

Family caregivers' experiences with healthcare services – a case of Huntington's disease

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Summary

Introduction. Despite a growing interest in the health and psychosocial consequences of caring for a person with Huntington's disease (pHD), little is still known about family caregivers of such patients in Poland. At the same time, while researchers focus on the needs, quality of life and caregiving burden, they frequently omit caregivers' experiences with healthcare services.

Aim. This paper aims to report a study on the perception of healthcare services of family caregivers of pHD.

Material and method. The research was carried out between August and December 2014 among 55 family caregivers of pHD. The respondents were recruited via the Polish Huntington's Disease Association and a discussion forum for pHD and their carers. The material was collected via semi-structured interviews and analysed using a content and thematic analysis of the transcripts.

Results. Four themes emerged during the interviews: 1) Lack of information on HD from physicians; 2) Negative experience with health professionals 3) Lack of emotional support, and 4) General dissatisfaction with healthcare services. Caregivers were frustrated by the lack of knowledge about HD from physicians and believed that they do not show enough empathy and support to caregivers. They also felt let down by the system and expressed general lack of trust in the standard of healthcare.

Conclusions. This study revealed HD caregivers' complex needs for healthcare assistance and emotional support. For that reason health and social professionals should monitor caregivers' mental health, identify the sources of their distress and support effective strategies to cope with the stress.

Key words: family caregivers, healthcare services, Huntington's disease

Introduction

Huntington's disease (HD) is a progressive neurodegenerative disease of the brain caused by a mutation in HTT gene. It causes a loss of motor skills and movement abnormalities, cognitive and affective disturbances and a loss of behavioural functions. HD usually starts at the age of 35–45, but there is a wide variation of the age of onset. The course of HD runs, on average, for 15–20 years. Currently there is no cure for HD. The patient's death is usually caused by secondary illness, mainly aspirational pneumonia, choking and suicide. HD is inherited as an autosomal dominant trait. Due to its genetic character, HD may be present in multiple family members. Since the gene mutation that causes HD was identified in 1993, predictive testing for those at risk is possible [1–3].

While research focuses on the clinical dimension of HD, less attention has been paid to informal carers of persons with HD (pHD). On the other hand, although there are studies on the psychosocial consequences of caring for pHD [1, 2, 4–8] little is still known about such caregivers in Poland [9]. Meanwhile, research shows that it is often the unaffected family carer who needs the most attention, support and help [1, 2, 4–9]. Nevertheless, despite all the problems related to caregiving and HD itself, one of the most common themes in caregivers' narratives refers to their negative experiences with the healthcare system [10, 11], the reason being that health professionals lack knowledge about the clinical aspects of HD and practical information on management of its symptoms and treatment [1, 2, 6, 10, 12,–18]. They also lack experience in working with pHD and their families. HD carers are often disappointed with the time and amount of information they receive from physicians who are unaware of caregivers' needs and do not understand their problems [10, 18, 19]. Furthermore, as pHD are relatively young, they are frequently refused treatment that is usually offered to gerontological patients [11–13]. On the other hand, health services are often available to them only in crisis situations [2, 14, 15]. Finally, such services are not only less available to pHD but also ineffectively organised and unadjusted to their needs [1, 10, 11, 16, 17]. Additionally, as HD in Poland is not found on the governmental list of chronic diseases, pHD have a limited access to modern drugs for symptomatic treatment [10]. For all these reasons HD carers feel neglected by the healthcare system and describe their caregiving as a 'lonely ride' [11].

Aim

This paper aims to report a study on the perception of healthcare services of family caregivers of pHD and to describe the problems they experience in a medical setting.

Material and method

Design and procedure

This research is part of a larger study on family caregivers of pHD. The data reported here are from semi-structured interviews with such caregivers. The questions asked during the interviews were based on a review of the literature [20] and objectives were focused on the participants' experiences with the healthcare system, including family physicians and specialists, accessibility to modern treatment, contact with a genetic clinic, availability of information on HD and support from physicians. The themes were explored using open-ended questions.

The study was carried out between August and December 2014 on 55 family caregivers of pHD. The respondents were recruited via the Polish Huntington's Disease Association and a discussion forum for pHD and their carers (<http://forum-hd.zamki.pl>). Potential participants received an invitation via HD website and those who responded were interviewed. Not all caregivers addressed responded and agreed to participate in the study. Those who volunteered were interviewed either by an emailed questionnaire (n = 40) or personally by the author (n = 15). The respondents questioned in person were interviewed only once and those interviewed via a mailed questionnaire were encouraged to develop some issues by answering additional questions via email or a telephone conversation.

The participants were included if they: were aged over eighteen, identified themselves as a family member of pHD, were directly involved in the patient's care, and were eager to participate in the study.

Methods of analysis

The data from interviews were read, coded and analysed using a content and thematic analysis of the transcripts [21]. A matrix of the codes was constructed according to the themes that emerged from the interviews. The codes were organized into domains and descriptive results were outlined. A grounded theory approach was the basis for the analysis [22].

Ethical issues

The author was aware that the caregivers of pHD formed a vulnerable group and that the questions asked during the interviews could be distressing to them. Thus, all the respondents were informed that they were free to quit the interview at any given moment and/or not to reveal information on their personal circumstances. All the participants gave their voluntary informed consent.

Participants

All study participants ($n = 55$) were family caregivers of pHD living at home. The sample consisted of 39 females (70.9%) and 16 males (29.1%), all of Polish origin and white. The majority were aged between 50 and 70 ($n = 24$; 61.8%). 24 caregivers were patients' spouses (37.4%), 12 caregivers were their parents (18.8%) and 11 were their children (17.2%). Of caregivers having children, 15 had one child (27.3%), 20 had two children (36.4%) and 11 had three or more (20%). Only 8 (13.8%) of those children were HD negative, while 24 were somehow affected by HD: 8 of them had juvenile HD (13.8%), 8 were HD carriers (13.8%) while another 8 suffered from HD (13.8%). Another 26 children (44.8%) were at risk of HD but did not undergo testing. 44 respondents (80%) were primary caregivers. 25 caregivers (45.5%) declared spending an average of 6–12 hours per day on caregiving while for another 15 (27.3%), it took more than 12 hours per day. The mean time of caregiving was 8.4 years ($SD = 4.9$; range 1–20). While all stages of HD were represented in the sample, 40 (72.7%) patients were in an advanced stage. The mean time of diagnosis was 10.5 years ($SD = 7.1$; range 1–30). 28 respondents declared membership in local support groups. Detailed characteristics are shown in Table 1.

Table 1. Socio-demographic characteristics of the caregivers

	N	%
Gender:		
male	16	29.1
female	39	70.9
Age:		
20–29	6	10.9
30–39	2	3.6
40–49	13	23.6
50–59	18	32.7
60–69	10	18.2
Above 70	6	10.9
Marital status:		
Single	2	3.6
Married	35	63.6
Cohabiting	6	10.9
Widowed	10	18.2
Divorced	2	3.6
Domicile:		
Rural	12	21.8
Small town	12	21.8
Sub-urban	4	7.3
Urban	9	16.4
Metropolitan	18	32.7

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Children:		
1	15	27.3
2	20	36.4
3 or more	11	20.0
No children	9	16.4
Child's health status (n = 58)		
Juvenile HD	8	13.8
HD carrier	8	13.8
Suffers from HD	8	13.8
Negative test result	8	13.8
At risk, but did not undergo testing	26	44.8
Caregiver status		
Primary caregivers	44	80.0
Secondary caregivers	11	20.0
Relationship with HD patient (HD patient is my) (n = 64*)		
Spouse/partner	24	37.4
Parent	11	17.2
Child	12	18.8
Sibling	6	9.4
Other relative	11	17.2
Stage of disease		
Early stage	2	3.6
Middle stage	13	23.7
Late stage	40	72.7
Diagnosis (in years); mean (SD)	10.5 (7.1)	
Daily time dedicated to caregiving		
More than 12 hours per day	15	27.3
6–12 hours per day	25	45.4
Less than 6 hours per day	15	27.3
Time of caregiving (in years); mean (SD)	8.4 (4.9)	
Membership in local support group		
Yes	28	50.9
No	27	49.1

* N = 64 is the number of patients. Some of carers took care of several patients, for example: spouse and his/her parent or child, this number is different from the number of the surveyed caregivers, which was 55.

Results

The core identified themes were: 1) Lack of information on HD from physicians; 2) Negative experiences with health professionals; 3) Lack of emotional support and 4) General dissatisfaction with healthcare services.

Lack of information on HD from physicians

The most frequent caregivers' complaint was that physicians' lack of knowledge on HD, its symptoms, management and treatment. As shown in Table 2, the main source of information was the Internet (81.8%), a local support group (38.2%) and scientific publications (30.9%), and only 4 caregivers (7.3%) indicated family physicians as a reliable source of information on HD. Additionally, only 17 respondents (30.9%) indicated the neurologist and 13 (23.6%) the genetic counsellor.

Table 2. Source of information on HD

Source of information on HD	N	%
Family physician	4	7.3
Neurologist	17	30.9
Genetic clinic/counsellor	13	23.6
Local support group	21	38.2
Internet	45	81.8
Scientific publications	17	30.9
Others	4	7.3

In their accounts, the respondents complained about the time and quality of information they receive from family doctors. While stressing their ignorance, the caregivers felt neglected by physicians who often limit themselves to prescribing psychiatric drugs for pHD and they neither address their other health problems nor take into account their treatment preferences.

Although there is this disease – HD, we know little about it, and nobody informs us about anything: what are the symptoms, disease trajectory, treatment options, ways of managing the symptoms. Absolutely nothing.

Caregiver 21

One neurologist refused further treatment of my sick mum because “his level of knowledge on HD was too low and he was not able to help her in anything”. Others limit themselves to prescribing Tedmodis and incontinence pads.

Caregiver 6

The caregivers were also unhappy about the time they had to spend searching for information. Moreover, they believed that physicians did not show enough interest in HD and did not try to learn more about it. Consequently, the caregivers had to rely on other, external sources, and sometimes took up the role of educators themselves.

In my town physicians know very little about HD. For ten years, nobody in the outpatient clinic has shown any interest in it, either in getting more information or experience in HD.

Caregiver 1

Physicians know nothing about HD: its origin, symptoms, progression and treatment options. We have to look for all these information by ourselves, mainly in the Internet (mainly in English). Sometimes, I even bring my materials and try to educate physicians about HD.

Caregiver 3

Negative experience with health professionals

Not only family physicians, but also other health professionals, including neurologists, nurses and social workers were said to be ignorant in clinical and practical dimension of HD. Consequently, specialists refuse pHD treatment which, in turn, is frequently reduced to psychiatric drugs, and caregivers are not informed about other treatment options. The caregivers also reported problems with access to specialists, especially neurologists, and genetic counselling. Some were also dissatisfied with the diagnostic process which is sometimes reduced to basic examination, such as blood count.

Neurologists to whom I turned for help refused treatment. There are problems with getting referral to specialists. And from the time of diagnosis, my husband has got no examination, except for blood count.

Caregiver 24

Many claimed that they knew more about HD than the specialists they had to educate. At the same time, they complained that their voice was often ignored.

Since half of a year the patient is a resident in a community nursing home, where are good conditions, but the staff lack knowledge on HD. Only after my intervention, after two months, the personnel were trained, although I left them my materials on HD the very first week. Nevertheless, not everybody participated in the training, so still there are many irregularities in care.

Caregiver 20

One neurologist told me – almost graduated pharmacist, that there are no contraindications against powdering the pills with modified released dosage. But, it is unacceptable not only because the active substance will get to the bloodstream, but mainly because it can seriously harm the patient, especially if one uses multidrug therapy! When I told him that, he laughed at me and insisted on his opinion.

Caregiver 3

The participants also stressed lack of communication skills from health professionals. In their stories, pHD were often treated as “objects” and not human beings who require treatment and empathy.

We have problems with calling the emergency unit. When dad refuses to eat and take medications (he is not incapacitated, so he cannot be forced), some paramedics definitely lack tact and manners, which should never happen. During his depression episodes, dad refuses everything and has a “wall” – whatever we say, it does not come to him. Thus, when the rescue team arrives, it goes like that:

– Sir, maybe you will take your medications?

– Leave me alone, I want to die!

– So maybe I will give you an injection?

– No! I want to die in peace!

– An injection for dying, perhaps?

I do not know whether it was supposed to be funny or to ease the tension, but it knocked me out even more.

Caregiver 5

My relative who currently lives in a community nursing home is treated like an object, or “necessary evil”. Especially during holidays. Community nursing homes in Poland are not adapted to providing care for patients with HD.

Caregiver 41

Also, contacts with a genetic clinic left traumatic memories among many caregivers who report that such visits are often reduced to blood tests and are not accompanied by genetic counselling or psychological consultation, either for the patient or a caregiver.

Apart from genetic testing, which was limited to two visits to a genetic clinic, but without any genetic counselling, I did not receive any medical help for myself.

Caregiver 54

On the other hand, some caregivers experienced a violation of the basic ethical principles of genetic counselling: privacy and confidentiality, as they reported that they were not in control over the share of genetic information which was firstly spread to one’s family. Consequently, while describing their experiences as a “nightmare”, some emphasised their lack of trust toward such clinics.

Genetic counselling, in the form it should look like, was not possible in the place I was doing the test. I took a decision about testing by myself (...). But my mum, without my sister’s or mine consent called my dad’s cousin whose partner “magically” managed to know the result of my sister’s presymptomatic testing. He passed it to my aunt who called my mum who informed me and just after that my sister was informed about her private test result. For that reason I was afraid

that the same scenario will repeat with my testing, which further increased my stress. Total lack of education. It was shocking for me. Consequently, I constantly asked every physician for something that should be guaranteed: to keep the medical secret. But I did not trust them anyway. An absolutely unacceptable nightmare, which, unfortunately still repeats (...) Earlier the same situation happened with my dad, when my aunt's partner managed to get his test result from the hospital where the test was done, and passed it to her and she told it to me by phone.

Caregiver 52

During my first visit at genetic clinic I was alone, during the second I came with my friend. I had to be with somebody; at least they followed that rule.

Caregiver 31

Lack of emotional support from health professionals

While the respondents were frustrated at health professionals' ignorance about HD, they also complained about the lack of understanding and emotional support in the medical community. As shown in Table 3, only 9 respondents (16.4%) indicated their physician as being supportive and the majority of the respondents turned to their families, support groups and friends' support.

Table 3. Source of support for caregivers of pHD

	N	%
Family	34	61.8
Neighbours	4	7.3
Friends	11	20.0
Family physician	9	16.4
Religion	6	10.9
Psychologist	5	9.1
Local support group	13	23.6
Others	6	10.9

The caregivers often felt ignored by health professionals who focus on pHD and neglect the caregivers' health. Moreover, they do not pay attention to pHD and the caregivers' psychological and emotional needs. Consequently, the caregivers felt as not being understood by health professionals and often described themselves as 'invisible patients'.

Physicians focus only on the patients. They do not notice that the caregivers are also sick and require treatment.

Caregiver 1

What I missed the most is psychological support for me and my children. There is no psychological help neither for the sick nor the caregiver. (...) Neither physician, nor other institution showed us any interest. In the medical setting there is no understanding for caregivers.

Caregiver 39

General dissatisfaction with healthcare services

Apart from the negative experiences with the themes already described, all participants expressed their general dissatisfaction with Polish healthcare system. What was significant, only 5 respondents (9.1%) described their experiences as positive, while 23 respondents (41.8%) said it was negative (Table 4).

Table 4. Caregivers' experiences with healthcare system

	N	%
Very positive	0	0.0
Positive	5	9.1
Neutral	27	49.1
Negative	15	27.3
Very negative	8	14.5

The caregivers mainly complained about the low level of support from governmental and social institutions. They felt unappreciated and were frustrated by the fact that family carers are not perceived as an integral part of the healthcare system. Meanwhile, they emphasised that by caring for the sick they relieve the system and for that reason alone they should be more rigorously supported by the government and provided with better medical care.

The government do not appreciate those who care for the sick in their homes. I want to care for my HD relative at home. By doing so, I relieve the healthcare system. Caregivers should have it guaranteed to get maximum medical care at their homes.

Caregiver 1

The respondents struggled with an insufficient number of resources to support care and stressed that the available medical care for their affected relatives was of poor quality which resulted in extra costs for rehabilitation, diets and therapies. They stressed problems in access to specialists and experienced difficulties in access to routine medical care for pHD, including residential care. Some missed appropriate activities for pHD such as occupational therapy and rehabilitation.

Providing systematic neurological care and rehabilitation from the National Health Found (NFZ) is impossible. We have to spend extra money on private visits, supplements, speech and language therapist,

and psychologists, etc. I also miss a possibility of participation of my sick daughter in occupational therapy for young persons with HD. We lack places where people can combine one's interests with rehabilitation which could minimise the "nonsense of existence".

Caregiver 8

Will there ever be places for the sick that could help alleviate their health and quality of life?

Caregiver 23

Yet another problem was related to caregivers' difficulties with obtaining financial benefits from disability services and reimbursement of medications that could alleviate patient's symptoms.

Nursing allowance and disability pension should be much higher.

Caregiver 17

Huntington's disease is a lethal disease, but most medications are not reimbursed, so you have to pay 100%, because it is a clerk from the Department of Drug Policy and Pharmacy who decides whether a drug is reimbursed, and he has no idea about HD.

Caregiver 38

These textual data were supported by quantitative findings where most dimensions of the Polish healthcare system were evaluated negatively (Table 5). The caregivers expressed the worst opinions on the support system for pHD and their carers from the government and social institutions (96.3%), society (92.7%) and physicians (72.7%). They criticised physicians' knowledge (70.9%) and practical information about HD (60.1%). Five other items were also perceived negatively, although by fewer respondents: quality of medical care for pHD (49.1%), access to specialists (45.5%), physicians' empathy (45.4%), contact with genetic clinic (45.4%) and physicians' communication skills (41.8%). Only two items were judged positively: access to information on HD (74.2%) and access to medications for pHD (60%). Nevertheless, it can be explained by the fact that caregivers declared the Internet as the main source of information about HD. As for medications, although access to them was perceived positively, caregivers stressed the problems with reimbursement of such drugs.

Table 5. pHD Caregivers' perception of healthcare services

	Very good	Good	Bad	Very bad
	N (%)	N (%)	N (%)	N (%)
How do you rate support for caregivers from government and social institutions?	0 (0.0)	2 (3.6)	23 (41.8)	30 (54.5)
How do you rate quality of medical care for pHD?	1 (1.8)	27 (49.1)	21 (38.2)	6 (10.9)
How do you rate access to specialists?	6 (10.9)	24 (43.6)	21 (38.2)	4 (7.3)

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How do you rate access to medications for HD?	3 (5.5)	30 (54.5)	14 (25.5)	8 (14.5)
How do you rate access to information on HD?	6 (10.9)	35 (63.3)	10 (18.2)	4 (7.3)
How do you rate social support for pHD and their caregivers?	0 (0.0)	4 (7.3)	34 (61.8)	17 (30.9)
How do you rate physicians' knowledge on HD?	1 (1.8)	15 (27.3)	23 (41.8)	16 (29.1)
How do you rate physicians' practical information on HD ?	1 (1.8)	16 (29.1)	26 (47.3)	12 (21.8)
How do you rate physicians' communication skills?	4 (7.3)	28 (50.9)	17 (30.9)	6 (10.9)
How do you rate support you receive from physician?	1 (1.8)	14 (25.5)	30 (54.5)	10 (18.2)
How do you rate physicians' empathy?	1 (1.8)	29 (52.7)	17 (30.9)	8 (14.5)
How do you rate contact with genetic clinic?	7 (12.7)	23 (41.8)	23 (41.8)	2 (3.6)

Discussion and conclusions

The study aimed to describe the lived-in experience of family caregivers of pHD with healthcare services. It is striking that apart from the many problems related to caregiving, the respondents emphasised that finding appropriate professional care for their relatives was the most challenging aspect of caregiving. The participants most often complained about the lack of support from governmental, health and social institutions. They were dissatisfied with physicians' knowledge about HD, communication skills and lack of empathy. Many worried about the availability and adequacy of healthcare services, including access to specialists and modern medications. All in all, the caregivers from the study felt let down by the system and expressed general lack of trust in the standard of care.

Such results confirm the findings of studies from countries where healthcare service is of better quality. For example, British studies show that caregivers feel burdened not so much by the physical and mental state of a care recipient as by the lack of access to healthcare services, including the specialists [2, 6, 14]. Access to routine medical and domestic care is also problematic for many carers of pHD in the United States. Moreover, there are also not enough places in social and nursing homes for the patients, especially those suffering from juvenile HD. Research has proven that many caregivers lack the resources required to provide proper care [18]. Similar results were obtained in a comparative study of HD carers in the US and the UK by Skriton et al. [11], and by researchers from Canada [10, 13] and Australia [15]. In Poland, as in other countries, caregivers meet with lack of understanding and support from medical professionals who lack adequate knowledge on HD [2, 6, 10, 11, 13, 15, 18].

At the same time, it is important to emphasise that although research shows that caregivers of pHD have similar problems and needs to those caring for persons suffering from other chronic diseases, including Alzheimer's and Parkinson's disease [23, 24], stroke [25, 26] or psychiatric disorders, such as schizophrenia or bipolar disorder [27, 28], at the same time the specificity of HD results in that there are some issues

that are absent or minor in other diseases, yet are the most burdensome for HD carers [15, 20, 29–31]. The disease changes relations and roles within the family, decreases the caregiver's quality of life, it is a serious stress factor and a predictor of a feeling of burden [5, 29]. It also results in social isolation of HD carers [1, 15, 30], their financial problems [1, 32] and decrease in health [7, 19, 32]. Nevertheless, the most important difference is hereditary character of HD which puts other family members, especially children, at risk of HD [5, 14, 33]. As a result, HD carers are often forced to care for multiple generations of patients (a parent, older sibling and children). At the same time, they are afraid that they may develop the disease themselves [1, 5, 7, 13–15, 17, 18, 29–33]. Moreover, caring for a couple of persons intensifies contacts with the healthcare system, which may increase caregivers' negative experiences. Another important difference is that in contrast to other neurodegenerative disorders the onset of HD is much earlier, as it usually starts at the third, fourth decade of life. Consequently, also caregivers are relatively younger than those caring for patients with Alzheimer's or Parkinson's disease [32]. Patients' younger age creates problems with obtaining gerontological services. Their access to healthcare services can be also hindered by the fact that in preclinical stage of the disease HD subjects are often not active participants of healthcare services [32]. As a result, HD carers are forced to spend more time struggling with the system from which they feel excluded. This, in turn, influences their ability to perform family and professional roles [14, 32]. In contrast to other types of dementia, HD is also characterised by slower progression of symptoms, which results in a prolonged time of caregiving which may last up to thirty years. Such a long time of caregiving intensifies the number of contacts with the healthcare system and the number of barriers experienced. Moreover, in contrast with cancer or Alzheimer's disease, health professionals often lack basic knowledge on HD and are unaware of the unique problems and needs of HD carers. Finally, healthcare services for patients with cancer or Alzheimer's disease are better organised [1, 2, 6, 10, 11, 15–18, 33].

Thus, by showing caregivers' complex needs for healthcare assistance and emotional support this research demonstrates that health professionals, social workers and health policy planners must recognise that, as most HD caregiving is done by family carers, they need special attention and help. While it is important to change the regulations that will improve the organisation of care, including consultations with specialists and rehabilitation, reimbursement of modern drugs and using of dependency leave, it seems equally important to develop better education that will provide physicians, nurses and other health professionals with knowledge on both clinical dimension of the disease and its psychosocial consequences for the patient and the caregiver. Meanwhile, curricula of many medical universities lack education on rare diseases and especially on their extra medical aspects. Such knowledge can help future health professionals to pay more attention to the problems and needs of caregivers and to identify the sources of their distress and support development of effective strategies of coping with the

stress. At the same time, it is important to provide caregivers with adequate practical information regarding planning and providing care, i.e. feeding and swallowing, ways of communicating and reactions towards patients' problematic behaviour.

HD carers should have better access to emotional support, both in terms of psychological consultations and genetic counselling. Moreover, it should be borne in mind, that such care is required from the time of the diagnosis throughout the prolonged disease trajectory and should include psychological support and practical help [32, 33]. It is important, as caregivers who feel understood and supported perceive the caregiving task more positively and have an increased perception of personal control [7, 18, 19]. Many carers also opt for special programmes in occupational therapy for the sick and courses of stress coping for themselves.

It is also important to remember that persons with Huntington's disease and their carers often have different opinions on what is needed to provide care [9, 31]. Thus, one must agree with Soltysiak et al. who argue that care for pHD should be more individualised [2]. The reason is that while in some cases HD progresses rapidly, depriving an individual of work and social contacts, other patients, although in need of some help, may function relatively independently in their own homes. Therefore, the most important thing is to develop a system of social workers who as caregivers' assistants would provide them with practical information on possible therapeutic and payment options and monitor their current needs [15]. Such a solution is highly desirable as the complex nature of HD and the serious consequences it brings to patients and their families make it impossible for physicians to care and support them only by themselves. That is way it is indispensable to create interdisciplinary teams that would include physicians, nurses, social workers and psychologists. Similar solutions already exist in some countries, for example in Australia [15, 33].

Moreover, HD can be a model example of how long-term palliative care should look like, especially for younger and mobile patients who require longer institution-alisation, as traditional palliative care may not be sufficient for HD subjects [15, 31]. As such persons need stable environment and do not respond positively to changes, they should be cared for in their own homes, where nurses, social workers and psychologists should play a crucial role. Research proves that, according to caregivers themselves, it is the most important source of support. This, in turn, may lead to better care of pHD and an improvement of the quality of life of both caregivers and pHD.

While this paper brings a new insight into the situation of caregivers of pHD, some limitations need to be mentioned. First, the sample was small, with only 55 caregivers completing the interview. However, the aim was to identify the main problems of caregivers and not their quantitative evaluation. Second, this paper represents only the view of caregivers who volunteered and agreed to participate in the study. Consequently, the results may not reflect the opinions of other caregivers who do not use the HD chat forum and are not members of the Polish Huntington's Disease Association or those

who do not feel comfortable speaking personally about their experiences. Finally, the primary focus of interest may have led to an overrepresentation of negative experiences. Another factor that might have influenced the respondents' experiences is their kinship with the patient. As research show parents and spouses of pHD feel highly stressed that they will not be able to provide proper care [11]. Furthermore, an additional factor that should be included in the analysis and planning of care is whether the caregiver him/herself is an HD carrier or at risk of developing it, which is an important stress factor [7, 14, 17, 32, 33]. Nevertheless, on the basis of this research it was not possible to determine whether individuals' risk status influenced caregivers' experiences. Thus, this topic deserves further research. However, some advantages of this study should also be acknowledged. Most importantly, as there is a scarcity of previous work on the topic, it gives a new insight into the experiences of family caregivers of pHD with healthcare services. The author also believes that facilitating caregivers to tell their stories as a narrative has a therapeutic value.

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