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# Family Caregiver Personal Concerns in Huntington Disease

**Janet K Williams, PhD, RN, FAAN[Kelting Professor of Nursing]**,
The University of Iowa Iowa City, IA 52242 USA Telephone 319-335-7046 Fax 31353-5326 janet-williams@uiowa.edu

**Heather Skirton, PhD, RGN[Registered Genetic Counsellor Professor of Applied Health Genetics]**,
Deputy Head (for Research) of the School of Nursing and Midwifery, University of Plymouth, Wellington Road, Taunton, TA1 5YD, UK Telephone (44) 01823 366911 Fax (44) 01823 366901 heather.skirton@plymouth.ac.uk

**J.Jackson Barnette, MA, PhD[Associate Dean for Academic and Student Affairs Professor of Biostatistics and Informatics]**, and
Colorado School of Public Health University of Colorado Denver Room C3000D Building 500 13001 East 17th Place Campus Box B-119 Anschutz Medical Campus, Aurora, CO 80045 Telephone 303 724 4472 Fax 303 724 4620 jack.barnette@ucdenver.edu

**Jane S. Paulsen, PhD[Professor of Psychiatry, Neurology, Psychology and Neurosciences]**
The Carver College of Medicine The University of Iowa, 438 Medical Education Building Iowa City, IA 52242 Telephone 319 353 4551 Fax 319 353 3003 jane-paulsen@uiowa.edu

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Author Contributions:
JKW, HS, JJB & JSP were responsible for the study conception and design
JKW & HS performed the data collection
JKW, HS & JJB performed the data analysis.
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**What is already known about this topic**

- People with Huntington disease require care that changes as the disease progresses.
- Family carers provide much of the care required by people affected by Huntington Disease.
- Carer burden for persons with HD is associated with carer mental health.

**What this paper adds**

- Family carers of people with Huntington Disease have concerns that are similar to those of carers for family with other neurodegenerative disorders.
- Family carers are concerned for their children's risks to develop HD and the children's relationship with the person with Huntington Disease.
- Concerns voiced by family carers are not identical across national boundaries.

**Implications for practice and/or policy**

- Tailored assessment of carers should include caregiver health, adequacy of extended family support, and child rearing concerns.
- Family carers may need multiple support services that are matched to their specific concerns.
- While some caregiver concerns are shared across national boundaries, further research is needed to assess specific factors influencing them and the effectiveness of interventions to address them in particular national contexts.

## Abstract

**Aim—**To examine and compare the personal concerns of family members providing care for people with Huntington disease in the United Kingdom and the United States.

**Background—**Family caregivers of people with Huntington disease may feel burdened by caregiving responsibilities and concerned about illness risk for relatives.

**Method—**A mailed Personal Concerns survey was completed by 108 United Kingdom and 119 United States adult family caregivers of people with Huntington disease in 2006 and 2007. Survey responses included frequency and intensity of concerns, and narrative comments. Data were analyzed using descriptive statistics of the products of frequency and intensity of reaction scores to identify a Personal Concerns Index for items with the twelve highest combined scores. Factor analysis identified three factors, which were compared between respondents by factor and items within factors using t tests mean frequency by intensity scores. Narrative comments were thematically analyzed.

**Results—**Three main factors were labelled Impact of Role Change, Sense of Isolation, and Concerns for Children. Within the Role Change factor, United States family caregivers had significantly higher concerns regarding family finances and United Kingdom caregivers expressed significantly greater personal sadness. Both groups expressed concern regarding isolation from family. Although family caregivers in both countries expressed concern regarding their children, those of United States caregivers were significantly higher.

**Conclusion—**Further studies are required to identify benefits of support services that are specific to caregiver concerns and consistent with national healthcare systems.



### Keywords

Family; Nursing; Survey; Caregiving; Huntington disease; United Kingdom; United States


## INTRODUCTION

Caregiving for people with Huntington disease (HD) by family members is a complex and lengthy process, often beginning when the person with the disease is in their young to middle adult years, and continuing for decades. Huntington disease causes ongoing loss of neurologic function leading to inability to control motor movements, loss of cognitive skills for thinking, memory, and judgement, and alterations in mood and behaviour. These changes affect not only the person with HD, but family members who provide increasingly demanding and complex care (Kessler 1993, Williams *et al.* 2009b). Although burdens of caregiving are common across conditions, caregiving for one or more family members with HD may create additional concerns for the family caregiver. In a study conducted in Scotland, LoGuidice and Hassett (2005) found caregivers may have paid employment and significant childrearing responsibilities while caring for their relative. Emotional burdens of family caregivers of people with HD in the United Kingdom (UK), United States (US) and Canada not only include role changes and loss of the former relationship with the patient, but also concerns about risk to develop HD in the children (Williams *et al*. 2009b). Although spousal carers are recognized as the forgotten person in an HD family (Kessler 1993), it is only recently that researchers reported quality of life in caregivers in the UK (Aubeeluck & Buchanan 2007), the Netherlands (Kaptein *et al*. 2007), the US (Ready *et al.* 2008), and US caregiver burden (Pickett *et al.* 2007). While supportive services are provided by voluntary organizations, services provided by health care providers vary in countries with privatized or universal healthcare. Despite the presence of people affected by HD in many countries, no reports were found that addressed caregiver concerns across national boundaries and differing healthcare systems. Information on similarities or differences in concerns may

enhance interpretation of existing and future evidence, and inform health service policies and supportive care interventions for family caregivers of people with HD.

## Background

Huntington disease is an autosomal dominant neurodegenerative condition resulting in progressive loss of motor, cognitive, and behavioral functions that may extend over decades. People with HD lose their abilities to carry out responsibilities as wage earners, spouses, parents, and eventually the ability to care for themselves (Rosenblatt *et al.* 1999). The Iincidence is 4-7 per 100,000 (Online Mendelian Inheritance in Man 2008) resulting in approximately 12,000-21,500 affected people in the US and 2,550-4,300 in the UK. In both countries, some people with HD may be cared for in long term care facilities, while others remain at home under their family's care until they die. Although age of onset has traditionally been described as between the ages of 30-40 (Pickett *et al.* 2007), subtle signs and symptoms may be present up to decades before the clinical diagnosis (Paulsen *et al.* 2008) extending caregiving activities by family members, typically across 30 years. If caregivers are biologic siblings or offspring, they too are at risk to develop HD, multiple family members may be affected by HD, and each offspring of a person with HD has a 50% risk of developing the condition. Symptoms of HD are difficult to manage (Ramaswamy *et al.* 2007), and although clinical trials for drugs that may slow the progression or modify the symptoms are ongoing, there currently is no cure.

Although measures exist to assess caregiver burden, few address other concerns for HD family caregivers. Measures of the impact of caregiving for persons with chronic illness and/or dementia address burden, needs, and quality of life (Deeken *et al.* 2003, Ohaeri 2002) , but none were located that include the risk of disease for caregivers, or for their children. Studies of the impact of caregiving on family members often use the term burden, meaning threats to wellbeing of the carer as well as coping capacity (OHeari 2003). Pickett and colleagues (2007) reported that HD caregiver burden, depression in the person with HD, and weaker ability in the caregiver to problem solve were associated with caregiver depression, reinforcing the need for mood assessment and treatment for this population. Quality of life measurement for the caregiver focuses on experiences that can encompass physical, psychological, social, and financial domains (Deeken *et al.* 2003). Aubeeluck and Buchanan (2007) developed a questionnaire for quality of life relevant to spousal carers of people with HD in which the main factors influencing quality of life were practical aspects of care-giving, satisfaction with life and feelings about living with HD. However, breadth and level of caregiver concerns are not addressed. Furthermore, caregivers of people with HD may also include biologic family who may themselves be at risk to become ill with this condition. Thus, the personal concerns of family primary caregivers for people with HD may be broader than those elements captured in more traditional measures. According to Life Stage Development theory, people between the ages of 40-60 years are in the midlife period (Thomas 1990) when offspring develop their own independence before leaving the family home, a situation that allows the parents to pursue their own interests to a greater extent than when the children were young. Employment pressures may be significant during this phase, when the individual may have achieved a senior level position and is dealing with the responsibilities concomitant with that seniority. Thomas claims that during the midlife years, partner or spousal support is crucial in maintaining the difficult and sometimes conflicting demands of home and working life. However, for the person caring for a spouse or partner with HD, responsibilities for offspring may be compounded by increasing responsibility for the affected person, and freedom from caring does not follow when the children become independent. If one breadwinner becomes too ill to work, maintaining employment becomes more critical to the family's ability to manage financially and must be achieved without appropriate spousal support.

How families negotiate their roles as caregivers, and resources to support these efforts may vary according to where people live. In the United States, the majority of persons with or at risk for HD who are employed can qualify for group health insurance plans provided by employers, but some do not qualify for individual health care plans (Erwin et al 2010). However, functional losses may make it impossible for some people to maintain employment even in the period of time prior to clinical diagnosis (O'Rourke 2009). Multidisciplinary specialists can be found in the 21 Centers of Excellence supported by the Huntington Disease Society of America (HDSA), but not all families live near these centres, and extent of training of local care providers varies. In the UK, a National Service Framework for people with long term neurologic disorders includes guidance for caregiver services (Department of Health 2005). However, lack of knowledge by community based health care providers regarding care of persons with HD is a major concern of HD family in the UK and the US (Skirton *et al*. 2010). Despite differences in services provided by voluntary organizations and health care systems, information is needed regarding similarities and differences in caregiver issues across national settings. These data are required to enable health professionals to interpret findings from a range of studies and to inform policy in each setting.

## THE STUDY

### Aims

The aim of the research was to examine and compare the personal concerns of adult family members who have primary caregiving responsibilities for a person with HD in the UK and in the US.

### Design

The study used a cross-sectional survey design. The Huntington Disease Family Concerns and Strategies Survey (HDFCSS) with closed and opened ended responses (Williams *et al.* 2010) was used to obtain caregiver concerns from family who serve as primary caregivers for people with HD, including those who had received a clinical diagnosis or had been identified as having the mutation in the gene and who lived in the UK or in the US. In an earlier qualitative study (Williams *et al*. 2001, Sparbel *et al*. 2008, Williams *et al*. 2007, Williams & Ayres 2007, Williams *et al.* 2009a, Williams *et al*. 2009b) focus group data were collected from HD family caregivers to identify both their concerns and the strategies they used to deal with those concerns. Those data informed the development of the HDFCSS (Williams *et al*. 2010). The Personal Concerns scale is a subscale of the HDFCSS and focuses on the frequency and intensity of these caregivers' concerns (Table 1). This paper reports findings from the Personal Concerns scale for adult family members who identified themselves as being the main person in the family responsible for the person with HD and who lived in either the UK or in the US.

### Participants

The sample, reported elsewhere (Skirton *et al*. 2010), consisted of adult family members of people with HD who were primarily responsible for the care of the person with HD and who were able to respond to an English language mailed paper and pencil survey. The study was conducted in 2006-2007. In the US, the study was announced through a research registry, the Huntington's Disease Society of America (HDSA) annual meeting, an HD family support website, and a clinical HD center. All recruitment sources are accessible by family members of people with HD across the US. Family members in the UK were invited to complete the survey through announcements on the Huntington's Disease Association (HDA) website, by Regional Care Advisors in England and Scotland, and via local HDA support groups (Skirton *et al*. 2010). All sites are accessible by family members of people

with HD in the UK. A total of 379 questionnaires were requested by US family members, and 171 by UK family members. Questionnaires were received from 241 US respondents and 119 UK respondents, yielding 119 (31%) usable US caregiver surveys and 108 (63%) usable UK caregiver surveys. The remainder of the returned surveys were from people with HD, or family members who were not primary caregivers. These were not included in this study, which was focussed on the concerns of the primary caregivers. Participants reflect adult family caregivers of approximately 1% HD cases in the US and 3-4% of HD cases in the UK.

## Data Collection

**Measures—**The HDFCSS is a 15 page questionnaire containing four scales, one of which is the two page Personal Concerns scale. Reliability of the Personal Concerns data was assessed using Cronbach's coefficient alpha and confidence intervals for the Cronbach internal consistency coefficients were determined using ScoreRelCI (Barnette 2005). Internal consistency for the Personal Concerns scale is .905 (95% CI= .888-.922) for frequency and .918 (95% CI= .902-.933) for intensity of reaction (Williams *et al*. 2009), both well above the standard of .80 generally accepted as being evidence of reliability. The scale contains 31 items reflecting the family member's feelings about their own wellbeing and feelings about other family members at risk for HD. The scale was developed from focus group data from family HD carers in the US and in Canada. Scale content was validated by expert review and cognitive interviews (Williams *et al*. 2010). A subsequent cognitive interview validation was conducted with HD family carers in the UK to assure appropriateness of language and completeness of survey items.

**Collection procedure—**Family caregivers were asked to contact the researchers by email, phone or letter to request a copy of the questionnaire, which was sent to them by post with a reply paid envelope. The completed questionnaires were returned to the researcher by postal mail. In the UK, participants were not offered compensation for participation. In the US, participants were offered a telephone card.

## Ethical considerations

The study was approved by The University of Iowa Institutional Review Board and the Ethics Committee of the Faculty of Health at the University of Plymouth (UK). Participants indicated their willingness to participate by returning the completed surveys. Survey data were anonymous.

## Data analysis

The Personal Concerns Index Score was developed for each item by finding the product of the Frequency (How often this has occurred) score and Reaction (How much this has bothered you) score. Each score had a range of 0 – 4 on frequency and 0 – 4 on reaction (Table 1). The Index score represents the product of scores for each item's frequency and reaction to an item in the survey (measured by intensity ratings). Each survey item represented a topic from the focus group data, for which family caregivers had expressed concerns. A product of 0 represents never happening or not bothered by it, while a score of 16 represents something that happened most often that was extremely bothersome. Based on comparisons of factor analysis results, reliability, range of the scores on the possible range scale, and scores having properties closest to a normal distribution of the items in the 12 item, 17 item, or 31 item sets, 12 of the 31 items provided the most parsimonious set of items to be used in these comparisons. Little was gained in improvement of psychometric properties by using more than the 12 items that had the highest means on the product of frequency and reaction scores. The set of 12 items included items with the highest mean

frequency and reaction scores and produced data with internal consistency reliability of alpha= .818 (95% CI= .781-.851). Factor analysis of the 12 items revealed three factors, *Impact of Role Change* (7 items with 33.5% of the variance), *Sense of Isolation* (3 items with 12.1% of the variance), and *Concern for Children* (2 items with 8.6% of the variance) accounting for a total of 54.2% of the variance.

A deductive analysis of narrative comments provided in free text boxes was undertaken using thematic analysis (Braun & Clark 2006) and comments are used to illustrate the quantitative findings. These statements provided further elaboration regarding the context or meaning of the concern. To ensure rigor, a second researcher reviewed the analysis and a consensus was reached concerning the assignment of statements to factors.

## RESULTS

66% of the participants were female, 95% were of white ethnicity, 71% had attended college, and 65% were partners of the person with HD. Ages of respondents ranged from 18 to 80 with no significant differences in mean ages between UK and US respondents (Skirton *et al*. 2010). Among the UK respondents, fewer had formal education beyond secondary school, and more rated their health as poorer than the US respondents (Table 2).

Item scores could range from 0, where there was lack of frequency and reaction to that survey item, to 16 where there was maximum frequency and reaction to that item. Factor scores were the mean of the individual items in the factors and the total score was the mean of the 12 items. The US and UK group means were compared using the independent *t* test. While the distributions of item and factor scores departed from normality, it is well recognized that the *t* test is robust to departures from normality. For each comparison, the homogeneity of variance assumption was tested and if significant, the unequal variance *t* estimation was used to compare the group means. Alpha was set at 0.05 for all tests. Results of the comparisons between US and UK on the items, factors, and total score are found in Table 3.

### Impact of Role Change

On the impact of role change factor, there was not a significant difference in the means of the two groups (5.34 for US and 5.98 for UK). There were significant differences on two Impact of Role Change items. On the “I feel sad” item, the UK group mean (7.14) was significantly higher than the mean of the US group (5.39), $p$= 0.011.There was a higher mean for the US group (5.69) than for the UK group (3.74) on the item “I worry about our family's finances”, $p$= 0.006. Role change for family caregivers of people with HD reflected the strain of long term responsibility for care of people with psychiatric symptoms and complex losses of motor and cognitive function. It included loss of former roles and relationships, not feeling that anyone truly understood their situation, and added worry about maintaining family goals for financial stability and affection between the children and their parent or family member with HD. Respondents reported difficulty in distinguishing the multiple symptoms of HD as separate from the person. However, the impact of their role change from their prior relationship to primary caregiver was described in terms of the ill person's symptoms.

> ‘I feel that I am drained. I need to feel love from her but she is void of any emotions. She really does not care about my health, in fact our relationship is making us both more ill. I wanted to stand by her forever, but now I realise I am not a saint who can go on giving and giving without getting any love or peace. I don't expect we will manage to remain a family much longer. There are times when I cannot even stand to sleep in the same bed with her, drives me crazy.’ (UK1)

> ’He doesn't talk much anymore, and that makes emotional and physical intimacy very difficult’ (US1)‘

Family also elaborated on the toll of caregiving in their own life planning apart from their caregiver responsibilities.

> ‘Having effectively given up my life to be a carer I need to spend at least six hours a day on a personal project to keep my own brain from seizing up. I also need to try keeping myself groomed and feeling it is worthwhile making the effort although no one is there to appreciate me anymore’. (UK2)

> ‘My own physical health has gotten worse. My health is good now but I am 78 years old and you never know when something could happen. I just trust in the Lord.’ (US2)

### Sense of Isolation

On the sense of isolation factor, there was not a significant difference in the means of the two groups (3.54 for US and 3.17 for UK). There was a significant difference on the item “I worry that I will develop HD”, the mean for the US group (3.95) was significantly higher than the mean for the UK group (0.00), $p = 0.003$.

Caregivers specifically expressed concerns regarding isolation within their families regarding discussion of HD and support for the caregiver. This reflected both a distancing of others in the family from caregiver, who, in some cases, was also at risk for HD.

> ‘I would like/be able to have someone to talk to, as I don't cope very well with my mum being ill, and having to cope with a positive genetic test – coping with both of these has had a massive impact on my life. I am not the same person anymore and my relationships with my partner/children/family/friends are almost non-existent.’ (UK3)

> ‘The family doesn't realize the importance of the caregiver having time to themselves.’(US3)

### Concern for Children

On the concern for children factor, there was a significant difference for the total score (7.05 for the US group and 3.13 for the UK group), $p = 0.000$. On both items, the mean score was higher for the US group compared with the UK group. Both of the items on this factor had significant differences. On the “I worry that my child(ren) will develop HD” item, the mean for the US group was 8.78 and the mean of the UK group was 5.23, $p = 0.007$. On the “I worry that the quality of my children's relationship with him/her has declined since the illness” item, the US group mean was 5.38 and the UK group mean was 2.79, $p = 0.011$ Caregivers not only were concerned about themselves, but also for the children who may have inherited the mutation for HD from the ill parent. This concern encompassed the possibility that their children could eventually develop HD.

> ‘My wife has mainly mental symptoms (mood swings, rigid thinking, emotional blunting, organisational problems) and those have worsened very slowly over the past 10 years. Given that she does not acknowledge the symptoms it is hard for people to help us. I find the strain of trying to maintain some normality at home for my daughter overwhelming at times.’ (UK4)

> ‘Our children-I worry about them developing HD and who would take care of them if I am physically incapable or not there.’ (US4)

# DISCUSSION

## Limitations of the study

The study is limited by the use of a convenience sample, and being a cross sectional self report. A more in depth study, including cognitive interviewing to clarify meaning of responses, may help to clarify issues of most concern to each national group. Findings in this study represent the views of family caregivers who participate in HD research or support organizations and it is not appropriate to generalise the results to the caregiver population of people with HD in the US and UK.

## Similarities of HD carers to other carers

It is not surprising that some of our findings are reflected in the results of other studies of carers in neurological conditions. The sense of social isolation that was reported by our participants also featured in the study of individuals caring for a spouse with Alzheimer disease (Croog et al., 2006). In that study, caregivers also reported strong feelings of anger related to the changes in their roles due to cognitive decline and emotional lability of their partners (Croog et al., 2006), while spouses of patients who had suffered a stroke described similar feelings of disquiet about the distortion of their role in relation to their affected husband or wife (Thomas & Greenop, 2008). Concerns about adopting unusual roles within a family are not confined to spouses. Parents of adult children with learning disabilities also report concerns about the nature of their relationship with the person for whom they care (Loue et al., 2006). One aspect of our findings that is not reflected in the studies cited above is the worry about offspring developing the disease.

Despite the relatively small sample, findings provide insights into concerns of caregivers of people with HD who were able and willing to share these concerns in research. Findings from the Personal Concerns Index validate and extend previous research on caregiving in HD, and add suggest that HD family caregivers experience many of the same concerns as caregivers of people with other neurodegenerative disorders. For example, concerns about mental and physical health and finances are frequently reported by caregivers of other dementia subtypes (OHaeri 2003). Findings confirm that concerns previously documented in other studies are similar to those in this sample of HD carers in the UK and US. For instance, caregivers in the US and Canada endorsed concerns regarding the disintegration of one's life, distress over loss of the relationship with the ill loved one, concern for their children (Williams et al., 2009), and separate studies of UK caregivers reported compromised health and lifestyle (McGarva, 2001), and components of satisfaction with life and feelings about living with HD (Aubeeluck & Buchanan, 2007). Findings in this study provide further evidence of the importance of support and assistance by extended family members, regardless of geographic location.

## Unique HD family carer concerns

Several aspects of HD may also provide insights into concerns of family carers, and how some concerns may not be shared by carers in other conditions. Manifestations of HD in the earliest phases of the condition, prior to the onset of motor symptoms, have only recently been described (Duff *et al*. 2008, Paulsen *et al*. 2008), and the impact of changes in the cognitive and behavioral domains may be apparent in day to day functioning long before actual diagnosis. This is difficult for family members who search for explanations of changes in behavior such as irritability or forgetfulness, but don't know if these are due to HD, other health problems, or a result of something the family member did to upset the person (Williams et al., 2007). The disease has a long trajectory, thus, the nature of assistance family caregivers need may change many times over the progression of the illness, taxing the ability of extended family to give support over many years. HD may be

present in multiple family members, further limiting the extent of assistance others can provide. Those in the family who are at risk (and not ill) may avoid their relatives who are manifesting symptoms of HD. It is also evident that the disease changes the lifestage trajectory (Thomas, 1990) not only of the affected person, but the carer and other family members. Part of the distress felt by carers may be due not only to the additional responsibilities they have to assume, but also due to their disappointment in the lack of spousal support.

### Concerns Unique for US and for UK Carers

The higher concern regarding finances among US caregivers may reflect the current health care system in the US, where the resources available for healthcare vary between families, as compared to the health care availability in the UK where healthcare is provided regardless of ability to pay. In the US, although changes in health care are anticipated with health care reform, at the present time payment for healthcare varies according to what may be covered by insurance plans for those who qualify, whether the person qualifies for any federal assistance, and in some cases people pay for health care on their own. Although the HDSA supports Centers of Excellence in the US, payment for these services may be charged to the patient. People with a family history of HD report that it is difficult to qualify for individually issued health insurance policies, and the majority of people who have HD and have health insurance are on group plan policies provided by their employer (Paulsen, 2009).

This survey documented that unsurprisingly, sadness was experienced by carers in both countries. Sadness was more pronounced in family caregivers from the UK than in those from the US. It is difficult to explain the differences between national cohorts, however cultural differences are observed in the way emotions are expressed and the social acceptability of particular emotions (Eid & Diener, 2001). It is possible that cultural expectations for expressing one's emotions or other factors that influence one's management of emotions may vary across the UK and the US. The importance of addressing carer needs and wellbeing is emphasized in England; where under the Carers (Equal Opportunities) Act of 2004 carers are entitled to an assessment of their own needs independent of the assessment of the affected person (The Stationery Office 2004). However, up to the present time this legislation does not appear to have had the impact on carers that is required.

Concern for the wellbeing of children of the person with HD by caregivers was pronounced in both groups, but more so in the US sample. The possibility that US respondents were more likely to have minor age children living at home cannot be confirmed, but may be an artefact of the study sample. The concerns were endorsed by family in both countries and confirm concerns extend across worries that the children may become ill with HD, but also the changes in family life that children experience when their parent has HD. Some children who have parents or grandparents with HD take on substantive caregiving roles (Williams *et al*. 2009a) and teens in HD families describe the challenges of watching their family member's illness progress and knowing that they too are at risk, feeling alone in the midst of their family, difficulties in day to day family life, and taking on roles usually reserved for adults (Sparbel *et al*. 2008). Findings from this study support the need to examine childrearing and parenting concerns when addressing caregiver burdens and adult family member quality of life issues for those with loved ones with HD.

## CONCLUSIONS

This study helps to quantitatively identify caregiver concerns that are most salient in the UK, and in the US. Policies that provide for family caregiver supportive care may be more effective when caregiver concerns regarding responsibilities, isolation within the community

or family, and wellbeing of the children are clearly addressed. Those who provide supportive care also may benefit from awareness of the breadth of concerns that caregivers must cope with, in addition to health care issues resulting from HD. Regardless of whether the family lives in the UK or the US, health care services should be tailored to fit family caregivers' concerns. Effectiveness of interventions to promote caregiver wellbeing has not been testing in HD caregiver populations, especially those in separate cultural settings and health care systems, and this should be a component of future research in this area.

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## Table 1

Personal Concerns Scale Sample Items and Response format

| | Frequency | Reaction |
|---|---|---|
| I feel no one knows what I'm going through. | 0 1 2 3 4 ? | 0 1 2 3 4 ? |
| I worry about our family's finances. | 0 1 2 3 4 ? | 0 1 2 3 4 ? |
| It is hard for me to find time for myself. | 0 1 2 3 4 ? | 0 1 2 3 4 ? |
| I feel sad. | 0 1 2 3 4 ? | 0 1 2 3 4 ? |
| I worry that my child(ren) will develop HD | 0 1 2 3 4 ? | 0 1 2 3 4 ? |

If you have concerns that have not been included: please write them below.

Frequency- how often has this occurred; 0= never occurred at any time, 1= not in the past month, 2= just a few times in the past month, 3= about once or twice a week in the past month, 4= several times a week, daily, or more in the past month.

Reaction- how much this bothered you;_0= not at all, 1= a little, 2= moderately, 3= very much, 4= extremely

**Table 2**

Demographic Characteristics of Respondents

| | US | UK | *p* |
|---|---|---|---|
| Age | 51.15 (12.265) | 52.63 (13.359) | 0.393[1] |
| Gender | | | |
| Male | 38 (31.9%) | 39 (36.1%) | 0.507[2] |
| Female | 81 (68.1%) | 69 (63.9%) | |
| Ethnicity | | | |
| White | 108 (92.3%) | 105 (98.1%) | 0.153[2] |
| Other | 9 (7.7%) | 2 (1.9%) | |
| Education | | | |
| No college | 26 (21.8%) | 39 (38.2%) | 0.015[2] |
| College | 93 (78.2%) | 63 (61.8%) | |
| Relationship to person with HD | | | |
| Significant other | 76 65.5%) | 69 (64.5%) | 0.876[2] |
| Other | 40 (34.5%) | 38 (35.5%) | |
| Health | | | |
| Good | 87 (73.7%) | 52 (46.4%) | 0.000[2] |
| Fair | 27 (22.9%) | 41 (36.6%) | |
| Poor | 4 ( 3.4%) | 19 (17.0%) | |

[1] Based on independent t test

[2] Based on chi-square homogeneity of proportion tests Skirton et al., 2010

**Table 3**

Comparison of Impact Scores

| Item | US | | | UK | | | | |
|---|---|---|---|---|---|---|---|---|
| | n | Mean | sd | n | Mean | sd | *P** | Direction |
| Factor 1 Impact of Role Change | | | | | | | | |
| 2 I feel sad. | 112 | 5.39 | 4.94 | 99 | 7.14 | 4.99 | .011 | UK>US |
| 6 I miss the relationship I had with him/her | 110 | 8.06 | 6.14 | 100 | 9.52 | 5.48 | ns | |
| 1 I feel no one knows what I'm going through. | 112 | 4.13 | 4.74 | 95 | 4.71 | 4.65 | ns | |
| 14 I feel overwhelmed by the changes in my life. | 112 | 4.31 | 5.16 | 102 | 4.07 | 4.69 | ns | |
| 7 I'm like a parent to him/her. | 103 | 5.18 | 6.14 | 92 | 6.95 | 5.48 | ns | |
| 5 It is difficult to distinguish the HD from the person | 110 | 5.43 | 5.87 | 89 | 6.36 | 5.30 | ns | |
| 3 I worry about our family's finances. | 118 | 5.69 | 5.60 | 102 | 3.74 | 4.70 | .006 | US>UK |
| Total for Factor 1 | 121 | 5.34 | 4.21 | 106 | 5.98 | 3.53 | ns | |
| Factor 2 Sense of Isolation | | | | | | | | |
| 16 Family doesn't want to be around him/her. | 113 | 3.52 | 4.83 | 93 | 2.95 | 4.48 | ns | |
| 21 I resent relatives who could help but choose not to. | 112 | 3.75 | 5.35 | 96 | 3.70 | 5.76 | ns | |
| 24 I worry that I will develop HD. | 20 | 3.95 | 5.38 | 11 | 0.00 | 0.30 | .003 | US>UK |
| Total for Factor 2 | 119 | 3.54 | 4.32 | 104 | 3.17 | 4.29 | ns | |
| Factor 3 Concern for Children | | | | | | | | |
| 27 I worry that my child(ren) will develop HD. | 79 | 8.78 | 6.76 | 39 | 5.23 | 6.29 | .007 | US>UK |
| 28 I worry that the quality of my children's relationship with him/her has declined since the illness. | 77 | 5.38 | 6.44 | 48 | 2.79 | 4.66 | .011 | US>UK |
| Total for Factor 3 | 83 | 7.05 | 5.36 | 54 | 3.13 | 4.32 | .000 | US>UK |
| Total | 121 | 5.23 | 3.83 | 107 | 5.23 | 3.17 | ns | |

*All tests were conducted using equal variance independent *t* tests when group variances were not significantly different or unequal variance independent *t* tests when group variances were significantly different.