male	45	At home and day care	8	Divorced	No	IV
R7	Female	50	At home and day care	2	Married	Yes	IV
R8	Female	54	At home	2	Divorced	No	III
R9	Female	58	At home	1	Widow	No	III

Table 3: Participants' characteristics.

*Stages of Huntington's disease as described by Shoulson (1980).

The focus group interviews identified numerous support need related to the HD patients' physical, psychological and emotional symptoms, treatment and care, social life and practical issues. The focus group discussions centered on three types of needs: healthcare-related support, practical support and social support.

Theme 1: Healthcare-related support

Physical support related to treatment and care

HD patients mentioned suffering from physical symptoms such as uncontrolled movements, physical instability, lack of energy and sleep disturbance. They expressed their need for support from nurses and other healthcare professionals to cope with these problems. Patients found it difficult to find a balance between their energy level and their activities. They greatly appreciated occupational therapists' practical support for their daily lives (e.g., making daily schedules for their energy distribution during the day). The occupational therapists also support patients in becoming aware of certain actions, such as deliberately placing a cup on the table, and providing them with equipment support, such as special drinking cups. We observed patients using these special drinking cups during the interview. Most patients experienced difficulties in swallowing and speaking.

"Many people ask me 'What did you say?' while I am not aware that I speak differently." (R9)

We observed one patient choking while drinking her coffee (P3), a swallowing problem she acknowledged as increasingly problematic. Several patients mentioned the speech therapists' support for speech and language therapy, controlling their swallowing difficulties and improving their communication skills. In addition, we observed that several patients had speaking and communication difficulties, such as slurred and slow speech, not finishing sentences and long pauses between sentences. Physiotherapists provide physical and balance exercises that enable patients to feel better.

"Last year, I had so many involuntary movements; it has become much less [movements] than before." (R9).

They all experienced positive effects from their medication, which reduced uncontrolled movements and indirectly stimulated their communication. Nevertheless, we observed chorea in all the patients, most prominently in those who were living in a nursing home. Some patients tried to disguise their uncontrolled movement by making gestures like straightening their jacket or shirt or keeping the arms tightly crossed. One patient told us she had deliberately hidden her legs under the table during the interview because she would not show involuntary movements of her legs. Finally, patients need the dietician's support to develop an appropriate diet plan with energy-enriched food to prevent weight loss.

"Although I have a good appetite, I suffer from weight loss." (R8)

Information related to disease and heredity

Patients emphasized their need for more information and support from healthcare professionals about how to inform their family members about the disease, HD testing and the consequences of

testing. Patients mentioned that their diagnosis and the hereditary nature of the disease led to enormous consequences for themselves and the rest of their families. On one hand, it "explained" certain (strange) symptoms of patients or family members.
"The diagnosis was fierce, but I wasn't shocked. It was a relief. [..] I was calm; it just fits." (R9)

On the other hand, patients found it difficult to perceive symptoms of HD among family members, and especially among those who do not want to be tested. These patients did not want to be confronted with the disease.

The diagnosis also leads to another dilemma: to have children or not? Two patients who do not have children expressed relief at not having them. Patients who do have children mentioned they did not know they had HD when their children were born. Patients who were parents expressed a great need for more support and information for their children because, from their perspective, professional support is lacking. These parents wanted to know how they could openly inform their children about the disease, especially when the children grew older. What could they tell them? In addition, patients expressed difficulties in talking with their children about HD and did not know how to best respond to their children's questions.
"What do you say when your child asks you if you will die soon?" (R4)

Patients think that information about the disease and its hereditability will help their children understand more about the disease and they need professional support for this.

Emotional support

HD patients expressed their need for emotional support from healthcare professionals. For example, they wanted support from a psychologist or nurse case manager to handle their emotions, problems and difficulties in coping with the disease.
"After [a consultation], it keeps me going for a while." (R7)

Patients frequently mentioned psychological and cognitive problems during the focus group interviews: memory loss, lack of concentration, angry outbursts, loneliness and an inability to control their impulses. Some patients indicated that they hear voices as well:
"Ten times an hour, I ask and tell the same thing." (R4)
"When I am in the city center, I HAVE to buy something." (R9)
"It says I have to kill myself." (R3)

Patients worry about their symptoms and psychological and cognitive decline. A mother expressed her concern and uncertainty about her memory loss:
"I have been fooled by my children. I just don't notice that." (R4)

Patients are depressed, anxious and uncertain about their future. They expressed their difficulties in coping with the disease and its consequences.
"I am aware of my rapid deterioration; that frightens me." (R9)
"I found it hard to lose everything in two years: my job, my relationships…everything." (R8)

Most patients found it difficult to see what kind of support they would need in the future.
"I know exactly what my future is. I want to arrange everything right now to get some control over that part of my life." (R9)

Theme 2: Practical support

Patients mentioned that the nurse case manager was the most important healthcare professional when it comes to practical support. All the patients who still lived at home highly valued the support of their nurse case manager.

Work-related support

Due to the disease, most patients were unable to work. They mentioned reasons for unemployment such as inabilities to cope with the demands of the workplace, a lack of understanding by colleagues and being unable to find a new job. Patients mentioned their regret at no longer being able to work; they mentioned feelings of loneliness, loss of contacts, and difficulties with acceptance. After quitting their job, they experienced the support of the nurse case manager in arranging financial reimbursements as very positive.

Only one patient was still able to work, and she had noticed a decline in her job performance, workload and working level. She mentioned being afraid of losing her job; her work made her feel she still had another life besides being a HD patient. She received a lot of support from colleagues in organizing and structuring her workday.

Living support

Patients who still lived at home expressed their need for support from a cleaner, an occupational therapist and/or a case manager for arranging adjustments in their homes.
"Domestic help or a housekeeper who will cook and look after the children. I really have no energy left to cook when I come home from the day care facility." (R4)

In the future, patients know they will have to find a customized home or a nursing home because their condition will deteriorate to an extent that primary healthcare professionals will no longer be able to provide the necessary care. Patients living in the nursing home mentioned that they found it hard to no longer be able to live at home.

Theme 3: Social support

Support related to a partner

Patients often indicated that it was their partner who noticed the first symptoms, such as forgetfulness, when they themselves were not yet aware of them. They also mentioned receiving the most support from their partners or spouses. Three of the nine patients were divorced.
"My husband said Huntington's was not the reason [for the divorce], but I think it was." (R8)

The divorced patients said they felt lonely and would really like to find new partners. Although patients are aware of the burden the disease places on their partners, they do not know how they can help and support them.

"If my wife were to seek help, she would probably find that she is not alone." (R5)

Most patients knew that the Dutch Huntington Association arranges special meetings for partners on a regular basis. Some patients indicated that visiting the day care facility or being admitted to a nursing home may unburden their partners. Nevertheless, the patients who were living in a nursing home dearly missed their partners.

Support related to children

The HD patients with children were concerned about the disease's consequences for their children. They were glad they could entrust their story to a psychologist or nurse case manager and could count on their support. One mother expressed difficulties with being different than other parents (e.g., being unable to do everything with her children because of her lack of energy). The patients were aware that their disease has an enormous impact on the lives of their children. Often, the situation at home is so complex (e.g., due to memory loss and anger outbursts) that children can no longer live at home. One patient dearly regretted her daughter leaving home, but knew there was no other option.

"Our oldest daughter wanted to come back, to live at my place, but it was impossible." (R4)

"I can't trust myself anymore. I am so afraid I will do something to my child, that I'll beat her black and blue… It is impossible to describe that … that fear." (R4)

Patients found it hard to watch their children struggle to cope with their disease.

"My daughter quit her studies because she wanted to travel. […] But she hasn't even been tested, so she doesn't know if she has HD or not." (R5)

Discussion

Huntington's disease is a progressive disease, accompanied by a great variety of physical, psychosocial and behavioral problems. We interviewed nine HD patients about their support needs for dealing with the problems they experienced.

In general, the support of nurses and other healthcare professionals is essential. HD patients mentioned their need for support from nurse case managers, physicians, physiotherapists, psychologists, occupational therapists and speech therapists. The nurse as the case manager is considered to be the first contact person for patients and caregivers [15]. In the nursing homes, nurses and physicians were also identified as important.

The patients needed different types of support. In addition to the support of healthcare professionals, they needed medication to stabilize, prevent or reduce their symptoms. Patients expressed several support needs related to professional, practical and social support from healthcare professionals, and social support from partners and family members. All the patients experienced physical, psychological and social problems, such as uncontrolled movements, instability, lack of energy, sleep disturbance (physical), memory loss, lack of concentration, outbursts of anger, inability to control impulses (psychological) and loss of employment (social). These issues match the problems mentioned by patients in the study by Veenhuizen and colleagues [15].

Although HD patients mentioned physical and psychological problems caused by HD, they are not always aware of their limitations. Their perceptions seem to be different from those of their partners or children. Sometimes, this makes it very difficult to really understand what they think, feel, want and need. The more progressive the disease, the more difficult this becomes. However, the patients in this study indicated that they were aware of their deterioration, although they contradicted themselves at times (e.g., "Many people ask me 'What did you say?', while I am not aware that I speak differently.").

Sitek and colleagues [18] concluded that people with HD may under-report the presence and severity of involuntary movements, under-estimate cognitive impairment and deny behavioral change. However, it is not clear which physiological or cognitive factors may contribute to the loss of awareness [18]. Sitek and colleagues [18] stressed that it is important that all involved healthcare professionals recognize this loss of awareness and they considered this to be crucial for optimal care and patient management.

HD patients may require encouragement to manage their disease because of loss of executive functioning and changes to illness perception [18-20]. However, it matters for patients to be known as the people they were before the changes inflicted on them by the progression of the disease [21]. In addition to the abovementioned factors, McCusker and Loy [22] found that there may be some indications that unawareness in HD patients is neurologically based due to impairment of functional networks in the frontostriatal pathways of the brain.

The patients in this study were aware of the burden on their partners and other family members. Nevertheless, they strongly rely on them and receive the most social support from these caregivers. When trying to understand HD patients, we undoubtedly need to understand their partners and loved ones as well.

A literature review by Domaradzki (2015) identified several aspects of caregiving as the most burdensome to family, such as loss of a meaningful relationship with the patient, family breakdown, concern for children, loss of social contacts and decrease in health [23]. These aspects make caring for HD-affected family members demanding and stressful. Particularly in the later stages of the disease, family caregivers tend to put their own lives on hold. Although professional attention is drawn to the affected family member, unaffected family caregivers probably need the most attention, support and help.

Healthcare professionals should be aware of the risk that caregivers can become isolated from family, relatives and friends and, therefore, they should monitor their mental health and identify their sources of distress [23,24].

Patients found it difficult to talk with their children about the disease. HD is not often talked about, as many families conceal the existence of HD and its consequences and/or implications [25]. In our study, patients who were parents expressed a great need for more support, education and information for the benefit of their children. Parents wanted to know how they can inform their children in an open way about the disease, especially when their children are getting older. Not knowing how to do so, underlying feelings and unspoken issues may strain the relationship between patients and their children. Growing up in a family affected with HD may increase the risk for psychopathology and other problems in childhood and adulthood [26]. This is particularly true for children who grow up with a single affected parent who is emotionally unavailable or exhibits increasing unmanageable symptoms [27].

Limitations

A limitation of this study is that only nine HD patients participated in three focus groups. This is a small number of patients and group size but, given what is known about HD, we deliberately chose to interview patients in small groups. Speaking to each other and sharing experiences in large groups is very difficult for HD patients. Nevertheless, we noticed that some patients, especially those living in a nursing home, had difficulties answering and discussing questions and issues we presented to them. But we really wanted to learn from their perceptions and not those of partners or other significant others.

Another potential limitation was the recruitment of HD patients. Patients visiting the day care facility or living in one specialized nursing home were invited to participate in the focus groups. We do not know if there was a pre-selection for patients to which the invitation was sent. In addition, patients still living at home were invited using the website of the Dutch Huntington Association [5], combined with open invitation letters sent to members of the association living near this one nursing home. We have not achieved saturation, so our results cannot be fully generalized, so further research is needed. However, our results provide a better understanding of the HD patient as a person and their perceptions of their problems and support need.

Conclusion

This study taught us about HD patients' perceptions of the problems they experience, and we heard their needs for care and support. Their perceptions may well differ from those of others, such as nurses and other healthcare professionals, informal caregivers, partners and family. Yet it is vital to be aware of their stories, so we can try to place ourselves in their shoes. This may help us better understand this complex patient group and find better client-centered care and interventions.

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