

3-2009

The Emotional Experiences of Family Carers in Huntington Disease

Bonnie L. Hennig

University of Connecticut School of Medicine and Dentistry

Follow this and additional works at: http://digitalcommons.uconn.edu/pcare_articles



Part of the [Medicine and Health Sciences Commons](#)

Recommended Citation

Hennig, Bonnie L., "The Emotional Experiences of Family Carers in Huntington Disease" (2009). *Articles - Patient Care*. 44.
http://digitalcommons.uconn.edu/pcare_articles/44



Published in final edited form as:

J Adv Nurs. 2009 April ; 65(4): . doi:10.1111/j.1365-2648.2008.04946.x.

The emotional experiences of family carers in Huntington disease

Janet K. Williams^{1,*}, Heather Skirton², Jane S. Paulsen³, Toni Tripp-Reimer⁴, Lori Jarmon⁵, Meghan McGonigal Kenney⁶, Emily Birrer⁷, Bonnie L. Hennig⁸, and Joann Honeyford⁹

¹Janet K. Williams PhD RN FAAN Kelting Professor of Nursing College of Nursing, The University of Iowa, USA

²Heather Skirton PhD RN Registered Genetic Counsellor and Professor of Applied Health Genetics Deputy Head (for Research) of the School of Nursing and Community Studies University of Plymouth, UK

³Jane S. Paulsen PhD Professor of Psychiatry, Neurology, Psychology and Neurosciences Departments of Neurology, Psychiatry, Psychology, and Neurosciences, The University of Iowa, USA

⁴Toni Tripp-Reimer PhD RN FAAN Professor and Associate Dean for Research Co-Director, John A. Hartford Centre for Gerontologic Nursing Excellence, The University of Iowa, USA

⁵Lori Jarmon MS Former Program Associate College of Nursing, The University of Iowa, USA

⁶Meghan McGonigal Kenney MSN RN PhD Candidate College of Nursing, The University of Iowa, USA

⁷Emily Birrer BSN RN Research Assistant College of Nursing, The University of Iowa, USA

⁸Bonnie L. Hennig MSW LCSW Clinical Therapist Huntington Disease Program, University of Connecticut Health Center, USA

⁹Joann Honeyford BScN RN Manager in Clinical Genetics North York General Hospital, Toronto, ON, Canada

Abstract

Aim—This paper is a report of a study conducted to examine the emotional experience of caregiving by family carers of people with Huntington disease and to describe strategies they used to deal with that experience.

Background—Huntington disease, commonly diagnosed in young to middle adulthood, is an inherited single gene disorder involving loss of cognitive, motor and neuropsychiatric function. Many family members become caregivers as well as continuing as parents and wage earners. The emotional aspects of caregiving contribute to mental health risks for family members.

*Janet K. Williams: janet-williams@uiowa.edu.

Conflict of interest

No conflict of interest has been declared by the authors.

Author Contributions

JKW, HS, JSP, TTR, BLH & JH were responsible for the study conception and design. JKW & MMK performed the data collection. JKW, HS, TTR, LJ, MMK, & EB performed the data analysis. JKW, HS & EB were responsible for the drafting of the manuscript. JKW, HS, JSP, TTR, LJ, MMK, EB, BLH & JH made critical revisions to the paper for important intellectual content. JKW & JSP obtained funding. LJ provided administrative, technical or material support. JKW supervised the study.

Methods—Focus groups were conducted with 42 adult carers of people with Huntington disease in four United States and two Canadian Huntington disease centers between 2001 and 2005. Data were analyzed through descriptive coding and thematic analysis.

Findings—All participants reported multiple aspects of emotional distress. Being a carer was described as experiencing disintegration of one's life. Carers attempted to cope by seeking comfort from selected family members, anticipating the time when the care recipient had died and/or using prescription medications. Spousal carers were distressed by the loss of their relationship with their spouse and dealt with this by no longer regarding the person as an intimate partner. Carers were concerned about the disease risk for children in their families and hoped for a cure.

Conclusion—Emotional distress can compromise the well-being of family carers, who attempt to maintain multiple roles. Nurses should monitor carer mental health, identify sources of emotional distress and support effective strategies used by carers to mediate distress.

Keywords

caregiving; focus groups; Huntington disease; psychological impact; qualitative; research report

Introduction

Informal caregiving is characterized by roles and tasks (Bowers 1987, Swanson *et al.* 1997) provided by family and friends who give unpaid assistance to people in the community who are unable to fully care for themselves. Caregiving for people with dementia (Cooper *et al.* 2007), stroke (Visser-Meily *et al.* 2004) and chronic illness (Deeken *et al.* 2003) can result in positive experiences. However, caregiving may involve burden, including potential effects on carer mental and physical health, other family members and finances (OHaeri 2003). Most caregiving literature addresses older adults, and little is known about caregiving for young and middle adults who experience loss of cognitive and behavioral function due to an inheritable disorder such as Huntington disease (HD).

Background

Huntington disease is a progressive neurodegenerative condition characterized by loss of cognitive, behavioural and motor function over a 10–25 year period and resulting in severe disability (LoGuidice & Hassett 2005). The incidence varies across populations, but is generally around 4–7 per 100,000 (Online Mendelian Inheritance in Man, 2008), with onset most commonly in the fourth decade. There are currently no means to slow or prevent the progress of this disease. Family members often care for people with HD until the person's symptoms exceed their capacities to provide care at home. Surveys in the United Kingdom (UK) (Skirton & Glendinning 1997) and Australia (Shakespeare & Anderson 1993) indicated that services available to families did not fit the needs of the people with HD or the caregivers. In both studies, the focus was on the affected person.

Issues for family caregivers of people with HD may overlap with those faced by family whose relatives have Alzheimer disease. These address dealing with change, managing competing responsibilities and stressors, providing a broad spectrum of care, finding and using resources, and emotional and physical responses to care (Farran *et al.* 2004). An additional factor when dealing with this inherited condition is the 50% chance that each first degree relative (sibling or offspring) of a person with HD will develop the condition. Concerns about preserving the privacy of other family members at risk and potential social stigma (Bombard *et al.* 2007, Penziner *et al.* 2008) may lead to secrecy regarding the presence of HD, thus reducing access to support.

The human lifestage model is based on the theory that individuals undertake specific developmental tasks at particular times in their lives (Thomas 1990). Thus, while every person's life is unique, there are some common phases of development that can be used to contextualize the challenges faced by that person at that time. According to this model, developmental tasks associated with young or middle adulthood focus on establishing and maintaining spousal relationships, raising children and investing in a career (Thomas 1990). Because of the age at which a person with HD is likely to become affected, it is possible that the caregiver is in paid employment and may have significant family commitments (LoGuidice & Hassett 2005, Aubeeluck & Buchanan 2007). Given the additional requirements of caregiving and reduction in the ability of affected people to contribute to family support, it is not surprising that in a study of 16 family caregivers in Scotland, the majority of participants reported compromised health and lifestyle (McGarva 2001). Lowit and van Teijlingen (2005) noted that the slow nature of HD progression facilitated carers in devising strategies to deal with things as they arose; however, work by Skirton and Glendinning (1997) contradicted this finding somewhat, as they reported caregivers' frustration at dealing with successive crises.

The findings of a UK study (Skirton & Glendinning 1997) demonstrated that the complexity of symptoms contributed to needs for support being unmet, and others have confirmed that healthcare providers are not aware of needs of patients and families and that services are available only in a crisis situation (McGarva 2001, LoGuidice & Hassett 2005). In some Canadian provinces, social workers with expertise in HD offer support groups, weekend retreats or workshops for family caregivers. Although home care is available in Canada regardless of diagnosis, the hours may be limited. A limited number of beds for respite care are available in some Canadian long-term care facilities. Home care services in the United States of America (USA) vary according to individual communities, and most are not targeted at young adults with neurodegenerative illness and their families.

While studies of the care of affected people have shown that being a carer of family members of young or middle aged people with HD can be challenging, ways in which caregiving threatens physical and emotional health of carers and how carers manage their emotions have not been reported

The Study

Aims

The aims of the study were to examine the emotional experience of caregiving by family carers of people with HD and describe strategies they used to deal with that experience.

Design

Qualitative methodology, and elements of a grounded theory approach (Strauss & Corbin 1988), was chosen for this exploratory study in a topic area in which there has been little previous work. Data were collected via focus groups. While many of the topics covered were personal, there is evidence that the group dynamics that operate in such groups can assist people to express and clarify views (Burns & Grove 2005).

Data were collected between 2001 and 2005, as part of a two-stage, mixed methods study (Williams *et al.* 2001). Other aspects of the study are reported elsewhere (Williams & Ayres 2007, Williams *et al.* in press, Sparbel *et al.* 2008).

Participants

Participants were included if they: 1) were aged 19 years or older, 2) spoke English, 3) were able to participate in a focus group and 4) identified themselves as family members or a significant other of people with HD. A purposive sample of 42 family members was recruited by site coordinators at six medical centers for HD in the USA and Canada to achieve maximum demographical variability. Data saturation occurred following the fourth focus group.

Data collection

Data were collected in conjunction with the PREDICT-HD study (Paulsen *et al.* 2006). One of four focus groups at each site was with adult family members of symptomatic people with HD receiving care at home. The focus groups were conducted according to procedures described by Krueger (1998), with questions based on a review of the literature and the study aims. Groups had from 5–8 members, lasted no more than 2 hours and were conducted by an experienced focus group leader. A research team member served as focus group assistant. Topics included: concerns about their relative's health, concerns about their own health, strategies used to manage these concerns and what further needs they had that were not currently being met (Williams *et al.* 2007). A pilot study was used to test the data collection procedures.

Ethical considerations

The study was approved by the appropriate institutional ethics committees. Potential participants received an invitation from the HD center site coordinator describing the study, a response form and a return envelope. On receipt of the response form, a member of the research team contacted each participant to answer questions about the study, obtain demographical data and discuss arrangements for the focus group meeting. Each participant completed an informed consent procedure.

Data analysis

Data analysis followed procedures used throughout the larger study (Williams *et al.* 2007). Focus group discussions were audiotaped, transcribed verbatim, validated and entered into NVivo software for data management (NVIVO Q 2000). Six team members coded the transcripts through descriptive analysis procedures (Knafl & Webster 1988, Sandelowski 2000). A code book contained definitions for each topical code. Two team members conducted further thematic analysis. The central theme to emerge is the focus of this paper, and this was labelled as 'caregiver emotional experiences'. Process codes were used to document group behaviour that may have influenced the data (Figure 1). A team member reviewed these codes and focus group assistants' notes to identify potential focus group effects.

Rigour

Rigour in qualitative research relates to use of a systematic design and provision of a detailed account of the method of data collection and analysis (described above). The process described by Strauss and Corbin (1988) was used to recruit a maximum variation sample and to collect rich data. Credibility of the analysis was ensured through use of multiple members of the team to code the transcripts independently before comparing codes and themes. Negative or disconfirming examples were sought and included in the analysis. The first two authors reviewed all original transcripts and the codes previously derived and arrived at consensus with the core theme and subthemes. All team members reviewed and agreed with the results of the final analysis. Trustworthiness of the data analysis was

confirmed through cognitive interviewing with a subsample of participants to validate relevance of survey items developed from the focus group data for the wider study.

Findings

Demographics

Participants ($n = 42$) were adult family caregivers of people with HD living at home. The mean age was 52 years (range 35–79) and 27 (64%) were women. Thirty-five (83%) were spouses of people with HD, 6 (14%) were parents and one was a sibling of the person with HD and at risk to develop HD. Table 1 shows the relationships to people with HD of the 22 participants discussed in this paper. To maintain anonymity, identifying characteristics including exact location and age are not included. The relevant participant number follows each quote.

Focus group processes

Although some members offered fewer comments than others, all participants contributed to the discussions. All groups were very interactive, with minimal direction from the moderator. Individuals in three groups wept while sharing their experiences, and no group experienced periods of silence. Members in four groups shared personal contact information or healthcare resources information. In one group, when participants engaged in a discussion in which opposing points of view were expressed, the group developed ways to sustain the conversation and resolve conflict. These included validating others' responses, challenging knowledge or expertise and disclosing thoughts and feelings that may be personally painful or not consistent with societal norms (Williams & Ayres 2007).

Core theme

The core theme identified was 'caregiver's emotional experiences'. Participants were asked to describe their concerns and comments about themselves as they portrayed their lives as carers of people with HD. It was striking that while most of the carers were willing to undertake this role, the emotional burden of caring was extremely heavy and many carers were offering care for their loved one at considerable cost to their own health. However, a thread that was observed through all of the themes was the adaptability carers used to deal with their situations and experiences. Under the core theme 'caregiver's emotional experiences', there were three sub-themes, labelled 1) 'disintegration of the carer's life', 2) 'loss of life as it was' and 3) 'the ever-present shadow'. Consideration of each sub-theme below is followed by findings on adaptation.

Sub-themes

Disintegration of the carer's life—When asked to comment on experiences and concerns relating to themselves, participants in every focus group reflected initially on the ways in which they had been negatively affected by the disease, resulting in 'disintegration' of at least some aspects of their own lives. While 'disintegration' is a strong term, it reflects the intensity of feeling expressed by participants. In many cases, fulfilling the caregiver role resulted in the deterioration of the carer's health due to the need to be available day and night. In some cases, a lack of empathy for the carer's needs by people with HD (as a result of the condition) exacerbated the carer's situation:

I may get, if I'm lucky, some nights maybe an hour or two hours of sleep...I've had 5 surgeries myself and...my husband would call me to help him to the bathroom and I could barely take care of myself. (1)

For those with children or teenagers, the lack of respite was compounded by their other family responsibilities:

But there is no respite for me. And I've got two teenagers at home, young teenagers. (2)

It was clear that some carers who were not obliged to work outside the home felt that they had more flexibility and, as a consequence, experienced less stress and disintegration:

If I see (wife) is having a hard time, I can sort of plan the day differently...if I had to go to work everyday. I'd be worried about what's going on at home. (3)

However, the previous quotation reflects the worry that accompanies leaving the affected person at home without adequate support, so that even respite care or breaks are a source of stress:

I said, 'OK...I need to get away (on vacation)'...I cried the night before. I didn't want to leave him...it was one of the most miserable vacations that we ever had. (4)

Carers worried about ways to manage the expenses associated with loss of income, and one contemplated divorce because this would result in an increase in income for the family. The pressure to maintain the home and family was summed up by one participant as trying to avoid 'meltdown':

I'm very concerned, I have these meltdowns...it scares me, because I'm trying to be strong and I'm trying to be superwoman and be great at my job, be a great wife, be a great mom. (5)

A point was made that, while support staff encouraged carers to take care of themselves, in some cases, it was those carers who denied themselves any life and disregarded their own health who were praised:

Have you noticed that, in those caregiver groups, they say, 'You gotta do things for you'...they give the caregiver of the year award...they give it to people that have literally devoted their own lives and usually wrecked their own health. (6)

One participant described the strain of living with the unpredictability of the disease over a long period:

I've had three very close family members die of cancer, and you go through it and you don't necessarily get over it, but you do get on with your life...and there is support for the survivor. You know, with Huntington, the time period is so long and it's just this very slow walk down a very long road. You know each day is just slightly worse than the day before. And there is no end to the tunnel, and you don't know what you're going to face. (7)

Adapting to disintegration of the carer's life: Carers' means of dealing with disintegration took several forms, including appreciating positives, anticipatory mourning, setting boundaries and using medication. To some extent, mechanisms reflected the underlying outlook of the person, but it is also possible that strategies alter over time due to the long course of the disease.

While the physical death of the partner was expected at some time, some carers expressed the view that they had already lost their partner:

I told somebody not too long ago, 'I'm done grieving'. I said, 'When my husband's gone, don't look for me to cry because that's what I've done already'. (1)

Others coped by focusing on small blessings and drew support from faith and friends:

You look for little things. I got a great family, I got great friends. But our faith and my church has gotten me through more. (8)

Some carers set boundaries for themselves:

I come home from work and I want to relax, but I take the time...to do something with him. And then, right after supper, usually I take my time to do my thing. I've learned that I need that time...just to get my focus back. (9)

One family member noted that it was difficult to explain her situation or feelings to others:

Other people don't understand - it's much easier to kind of keep it to yourself and not share with people. Because, when you do, they look at you a bit askance, like you're imagining things. (7)

Perhaps, because of this difficulty in sharing the experiences with others, approximately 20 per cent of carers discussed taking medications to address depression:

I take more, more of the antidepressants than my husband does. (10)

Loss of life as it was—The second sub-theme dealt with dimensions of grief. Carers spoke of the ways in which their lives had changed with a profound sense of loss, often characterized by the belief that living such a life as a young person was unfair. Some described their lives as if being 'on hold', the caregiving being an interruption to the normal life that they hoped would resume in the future:

I definitely feel like I'm, in some ways, like my life is on hold. Life has been put on hold and it needs to be taken off hold. (10)

However, not all carers felt this way. One felt that he had changed in a positive way as a person through his experience and felt blessed by it:

I'm very, very dedicated to my dear wife...I'm not the same person I was. And the person I am is someone who's true to his wife and enjoying...we really, we enjoy our life. (11)

For some, tasks reminded them of loss. These people were under pressure from their families to inform the person with HD when their abilities were waning to the point that they were no longer able to work or drive:

They've had too many complaints of his driving...I said, 'Then you're going to have to be the one to tell him'. I don't always want to be the one to tell him the bad news. (12)

Ambivalence about trying to keep the affected person alive was also expressed:

I can tell you, I'm worried about what will happen when (wife) gets ready to die. Uh, will I try to prolong her health as much as I can? (11)

Mood swings and cognitive changes experienced by affected people meant that carers were often juggling to maintain some semblance of normality in the household:

In terms of our social life, he (husband) has made a decision not to see anybody... and unfortunately for me, the burden is left with me to keep him company. (13)

For many who were spouses, their emotions centered on the loss of intimacy with their partner. For some, the yearning for companionship was palpable:

I don't need to be...you know, I don't miss the sex - that doesn't matter. I just miss the conversation. You know, um, I can still, you know, lay down next to him and enjoy his presence, you know, I do feel his presence. (2)

Adapting to loss of life as it was: One key strategy used to deal with the loss was to cease seeing the affected person as a partner with whom to share daily activities and intimacy:

We used to like to cook together and he'd do things...he was great helping me clean and do stuff. We're raising kids and we've got kid activities. And all of our friends do too. It's gone. I've kind of walled him off in so many ways...physical, mental...bond between a husband and wife, that's, that's gone. And I feel guilty about it, I feel horrible about that. (10)

Others attempted to modify expectations while continuing some form of previous joint activities:

We still do a lot - we go on trips, we go to the theater. I kind of pave the way before we do a lot of things...As long as I plan everything, she will do them, but it is hard to live with that part of it. (14)

Given the changes in people with HD and the loss of empathy towards the carer, several participants expressed the way in which they had survived by deliberately suppressing the romantic love they had once felt for their spouse:

And the thing that I had learned the greatest from it was that I had to learn to fall out of love with him. And I love him dearly and I take care of him. But I've got this mother-child relationship. And that is what has helped me a great deal. I love him dearly, he's very important to me, but I'm not in love with him anymore. And that was a very hard thing to do. But I learned to do it. (15)

The ever-present shadow—The third sub-theme addressed concerns about their children. Many carers were parents of children who had a 50% chance of developing HD, and they talked about their children's risk status when they introduced themselves to other group members:

We have four daughters, so we know that they are at risk. (16)

Those who were parents spoke of their vigilance for signs in their children or grandchildren:

I used to sit and watch my kids. One of my kids spilled something, I thought, 'Oh my God, no'... you know (17)

Participants shared thoughts about having had children at risk of HD:

Sometimes I think maybe it's an abusive thing that we've done, even to have children. (18)

However, one participant was taken aback by the approach of her son:

He turned to me, he said, 'You know what, Mom? I've had 32 years of good life'. And I'll tell you, that put me in my place, it did. (19)

Adapting to the ever-present shadow: Parents who had more than one child commented that their approach to discussing HD varied with each child. These discussions were described with regard to their adult children's decisions to have predictive genetic testing:

Our daughter doesn't want to be tested at this time. And I told her, that, it's her decision. When she wants to, we'll support her in that. (20)

One way of coping with the worry that children or grandchildren would be affected was to hope for a cure:

My daughter has two babies... they're just on the firm conviction that there's going to be something out there by the time those boys get to anywhere that... something's going to be done for them. (21)

Another strategy was to rely on faith:

I go, 'Lord, it's in your hands' and it's down the road. (22)

As the above quotes illustrate, despite feeling overwhelmed at times, caregivers continued to find some way to hope for the future of their families.

Discussion

Study limitations

This study represents the views of carers who volunteered to participate in focus groups at medical centers providing care to people with HD. The number of participants and the use of six different focus groups provided a large and varied sample. The findings may not reflect the experiences of those who are not comfortable speaking in such a setting, prefer not to meet with a group or received health care from other providers. We specifically sought information about concerns, and participants were not asked to describe experiences that were positive or fulfilling. Therefore, while participants were given the opportunity to contribute as they wished, these experiences may be under-represented.

This report adds to knowledge about the experiences of carers for people with HD, giving insights into the impact of emotional experiences on these carers. Other aspects of caregiving, such as tasks, effects on physical health, finances, childrearing, roles with family and society are not reflected directly in this report. However, what it does offer is awareness of the conflicting emotions and ways in which individual carers cope with these emotions so that they can carry out their multiple responsibilities.

Discussion of findings

Our findings confirm those of Lowit and van Teijlingen (2005), who reported that carers of people with HD adapt to changes as they occur and use an operational rather than a strategic approach to care, meaning that they deal with problems as they arise rather than seeking longer-term solutions. The ways in which carers adapt to different aspects of life as a carer was an important new finding in the present study. Carers experienced a degree of cognitive dissonance (Festinger 1957) with respect to their own roles and the roles of care recipients, as the new needs of care recipients conflicted with the place they had previously held in families. Spousal carers reported the painful process of converting their image of their spouses as people who were available in a reciprocal sense for physical and emotional support, to those who were wholly dependent. Feelings of discomfort persisted and carers tried to adapt to the new situation by taking steps (such as 'falling out of love') to resolve the conflict within themselves and allow them to continue to provide care.

Our findings add new insights into the emotional aspects of the experience and the many conflicting demands on time and resources that may limit carers' abilities to look beyond present challenges. However, offering guidance in looking beyond the present is a role that can be undertaken by healthcare professionals working closely with families by developing systems whereby challenges are anticipated and crises averted. Our data give insights into those topics and reactions to caregiver challenges that may limit the amount of energy that carers can devote to day-to-day issues.

There are many similarities between our findings and those reported in studies of other illnesses. The emotional distress that comes with dealing with dramatic change is not surprising. However, because HD caregivers are younger, there are additional pressures from fulfilling a complex array of roles and greater financial loss. Role reversal, giving up enjoyed activities, difficulties with personal health, and a need for antidepressants have also been described by other authors (Farran *et al.* 2004). In some cases, caregivers can find a balance in taking care of themselves. In the case of carers of people with HD, this balance was described in terms of emotion-focused coping, with little description of finding help from others. It may be that the length of time during which people with HD need care influences the nature of the help available. This emphasizes the importance of appropriate, long-term nursing input.

Our findings confirm that HD family caregivers resemble not only carers of people with dementia, but also carers for other conditions affecting people in younger adulthood. Families of individuals with severe traumatic brain injury, for example, also report that they used a great deal of energy to learn how to live with the injured family member, and report feelings of loneliness because others do not understand their situation (Jumisko *et al.* 2007). Carers of people with brain tumours report social isolation due to the withdrawal of friends and lack of understanding of their situations by social agencies (Janda *et al.* 2006).

Overall, our findings indicate a dissonance between the expectations and needs of individuals at a certain life stage and the reality of their situation. The mean age of participants was 52 years – a time when, according to lifestage theory, there is release from the responsibility of dependent children, re-establishment of the ‘couple’ relationship and high productivity in terms of work or career (Thomas 1990). However, for those caring for a partner with HD, the dependence of the spouse increases, and there may also be limited opportunities for a career because of caregiving duties. In addition, concern for the future of ‘at-risk’ children may alter the dynamic between parents and adult children. This contrast between the expected and reality could partially account for the mental health problems experienced by many participants.

Implications for research and clinical practice

The use of focus groups provided rich interactional data on personal topics that carers shared in common. However, it is not known if there were topics that individuals were hesitant to share in a group setting. Further examination through individual interviews might yield that information, and might afford an opportunity to use a phenomenological approach to examine deeply carers’ individual experiences.

Caregivers of people with dementia are more likely to experience anxiety and burden, and confrontative and escape/avoidance coping are associated with higher anxiety (Cooper *et al.* 2007). The participants in this study spoke about difficulties in coping with the multiple challenges in their lives, but did not specify anxiety as an issue; rather, they gave the impression of being depressed and careworn. It may be that those who are prepared to be involved in a focus group are using strategies other than avoidance to deal with their situations.

We have shown that carers of people with HD can face challenges that differ from those of other carers in some important aspects. Further work is needed to test the utility of interventions and research tools related to carers’ needs. Interventions such as support groups have been developed for carers in the context of other complex disorders involving dementia, and have been shown to reduce carer morbidity (Thompson *et al.* 2007). However, because of differences in the clinical manifestations of HD and other dementias and the inherited nature of HD, these interventions need to be tested with family carers of people

with HD. Measures of caregiver wellbeing (Deeken *et al.* 2003) should also be examined, so that they are appropriate for this younger population caring for people with known genetic risk.

Conclusion

The experience of being a carer for a family member with HD encompasses the emotions of not fulfilling one's own dreams for life, witnessing and being responsible for the care of a loved one who is increasingly unable to fill their desired roles and being aware that the children also are at risk to develop this disease. Nurses and other healthcare professionals can support carers through this long-term commitment by actively addressing mental health issues with carers, regularly discussing and endorsing appropriate strategies for dealing with the pressures of caring, and facilitating planning to avoid the need for crisis management. This research would be enhanced by further quantitative studies, using validated psychometric tools, to investigate the mental health impact of caring on a long-term basis for people with HD. Carers contribute to the healthcare of their family members in countless ways, and health service providers have a duty to ensure that their wellbeing is protected and that they are supported as they undertake this role.

Acknowledgments

We thank Mary Lou Klimek for her editorial comments.

Funding

Financial support was received for the study from the National Institute of Nursing Research (R01 NR 07970), linked with the National Institute of Neurological Disorders and Stroke (grant # 40068), the National Institutes of Mental Health (grant # 01579), Roy J. Carver Trust Medicine Research Initiative, Howard Hughes Medical Institute and High Q Foundation grants to Jane S. Paulsen.

References

- Aubeeluck A, Buchanan H. The Huntington's disease quality of life battery for carers: reliability and validity. *Clinical Genetics*. 2007; 71(5):434–445. [PubMed: 17489849]
- Bombard Y, Penziner E, Decolongon J, Klimek ML, Creighton S, Sucheowersky O, Guttman M, Paulsen JS, Bottorff JL, Hayden MR. Managing genetic discrimination: strategies used by individuals found to have the Huntington disease mutation. *Clinical Genetics*. 2007; 71(3):220–231. [PubMed: 17309644]
- Bowers BJ. Intergenerational caregiving: adult caregivers and their aging parents. *Advances in Nursing Science*. 1987; 9(2):20–25. [PubMed: 3099634]
- Burns, N.; Grove, SK. *The Practice of Nursing Research: Conduct, Critique and Utilization*. 5. Elsevier Saunders; St Louis, MO: 2005.
- Cooper C, Balamuali RBS, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *International Psychogeriatrics*. 2007; 19(2):175–195.
- Deeken JF, Taylor KL, Managan P, Yabroff K, Ingham JM. Care for the caregivers: a review of self-report instruments developed to measure the burden, needs and quality of life of informal caregivers. *Journal of Pain and Symptom Management*. 2003; 26(4):922–953. [PubMed: 14527761]
- Farran CJ, Loukissa D, Perraud S, Paun O. Alzheimer's disease caregiving information and skills. Part II: Family caregiver issues and concerns. *Research in Nursing & Health*. 2004; 27:40–51. [PubMed: 14745855]
- Festinger, L. *A Theory of Cognitive Dissonance*. Stanford University Press; Stanford CA: 1957.
- Janda M, Eakin EG, Bailey L, Walker D, Troy K. Supportive care needs of people with brain tumours and their carers. *Supportive Care in Cancer*. 2006; 14(11):1094–1103. [PubMed: 16710653]
- Jumisko E, Lexell J, Soderberg S. Living with moderate or severe traumatic brain injury. *Journal of Family Nursing*. 2007; 13(3):353–369. [PubMed: 17641113]

- Knafelz KA, Webster DC. Managing and analyzing qualitative data. A description of tasks, techniques and materials. *Western Journal of Nursing Research*. 1988; 10(2):195–218. [PubMed: 3394320]
- Krueger, RA. *Moderating Focus Groups*. Sage Publications; Thousand Oaks, CA: 1998.
- LoGuidice D, Hassett A. Uncommon dementia and the carer's perspective. *International Psychogeriatrics*. 2005; 17(Suppl):S223–S231. [PubMed: 16240492]
- Lowit A, Van Teijlingen ER. Avoidance as a strategy of (not) coping: qualitative interviews with carers of Huntington's disease patients. *BMC Family Practice*. 2005; 6:38–46. [PubMed: 16162290]
- McGarva K. Huntington's disease: seldom seen—seldom heard? *Health Bulletin (Edinb)*. 2001; 59(5): 306–308.
- NVIVO, Q. NVIVO Version 1.2. Scolar; Thousand Oaks, CA: 2000.
- OHaeri JU. The burden of caregiving in families with a mental illness: a review of 2002. *Current Opinions in Psychiatry*. 2003; 16:457–465.
- Online Mendelian Inheritance in Man. +143100 HUNTINGTON DISEASE; HD. 2008. Retrieved from <http://www.ncbi.nlm.nih.gov/entrez/dispmim.cgi?id=143100> on 28 January 2008
- Paulsen JS, Hayden M, Stout JC, Langbehn DR, Aylward E, Ross CA, Guttman M, Nance M, Kiebertz K, Oakes D, Shoulson I, Kayson E, Johnson S, Penziner E. the Predict-HD Investigators of the Huntington Study Group. Preparing for preventive clinical trials: the PREDICT-HD study. *Archives of Neurology*. 2006; 63:883–890. [PubMed: 16769871]
- Penziner E, Williams JK, Erwin C, Wallis A, Bombard Y, Beglinger L, Hayden M, Paulsen J. Perceptions of genetic discrimination among persons who have undergone predictive testing for Huntington disease. *American Journal of Medical Genetics Part B*. 2008; 147B:320–325.
- Sandelowski M. Whatever happened to qualitative description? *Research in Nursing and Health*. 2000; 23(4):334–340. [PubMed: 10940958]
- Shakespeare J, Anderson J. Huntington's disease – falling through the net. *Health Trends*. 1993; 25(1): 19–23. [PubMed: 10125696]
- Skirton H, Glendinning N. Using research to develop care for patients with Huntington's disease. *British Journal of Nursing*. 1997; 6(2):83–90. [PubMed: 9116444]
- Sparbel KJH, Driessnack M, Williams JK, Schutte D, Tripp-Reimer T, McGonigal-Kenney M, Jarmon L, Paulsen JS. Teens' experiences living with Huntington Disease. *Journal of Genetic Counseling*. 2008; 17:327–335. [PubMed: 18347962]
- Strauss, A.; Corbin, J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2. Sage Publications; Thousand Oaks, CA: 1988.
- Swanson E, Jensen DP, Specht J, Johnson ML, Maas M, Saylor D. Caregiving: concept analysis and outcomes. *Scholarly Inquiry for Nursing Practice: An International Journal*. 1997; 11(1):65–76.
- Thomas, RM. *Counselling and Life-Span Development*. Sage Publications Inc; Newbury Park, CA: 1990.
- Thompson C, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics*. 2007; 7:18–50. [PubMed: 17662119]
- Visser-Meily JM, Post MW, Riphagen II, Lindeman E. Measures used to assess burden among caregivers of stroke patients: a review. *Clinical Rehabilitation*. 2004; 18(6):601–623. [PubMed: 15473113]
- Williams JK, Ayres L. I'm like you: establishing, confirming and contesting common ground in focus groups with Huntington disease caregivers. *Journal of Research in Nursing*. 2007; 12(6):655–664.
- Williams, JK.; Paulsen, JS.; Schutte, DL.; Tripp-Reimer, T. *Family Health After Predictive HD Testing*. 2001. Grant NR07970, funded by the National Institutes of Health, National Institute of Nursing Research. Retrieved from <http://crisp.cit.nih.gov> on 28 January 2008
- Williams JK, Hamilton RJ, Nehl C, McGonigal-Kenney M, Schutte DL, Sparbel KJH, Birrer E, Tripp-Reimer T, Friedrich RM, Penziner E, Jarmon L, Paulsen J. “No one else sees the difference”: Family members' perceptions of changes in persons with preclinical Huntington disease. *American Journal of Medical Genetics Part B*. 2007; 144B(5):636–641.

Williams JK, Ayres L, Specht J, Sparbel KJH, Klimek ML. Caregiving by teens for family members with Huntington disease. *Journal of Family Nursing*. In press. in press.

What is already known about this topic

Huntington disease is an autosomal dominant neurodegenerative disease with onset in the young to middle adult years and with increasing symptom severity.

Carers of people with dementia are at risk for increased burden and compromised quality of life.

Much of the existing knowledge of caregiving for people with neurodegenerative disorders is derived research on dementia presenting in late adulthood.

What this paper adds

Stressors for carers of people with Huntington disease encompass ongoing loss and anticipation of disease occurrence in their children.

Carers' adaptations to stressors reflect personal resources available to them, with little inclusion of healthcare support.

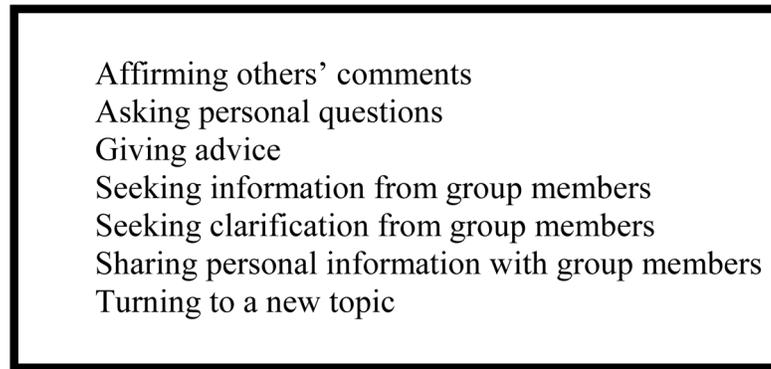
There is a need for examination of fit and usefulness of supportive resources for carers of people with Huntington disease.

Implications for practice and/or policy

Discussion of carers' mental health should be a routine component of their health care.

Supportive services are necessary for carers of people with Huntington disease.

Planning for potential future care needs may help carers to use effective coping strategies when their responsibilities change in response to symptom deterioration.



Affirming others' comments
Asking personal questions
Giving advice
Seeking information from group members
Seeking clarification from group members
Sharing personal information with group members
Turning to a new topic

Figure 1.
Process codes.

Table 1

Participant characteristics

Participant number	Focus group	Relationship to affected family member	Length of time since diagnosis, if known (years)
1	A	Wife	Unknown
2	F	Wife	15
3	D	Husband	9
4	F	Wife	Unknown
5	F	Wife	Unknown
6	A	Husband	10
7	B	Husband	6
8	C	Wife	11
9	A	Wife	3
10	C	Wife	7
11	B	Wife	12
12	A	Wife	Unknown
13	E	Wife	7
14	D	Husband	11
15	C	Wife	20
16	A	Wife	2
17	D	Mother	6
18	F	Wife	Unknown
19	D	Mother	8
20	D	Wife	11
21	B	Wife	7
22	C	Wife	8