Published in final edited form as:

J Fam Nurs. 2009 August ; 15(3): 273–294. doi:10.1177/1074840709337126.

Caregiving by Teens for Family Members With Huntington Disease

Janet K. Williams, RN, PhD, FAAN,

The University of Iowa

Lioness Ayres, RN, PhD,

The University of Iowa

Janet Specht, RN, PhD, FAAN,

The University of Iowa

Kathleen Sparbel, RN, PhD, FNP-BC, and

The University of Iowa

Mary Lou Klimek, RN, MA

University of Calgary

Abstract

The purpose of this report is to describe caregiving by teens for family members with Huntington disease (HD). Thirty-two teens in HD families in the United States and Canada participated in focus groups from 2002 to 2005 in a study to identify concerns and strategies to manage concerns. An unexpected finding was 24 (77%) described caregiving activities. Descriptive analysis of caregiving statements identified themes of Tasks and Responsibilities, Subjective Burden, Caregiving in Context of Personal Risk for HD, and Decisional Responsibility. Teens took an active part in nearly all aspects of care with the exception of contacting health care providers and attending doctors' appointments. Some described emotional distress, and many provided care knowing they had the potential to develop HD. Teens recognized the need for decisions but lacked the authority to make these decisions. Findings may be relevant for other teens who strive to meet caregiver and student roles and developmental tasks.

Keywords

family member caregivers; family caregiving; adolescents; focus groups; Huntington disease; adolescent caregivers

Caregiving by minor age children occurs within the context of the family, the broader social and health care community, and the child's own ongoing psychosocial development.

Approximately 3% to 6% of minor age children in the United States, the United Kingdom, and Australia provide some level of unpaid care to chronically ill family members (Carers

For reprints and permission queries, please visit SAGE's Web site at <http://www.sagepub.com/journalsPermissions.nav>

Please address all correspondence to Janet K. Williams, PhD, RN, FAAN, Kelting Professor of Nursing, 338 Nursing Building, The University of Iowa, Iowa City, IA 52242; ; Email: janet-williams@uiowa.edu

Australia, 2007; Becker, 2007; National Alliance for Caregiving, 2005). Numbers of minor age children providing caregiving to ill parents or family members are difficult to determine as health care providers often are not aware of their activities, and families may not disclose children's contributions. Clinical reports describe these children as unrecognized caregivers for persons in their families with chronic or debilitating conditions (Baago, 2004; Banks et al., 2002; Beach, 1994; Gates & Lackey, 1998; Godsall, Jurkovic, Emsoff, Anderson, & Stanwyk, 2004; Jacobson & Wood, 2004; Rotherham-Borus et al., 2006; Valiakalayil, Paulson, & Tibbo, 2004). These reports document that young caregivers may be invisible outside the home due to not seeking support, not socializing with peers who are caregivers, fear of disclosure to social services, fear of bullying at school, adhering to a requirement of secrecy within the family, and/or hesitation to express feelings and emotions within the family unit. A variety of motives have been described for teens to become caregivers including the perception that they have no alternative (Banks et al., 2002).

For minor age children who participate in unpaid informal caregiving of persons with a chronic illness, caregiving has both positive and/or negative consequences. Young caregivers have not yet achieved adult levels of physical, cognitive, or social maturation. In addition, teens have access to fewer resources to intervene in current problems or to prevent potential future difficulties. Caregiving activities may influence youth's abilities to simultaneously meet their own developmental demands, while being both a student and caregiver. Although dimensions of caregiving burdens and positive aspects are reported for adult caregivers, relatively little is known regarding caregiving within a family provided by minor age children.

Background

Family and friends provide valuable informal unpaid assistance to people who have disabling health problems and remain in the community. Caregiving can be defined as a process (Bowers, 1987; Swanson et al, 1997) that subsumes the provision of tasks and performance of a role. The process of becoming a caregiver can be seen as a transition, similar to other life transitions, causing changes and adaptations in persons' social networks and psychosocial well-being (Pillemer, Sutor, & Wethington, 2003).

Additionally, family caregivers of elderly persons with physical ailments and/or dementing illnesses often report high levels of stress, which can lead to a lowered sense of well-being, feelings of burden or depression, and potentially compromised emotional and physical health (Dunkin & Anderson-Hanley, 1998; Pillemer et al., 2003). The term burden refers to threats to the physical, psychological, and socioeconomic well-being of the care providers, as well as their ability to cope and adjust (Ohaeri, 2003). Mahoney (2003) asserts that although stress and burden are often used in relation to caregiving, this casts a negative connotation on the process. Mahoney's research suggests that the concept of vigilance may better convey what caregivers describe as their continual oversight or their careproviding activities and is a more neutral term.

Caregiving by Minor Age Children

Caregiving by youth occurs in a continuum in which tasks and levels of responsibility range from age appropriate, routine levels and types of caregiving and household tasks, to substantial tasks that would more appropriately be the responsibilities of adults. These are provided on a regular basis, and/or often provided without supervision or support (Becker, 2007). Research-based evidence on what caregiving youth do is modest, and little is known regarding caregiving activities that youth assume without adverse consequences. Eight descriptive studies report caregiving responsibilities by minor age children. Of these, five focus on specific disorders, one is a community study, one is based on a U.S. survey, and one is based on a school district survey (Table 1). Caregiving responsibilities vary across these studies, with most including direct caregiving tasks, such as activities of daily living or instrumental activities of daily living as well as household management (Table 2).

Researchers document both positive and negative youth reactions to caregiving. A study of adolescents assisting parents in caregiving for family members with Alzheimer disease reported that these teens experienced decreased time for school and family nurturance and reluctance to tell friends or teachers about their families (Beach, 1994). Others note that caregiving affects learning (Sislowksi, 2006) and time for studying (Gates & Lackey, 1998), and it is associated with increased occurrence of getting into trouble with teachers (National Alliance for Caregiving, 2005) and missing school, being unable to do homework, or being late for school (Banks et al., 2002). Increased levels of depression and lower self-esteem are reported when caregiving youth are compared to their noncaregiving peers (Banks et al., 2002), and caregiving youth may express feelings of sadness, fear, anger, resentment, and frustration (Valiakalayil et al., 2004).

Positive aspects of caregiving by youth include strengthened relationships with the healthy parent and siblings, less tolerance for peers' insensitive behaviors, and increased empathy for older adults (Beach, 1997), as well as feeling closer to the ill person (Valiakalayil et al., 2004), and finding caregiving "hard but gratifying" (Gates & Lackey, 1998, p. 11). Children may derive self-worth from their contributions to stability of the family if their caregiving behaviors are recognized and supported. However, young caregivers can be at a risk for exploitation by others in the family (Godsall et al., 2004). Thus, like adults, minor age children may take on multiple caregiving tasks, and may experience both positive and negative reactions as caregivers.

Psychosocial Development

Physical, intellectual, social, and emotional growth occurs throughout the lifespan, and these changes occur within the person's internal and external environments. Youth growing up in families where a person or persons have HD may experience additional challenges to achieving psychosocial developmental milestones. One component of early adolescence is identity formation in which youth may distance themselves from the expectations and definitions imposed by parents and other family members and create a vision of self that is personally meaningful (Newman & Newman, 2006). Following adolescence, young adults may experience a feeling of being in-between, where they are leaving behind the struggles of adolescence, feeling more responsible for themselves, but still feel close ties to parents and

families (Arnett, 2004). Adults who grew up in families where people had HD report varying experiences, with some saying that HD brought them closer together, whereas others report that HD split the family apart (Vamos, Hambridge, Edwards, & Conaghan, 2007). Growing up with a parent who has HD, who may have mood and personality changes, choreic movements, and who may be unable to maintain the role as the parent, has the potential to affect adults' abilities to form affectional relationships with others (Van der Meer et al., 2006). Research findings are not consistent. Thus, it is likely that caregiving can have both positive and negative impact on teens' personal development.

Family as Context of Care

Families function as systems in which crises and challenges affect the whole family, and family processes mediate the coping and adaptation of family members and the family unit (Walsh, 2006). Families vary in their adaptability regarding sharing tasks and shifting roles in response to changes, while maintaining the family's need for stability, enduring values, and predictable rules for behavior (McDaniel, Rolland, Feetham, & Miller, 2006). Although disabling illnesses and death are universal experiences in families, the presence of a disabling genetic condition may influence the function of the family network (Rolland & Williams, 2006). Teens who are biologically related to persons with HD may be living in the awareness phase of risk for a genetic illness. They have some knowledge of the possibility that they will develop this condition in the future, while also functioning in the long-term adaptation phase as caregivers of a person in their family who has the condition (Sparbel et al., 2008).

Huntington Disease

HD is a family disease in several dimensions. Symptoms begin at a time when childbearing, childrearing, and career development are part of the family life cycle (Vamos et al. 2007). Because it is an autosomal dominant genetic disorder, biologic offspring are at a 50% risk to develop the disorder, and more than one family member may have the condition. HD is a progressive neurologic disorder, and persons with HD have a prognosis of 10 to 15 years after it is diagnosed. Signs of the condition most commonly appear between the ages of 30 and 50 years, and persons with HD lose their abilities to carry out responsibilities as wage earners, spouses, parents, and eventually the ability to care for themselves (Rosenblatt, Ranen, Nance, & Paulsen, 1999). In many families, one wage earner can no longer provide financial support, and the other parent may be holding more than one job outside the home, leaving little time or energy for parenting or home management. Adult family members who are caregivers report multiple aspects of emotional distress (Williams et al., 2009). Although research continues to identify effective treatment, there is currently no cure (Penziner et al., 2007).

The findings presented in this report on caregiving by teens with family members with HD were obtained in a study whose purpose was to identify health-related concerns and strategies used by family members to manage their concerns (Williams, Paulsen, Schutte, & Tripp-Reimer, 2001). The purpose of this report is to examine caregiving responsibilities assumed by teens in families of persons with HD.

Method

Design and Sample

The design of the larger study is reported in more detail elsewhere (Sparbel et al., 2008; Williams & Ayres, 2007; Williams et al., 2007; Williams et al., 2008). In brief, the larger study was a two phase mixed methods study in which the conduct of focus groups and development of a family concerns and strategies survey were completed in the first phase, and the survey was distributed and analyzed in the second phase. The study was conducted in conjunction with the PREDICT-HD study (Paulsen, Hayden, et al., 2006), and participants were recruited by HD center coordinators. Thirty-two teens between the ages of 14 and 18 years with a family member who has HD were recruited for the teen component of the study. From 2002 to 2005, 6 teen focus groups varying in size from 2 to 8 participants were conducted across the United States and Canada. Some parents who declined indicated reluctance for their teens to be in a group where HD would be discussed. The sample was predominately female (3:1 ratio), with a mean age of 15.9 years, and the majority (84%) were at genetic risk for HD. Most persons with HD (78.1%) lived in the teen's home and had either tested positive for the gene expansion that causes HD or had clinical symptoms of HD. Teens in the focus groups had not met each other before the focus group meetings. Additional sample details are noted elsewhere (Sparbel et al., 2008).

Procedure

Each teen participated in a focus group consisted of 2 to 8 teens. The groups met in a conference room at the HD medical center, where other groups for adult family members were conducted on the same day. An experienced psychiatric nurse or the project principal investigator moderated each group, and a research team member served as an assistant. Groups extended from 1 to 2 hours, length did not appear to be related to the number of participants in the groups. Teen and adult participants were asked to describe concerns regarding themselves, concerns regarding the health of the family member with HD, strategies used to manage these concerns, and what could help them (Williams et al., 2008).

Human Research Participants' Protection

Institutional review boards from each participating site and the principal investigator's institution approved the study. All parents provided permission and teens provided assent through the informed consent process. Teens were encouraged not to repeat anything that was said during the focus groups. At the beginning of each focus group, teens were cautioned that, although the researchers would maintain confidentiality of information shared within the group, the researchers could not guarantee that group members would respect confidentiality. This information was also included in the informed consent document that was signed by each teen and a parent or legal guardian.

Data Analysis

All focus groups were tape-recorded and transcribed verbatim with all identifying information from participants removed. Analysis took place in three phases. As described elsewhere (Sparbel et al., 2008), content analysis methods were followed to code the

narrative data (Knafl & Webster, 1988; Sandelowski, 2000). First, each transcript was inspected to identify information teens provided that related directly to caregiving. Next, using NVivo software (QSR, 2000), investigators sorted this information into emergent categories. Emergent categories were refined, reconfigured, and sorted by two investigators into four overarching themes. These themes were reviewed by the authors for clarity and consistency with the data. Notes maintained by each focus assistant regarding interactions and nonverbal communication among group members were reviewed. An audit trail was maintained. The team compared the findings with the original transcripts and focus group assistant notes to increase trustworthiness of the analysis (Holloway & Wheeler, 2002; Morse & Field, 1995).

Findings

Twenty-four of 32 teens described caregiving experiences for a parent or grandparent with HD. Of those who did not talk about caregiving, 3 lived with their relative who has HD and four did not. Four common themes describe the overall experience of caregiving. Two themes were consistent with the adult caregiving literature, namely Tasks and Responsibilities, and Subjective Burden. Two themes unique to these teens were also identified: Caregiving in Context of Personal Risk, and Decisional Responsibility. Each theme has several components; these are presented with quotes to illustrate each component.

Tasks and Responsibilities

Teens provided a range of caregiving activities to family members with HD. These are similar to activities and categories of caregiving provided by adults to persons unable to care for themselves. In a prior examination of teens' experiences, "Having to behave like an adult" was identified as a component of the teens' experiences in being a member of a family where a person has HD. That experience included caregiving (Sparbel et al., 2008). Caregiving by these teens includes several dimensions of tasks and responsibilities.

Direct care—Teens managed components of day-to-day care of a parent or grandparent with HD. Although other adults may be in the home, these teens assumed responsibilities ordinarily provided by a primary caregiver. For example, "Well, I have to feed her, and watch her for my dad to work because she can't be alone for more than two hours" (Sparbel et al., 2008).

Promoting a supportive environment—In addition to attempting to prevent harm or injury to the person with HD and others in the family, teens also structured their own behavior to minimize temper outbursts or undesired behaviors. When explaining how they accommodated to their family member's needs, teens also expressed empathy for the adult with HD and their behaviors. Although teens or adults can be cruel to others who are different, these teens were not. For example,

Yeah, like relatives who really don't see them very much, they don't even know what to do or how to act ... like with my grandma, if she gets something in her head that she wants to do, you have to do it ... you know you just have to do it and

just get it over with ... it's not her fault ... and it's not a big deal, but it's still hard for other people to understand that.

Teens also devised solutions to caregiving problems associated with behavioral and psychiatric symptoms. Teens did not explain how they knew what to do; they described what they do to supervise their parent or grandparent with HD. For example, "You have to monitor him, like he's your kid or something, 'cause you're watching out for him, 'cause he's making bad decisions."

Subjective Burden

Although categories of subjective caregiver burden are reported for adult caregiver populations (Horwitz & Reinhard, 1995), these categories are also found in the experiences of teen caregivers. For teens, emotional health included the additional dimension of wanting to know and to enjoy time with their parent or grandparent.

Emotional distress—Teens described emotional distress associated with caregiving. For example, "I was actually diagnosed with depression from all the work, 'cause I was sleep deprived from staying up with my dad, so I have a lot of anxiety." Some expressed sadness regarding knowing that time was limited when their parent could still communicate, "trying to, you know, enjoy the last proofs of my mom before something real bad happens."

Social restrictions—Time with friends or others was restricted because of the time necessary for caregiving and dealing with problematic behaviors in the family member with HD. For some, caregiving cut into time that might ordinarily be spent with friends. Some teens created boundaries that worked for them: sometimes bringing friends home so that they could simultaneously manage caregiving responsibilities, and sometimes planning when to be with friends.

My friends understand, and they know that some nights I just need to be home because my mom's working. If she's working I tell her I'll stay home to watch my dad and that kind of gives her a comfort. Also when I go out with my friends, I have it all planned out. ... there's never just a time, like, I can't just sporadically leave the house. I need to get it okayed and make sure someone's there to take care of everything.

Other teens described avoiding contact between friends and the person with HD, assuring that time with friends was entirely separate and outside their homes, "I wouldn't describe it as affecting my friendships, but, like, I never bring friends over to my house."

Financial concerns—Teens cannot act on behalf of the person with HD to apply for benefits or seek financial assistance, and few teens addressed financial worries. However, some talked about financial concerns that affected the whole family.

Because my dad is under the age of sixty, we don't really qualify for Title 19. And also, my mom works, so we don't qualify, there are no qualifications that we have, and really we do need the help, and our insurance doesn't cover anything basically.

Caregiving in the Context of Personal Risk for HD

Teens with a family member with HD spoke at length about the pervasiveness of HD in their lives, and described the difficulty of caregiving within this genetic heritage.

Being surrounded by HD—For any family caregiver of a person with HD, the context includes the likelihood that there are several family members with the illness and that the caregiver himself or herself is at risk to develop HD. Teens are likely to see others with HD or hear stories about them. Whether HD is discussed or not, these impressions are part of the shared perceptions and experiences within the family. For example,

It killed my great-grandfather, killed my grandfather, it's killing my dad and one of his brothers ... now with my uncle, it's been really hard because he's had to live with his mother his entire life.. everyone is constantly having to take care of him. It's a lot of tough issues to deal with. [From a male teen]

The potential to become the patient—Teens expressed realistic worries regarding the possibility that they too would develop HD and would come to have the same limitations, problem behaviors, and dependencies as the family member for whom they were providing care. Empathy for the person with HD was complicated by the knowledge that they, themselves, might require such empathy later in their own lives. Awareness of the genetic risk for HD colored all aspects of their lives, influencing their decisions for their future as well as their activities in the present. This aspect of their experience is the psychological meaning of the illness beyond issues within the family; it is the space that the idea of HD takes up in the teen's emotional life.

When this is over, and if you don't get it, you'll be a better person in the long haul. You'll have, uh, spent your time in hell, so ... if you don't get this ... then, your life's going to be great because you went through hell already.

Decisional Responsibility

Teens who are caregivers for persons with HD take on adult roles in determining disease management. They make day-to-day decisions, implement caregiving tasks, and recognize the need to coordinate their family member's care. They have a powerful sense of responsibility, but have no administrative or legal authority to make decisions on behalf of their family member with HD or to coordinate what their family member needs.

Absence of authority—Much like a draftee who finds himself in charge during a battle, these teens lacked training to take on the administrative responsibilities of caregiving roles, and they had no authority to implement or delegate oversight responsibilities. All that the teens could do was worry about what could happen if they were not able to enlist the help of others within and outside the family to implement individualized care for their family member. For example,

I'm kind of stuck, like in my family ... I'm the only ... like my dad doesn't know everything that I know ... and then he yells at me, and I'm just saying look, I'm trying to help you out.

Inability to coordinate services—Teens had realistic worries about practical issues related to HD. Teens expressed concerns about multiple problems that, in other circumstances, adults would likely have the responsibility and authority to solve.

The problem right now is, to feed him; he almost has to have pureed foods because he can't swallow. It's just getting more difficult in getting that help, especially when everyone is leaving the house. And then it'll just be my mom, and I don't want her to have to deal with everything by herself. And we even just worry about the finances, there's only one income, my mom's.

Furthermore, as has been described elsewhere (Sparbel et al, 2008), although some in this situation may be eager to escape the family and attendant responsibilities, several teens in this situation were reluctant to leave once they finished high school. This hesitation reflected administrative concerns regarding who would be in charge, and reveals that teens do not have the authority to arrange for others to provide supportive services the teens had provided, once they were away from home.

My main concern probably is like, when I go off to college, how's my mom going to get around, because when I graduate, my dad's planning on moving back east, so I don't know how she will get her groceries, and what she needs because she doesn't drive anymore. So, just what would she do, because no one would be there, like all the time.

Thus teens caring for persons with HD had experiences both similar to and different from experiences of adult caregivers reported in the literature. Like adult caregivers, teens provided physical and emotional support for their family members, and teens sometimes were depressed or anxious, socially isolated compared to their peers, and experienced financial strains. In contrast to adult caregivers, however, teen caregivers lacked the legal authority to deal with the health care system and the status within the family to influence the conditions of care. They had responsibility without the ability to make changes. At the same time, because HD is heritable, these teens faced daily reminders of their own risk. Lack of authority, high responsibility, and high personal uncertainty made teen caregiving in families with HD a very demanding role.

Discussion

This report describes Tasks and Responsibilities, Subjective Burden, Caregiving in Context of Personal Risk for HD, and Decisional Responsibility aspects of caregiving implemented by teens in families in which members have a genetic neurodegenerative disorder. The responsibilities are consistent with those reported for minor age children for parents with other chronic illnesses, but it adds the dimensions of decision making and personal risk for the disorder present in care recipients.

Caregiving

The process of caregiving by teens who participate in caregiving for their adult family members with HD shares many similarities to the process described in the adult caregiver literature. One distinction of this study is that the stage of disease in the adult was not

specified. Thus, it was not possible to discern components of caregiving for teens whose parents or grandparents were in the earlier or later stages of HD. However, components of caregiving for the teens resembled the concept of vigilance. Findings are similar to Mahoney's (2003) vigilance categories of watchful supervision, protective intervening, and anticipating. Protective intervening, or "guarding everyone's welfare" (Mahoney, 2003, p. 27) fits the descriptions of caregiver tasks and responsibilities that teens reported including their attempts to provide care to the person with HD as well as protect the primary caregiver in the family.

Another component of caregiving by teens that is unique for teens is the nature of transitions. Transition to caregiving for persons with dementing disorders occurs for many family members in middle adulthood and later life (Pillemer et al., 2003), and is viewed as a status transition, similar to other major transitions in the life course such as marriage or becoming a parent. Although the teens describe multiple aspects of what they do and think about as caregivers, they have not acquired the status of a caregiver that is recognized by family or health care providers, despite fulfilling many responsibilities that are typical of this role. Furthermore, participation in caregiving is occurring when developmental transitions also occur. These developmental transitions may not be marked by events, but reflect increasing autonomy and planning for career choices and life away from one's parents (Newman & Newman, 2006).

Caregiving by Teens

Teens may have responsibilities not only toward parents but also toward siblings with chronic illness. Although few studies have addressed teens' concerns during adolescence, some researchers have described adults' retrospective accounts of their responsibilities as teens who had siblings with a chronic condition. Adult siblings of those with mental illness reported needing information on available services, suggesting that, although these siblings were not coordinating total care, they may require assistance in clarifying their role in future care (Friedrich, Lively, & Rubenstein, 2008). Other researchers have examined the psychosocial adjustment of healthy school-age siblings of children with sickle-cell disease or severe emotional disturbances. These studies documented multiple factors within the family, such as support, expressiveness, low levels of conflict, family cohesion, and the quality of the sibling relationship, as factors that contributed to adjustment by healthy children (Gold, Treadwell, Weissman, & Vichinsky, 2008; Kilmer, Cook, Taylor, Kane, & Clark, 2008).

Research-based literature on siblings of ill children focuses on the mental health and coping of the healthy sibling, with little specific information regarding the nature of their roles in caring for their siblings. Themes from these studies that resemble those from the present study are that the healthy siblings may feel protective toward their ill sibling (Batte, Watson, & Amess, 2006), yearn for usual routines (Kleiber, Montgomery, & Craft-Rosenberg, 1995), and try to not do anything that would cause further disruptions in their families' lives (Woodgate, 2006). In some instances, teenage siblings take care of others in families in an attempt to ease the burden on their parents. It is possible that the responsibilities of teens

providing care for a parent with HD are heavier than the impact of contributing to the care of an ill sibling, in part, because teens are supplanting a role usually taken by a parent.

Caregiving responsibilities by teens in this study are consistent with tasks identified in a recent study of young peoples' experiences in HD families. In a study conducted in Scotland, one third of 33 children and young adults participating in individual interviews reported providing household tasks, personal care, or caring for younger siblings as children or teens. Participants also described efforts to adapt their responses and the family environment to the increasing severity of psychiatric and cognitive symptoms in the persons with HD over time (Forrest Keenan, Miedzybrodzka, van Teijlingen, McKee, & Simpson, 2007). Caregiving for persons with HD is challenging for family and health care providers and requires continued problem solving as symptoms progress. The efforts by teen caregivers to adapt caregiving efforts that fit the needs of the person with HD may be overlooked by others who do not regard the teens as being experts in cognitive and behavioral management for their family member, reflecting the lack of recognition of their status as caregivers.

The teens in the present study described an additional responsibility of attempting to educate others in the family about approaches to care. This added role may be an attempt by teens to educate others in the family about individualizing the care for specific family members. In some families of persons with HD, the families have a disorganized pattern of functioning and become more chaotic when dealing with individual member's worsening symptoms (Vamos et al., 2007). The attempt to provide leadership within the family may reflect teens' attempts to help others see their family member as a person with unique characteristics and needs.

Two aspects may distinguish these teen caregivers from those in previous reports of caregiving youth for other diseases and contribute to the teens' advocacy efforts. One aspect is that more than one person in their families may have HD, giving teens some experience and foreknowledge of issues that the persons with HD may face. The second is that these teens had some level of knowledge regarding their biologic risk to develop HD. It is not surprising that teens who are caregivers worry about developing the same condition as their parent or grandparent. For example, adult caregivers worry about developing a condition that might have some genetic components, such as Alzheimer disease (Moscarillo et al., 2007). What is unique is that the risk for teens who are biologic offspring of parents with HD is known to be 50%. The impact of this awareness on all aspects of the teens' caregiving is unknown, but an important topic for further study. The presence of multiple family members with HD and the biologic risk may have unrecognized influences on the responsibilities assumed by teens in this study, the meaning of caregiving to these teens, and the ways in which they balance multiple challenges.

Implications for Understanding Ways to Support Caregiving Youth

Very little is known regarding teen caregiving, beyond the growing body of literature on their tasks and responsibilities. We do not know how teens acquire caregiving skills and if traditional sources of information would be useful for them. For teens in this study, their skills may have been developed through trial and error and/or by observing what others in

the family do. Traditional sources of information for caregivers are designed for adults, such as individual behavioral management therapy, supportive interventions, or informational interventions (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007; Thompson et al., 2007). The nature and sharing of caregiving responsibilities differ within families. Research is needed to determine factors that maximize positive and minimize negative outcomes. Future research may identify the relationships among family level factors and the effects of innovative efforts to support caregiving youth, and ways to provide socially acceptable support for these teens.

To enhance the construct validity of future research, we recommend that future studies consider caregiving responsibilities in teens to have potentially both positive and negative aspects; so as to produce a comprehensive representation of the caregiving experience. In addition, we recommend that future research with teens who may be at risk for the same condition that they see in their families (e.g., early-onset Alzheimer disease, late-onset muscular dystrophy, or schizophrenia) explore teens' evaluation of their own risks and the influence of that meaning on their experience of caregiving.

Support services for minor age caregivers are being developed in several countries. For example, formal services for young caregivers in the United Kingdom include opportunities to support youth carer achievement in school, overall health, social interactions, emotional well-being, and financial issues (Frank, 2002). In the United States, a pilot program is ongoing in which individual and group activities are available to educate and support caregiving youth in a middle school (C. Sislowksi, personal communication, August 7, 2007). However, no programs offer services beyond a local community. Caregiving support services for young carers in Australia (Carers Australia, 2007), and in Canada (Young Carers, 2007) are also being developed.

Several HD centers have reported attempts to organize specific teen group activities involving mainly social activities with time for sharing, but these are often poorly attended. Encouragement is often given to teens to attend Al-Anon or Alateen groups because of the similarities between many families with HD and substance use. Attention must also be given to teens who reportedly will not seek or accept support if they become very resentful and angry toward the family member with HD.

The ways in which families' function, support, and resources interact with teen caregiving have also not been explored, and they would provide important insights in the interpretation of outcomes of caregiving youth interventions. Outcomes of these interventions will contribute to understanding how services for teens can potentially protect youth from undesired effects of caregiving and support their roles as caregivers, students, and adolescents who are developing skills for adult independence.

Finally, when examining the effect of experiences such as caregiving on teens who are themselves at risk for an inherited neurodegenerative disease, the potential effects of early neurologic changes due to the presence of the gene mutation must also be acknowledged. In adults with the gene mutation, but without the typical choreic changes, it has been noted that changes in brain structure occur prior to the clinical diagnosis of HD (Aylward et al., 1996;

Paulsen, Magnotta, et al., 2006), and changes in cognition and behavior have been reported to precede the clinical diagnosis (Paulsen & Conybeare, 2005; Paulsen et al., 2005). Very little is known regarding how ongoing changes in neurological processes may or may not influence function in teens who have the gene mutation for HD.

Study Limitations

This was an exploratory study. Data from this study were obtained in focus groups which may have limited the scope of topics that teens would raise in front of others in the group. The study relied on comments volunteered by teens, and no focus group questions were asked regarding specific caregiver responsibilities, impact on the teens' own development, family values, rules and resources, ability to achieve in school, or how teens learned how to be caregivers. Although teens were asked to describe their concerns and ways they manage these concerns, no specific questions were asked regarding benefits that teens might derive from being caregivers for their family member or how their responsibilities fit within the caregiving provided by others in the family. Although findings reflect concerns of teens across multiple sites in two North American countries, these findings can not be assumed to be typical of teens in all HD families, or teens in families of persons with other chronic illnesses.

Conclusion

Some teens take on multiple aspects of caregiving for family members with HD. Teen caregivers supervise and protect the person with HD while at the same time attempt to maintain their identity as a developing adolescent, student, and at-risk child or grandchild of the person for whom they are responsible. Teens accomplish multiple dimensions of caregiving despite lack of authority to implement necessary caregiving decisions. Multiple aspects of teen caregiving for family members with HD may serve as a useful reference for examination of caregiving by youth in other clinical populations. Determining which teens require support, relationships of family function to teen caregiving, and how these teens can be supported in their multiple roles require additional research.

Acknowledgments

The authors would like to thank Carolyn Gray, Bonnie Hennig, Hillary Lipe, and Elizabeth Penziner for their collaboration in recruitment and arrangements for the focus groups; the HD Family study team for contributions to the overall project; and the teens and their parents who provided permission for the teens to participate. Funding was provided by the National Institute of Nursing Research (R01 07079), National Institutes of Health; and linked with 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

- Arnett, JJ. Emerging adulthood: The winding road from the late teens through the twenties. New York: Oxford University Press; 2004.
- Aylward EH, Codori AM, Barta PE, Pearlson GD, Harris GJ, Brandt J. Basal ganglia volume and proximity to onset in presymptomatic Huntington disease. *Archives of Neurology*. 1996; 53:1293–1296. [PubMed: 8970459]

- Baago S. The unrecognized caregiver: Children of dementia. *Perspectives*. 2004; 27(4):3–4. [PubMed: 15085612]
- Banks P, Cogan N, Riddell S, Deeley S, Hill M, Tisdall K. Does the covert nature of caring prohibit the development of effective services for young carers? *British Journal of Guidance & Counseling*. 2002; 30:229–246.
- Batte S, Watson AR, Amess K. The effects of chronic renal failure on siblings. *Pediatric Nephrology*. 2006; 21:246–250. [PubMed: 16240159]
- Beach D. Family care of Alzheimer victims: An analysis of the adolescent experience. *Journal of Alzheimer's Care Related Disease Research*. 1994; 9:12–19.
- Beach DL. Family caregiving: The positive impact on adolescent relationships. *The Gerontologist*. 1997; 37:233–238. [PubMed: 9127979]
- Becker S. Global perspectives on children's unpaid caregiving in the family: Research and policy on "young carers" in the UK, Australia, the USA, and Sub-Saharan Africa. *Global Social Policy*. 2007; 7:23–48.
- Bowers BJ. Intergenerational caregiving: Adult caregivers and their aging parents. *Advances in Nursing Science*. 1987; 9(2):20–5. [PubMed: 3099634]
- Carers Australia. Young carers in Australia. 2007 Oct. from: <http://www.youngcarers.net.au/>.
- Dunkin JJ, Anderson-Hanley C. Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention. *Neurology*. 1998; 51(1 Suppl. 1):S53–S60. [PubMed: 9674763]
- Forrest Keenan K, Miedzybrodzka Z, van Teijlingen E, McKee L, Simpson SA. Young people's experiences of growing up in a family affected by Huntington's disease. *Clinical Genetics*. 2007; 71:120–129. [PubMed: 17250660]
- Friedrich RM, Lively S, Rubenstein LM. Siblings' coping strategies and mental health services: A national study of siblings of persons with schizophrenia. *Psychiatric Services*. 2008; 59:261–267. [PubMed: 18308906]
- Frank, J. *Making it Work: Good Practice with Young Carers and their Families*. London, UK: The Children's Society and the Princess Royal Trust for Carers; 2002.
- Gates MF, Lackey NR. Youngsters caring for adults with cancer. *Image: Journal of Nursing Scholarship*. 1998; 30(1):11–15.
- Godsall R, Jurkovic G, Emsoff J, Anderson L, Stanwyk D. Why some kids do well in bad situations: Relation of parental alcohol misuse and parentification to child's self concept. *Substance Use & Misuse*. 2004; 39:789–809. [PubMed: 15202809]
- Gold JI, Treadwell M, Weissman L, Vichinsky E. An expanded Transactional Stress and Coping Model for siblings of children with sickle cell disease: Family functioning and sibling coping, self-efficacy and perceived social support. *Child: Care, Health and Development*. 2008; 34(4):491–502.
- Holloway, I.; Wheeler, S. *Qualitative research in nursing*. 2nd. Oxford, UK: Blackwell Publishing; 2002.
- Horwitz A, Reinhard S. Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illness. *Journal of Health and Social Behavior*. 1995; 36:38–50. [PubMed: 7738327]
- Jacobson S, Wood F. Contributions of children to the care of adults with diabetes. *The Diabetes Educator*. 2004; 30:820–826. [PubMed: 15510533]
- Kelley LS. Minor children and adult care exchanges with community-dwelling frail elders in a St. Lucian village. *Journals of Gerontology Series B. Psychological Sciences and Social Sciences*. 2005; 60:S62–S73.
- Kilmer RP, Cook JR, Taylor C, Kane S, Clark LY. Siblings of children with severed emotional disturbances: Risks, resources, and adaptation. *American Journal of Orthopsychiatry*. 2008; 78:1–10. [PubMed: 18444721]
- Kleiber C, Montgomery LA, Craft-Rosenberg M. Information needs of the siblings of critically ill children. *Child Health Care*. 1995; 24:47–60. [PubMed: 10142085]
- Knafl 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]

- Mahoney DF. Vigilance: Evolution and definition for caregivers of family members with Alzheimer's disease. *Journal of Gerontological Nursing*. 2003; 29(8):24–30. [PubMed: 13677157]
- McDaniel, SH.; Rolland, JS.; Feetham, SL.; Miller, SM. "It runs in the family": Family systems concepts and genetically linked disorders. In: Miller, SM.; McDaniel, SH.; Rolland, JS.; Feetham, SL., editors. *Individuals, families, and the new era of genetics*. New York: W. W. Norton; 2006. p. 118-138.
- Morse, JM.; Field, PA. *Qualitative methods for health professionals*. 2nd. Thousand Oaks, CA: Sage; 1995.
- Moscarillo T, Holt H, Perman M, Goldberg S, Cortellini L, Stoler JM, et al. Knowledge of and attitudes about Alzheimer disease genetics: Report of a pilot survey and two focus groups. *Community Genetics*. 2007; 10:97–102. [PubMed: 17380059]
- National Alliance for Caregiving. *Young caregivers in the U.S. Report of Findings*. Bethesda, MD: Author; 2005.
- Newman, BM.; Newman, PR. *Development through life: A psychosocial approach*. 9th. Belmont, CA: Thomson Wadsworth; 2006.
- Ohaeri JU. The burden of caregiving in families with a mental illness: A review of 2002. *Current Opinion in Psychiatry*. 2003; 16:457–465.
- Paulsen JS, Conybeare RA. Cognitive changes in Huntington's disease. *Advances in Neurology*. 2005; 96:209–225. [PubMed: 16385769]
- Paulsen J, Hayden M, Stout JC, Langbehn DR, Aylward E, Ross CA, et al. Preparing for preventive clinical trials: The PREDICT-HD study. *Archives of Neurology*. 2006; 63:883–890. [PubMed: 16769871]
- Paulsen JS, Nehl C, Hoth KF, Kanz JE, Benjamin M, Conybeare R, et al. Depression and stages of Huntington's disease. *Journal of Neuropsychiatry & Clinical Neuroscience*. 2005; 17:496–502.
- Paulsen JS, Magnotta VA, Mikos AE, Paulson HL, Penziner E, Andreasen NC, et al. Brain structure in preclinical Huntington's disease. *Biological Psychiatry*. 2006; 59(1):57–63. [PubMed: 16112655]
- Penziner E, Williams JK, Erwin C, Wallis A, Bombard Y, Beglinger L, et al. Perceptions of genetic discrimination among persons who have undergone predictive testing for Huntington disease. *American Journal of Medical Genetics Part B Neuropsychiatric Genetics*. 2007; 147:320–325.
- Pillemer K, Suitor JH, Wethington E. Integrating theory, basic research, and intervention: Two case studies from caregiving research. *The Gerontologist*. 2003; 43(Special Issue 1):19–28. [PubMed: 12637686]
- QSR. NVivo [Computer software]. Doncaster, Victoria, Australia: Author; 2000.
- Rolland, JS.; Williams, JK. Toward a psychosocial model for the new era of genetics. In: Miller, SM.; McDaniel, SH.; Rolland, JS.; Feetham, SL., editors. *Individuals, families, and the new era of genetics*. New York: W. W. Norton; 2006. p. 36-78.
- Rosenblatt, A.; Ranen, N.; Nance, M.; Paulsen, JS. *A physician's guide to the management of Huntington's disease*. 2nd. New York: Huntington's Disease Society of America; 1999.
- Rotherham-Borus M, Lester P, Linn Y, Beckwith L, Song J, Leonard N, et al. Intergenerational benefits of family-based HIV interventions. *Journal of Consulting and Clinical Psychology*. 2006; 74:622–627. [PubMed: 16822118]
- Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health*. 2000; 23:334–340. [PubMed: 10940958]
- Selwood A, Johnston K, Katona C, Lyketsos C, Livingston G. Systematic review of the effects of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*. 2007; 101(1–3):75–89. [PubMed: 17173977]
- Sislowski D. Young caregivers: Effect of family health situations on school performance. *Journal of School Nursing*. 2006; 22(3):163–169. [PubMed: 16704286]
- Sparbel KJH, Williams JK, Driessnack M, Schutte DL, Tripp-Reimer T, McGonigal-Kenney, et al. Teens' experiences living with Huntington Disease. *Journal of Genetic Counseling*. 2008; 17:327–335. [PubMed: 18347962]
- Swanson E, Jensen DP, Specht J, Johnson ML, Maas M, Saylor D. Caregiving: Concept analysis and outcomes. *Scholarly Inquiry for Nursing Practice*. 1997; 11:65–76. [PubMed: 9188270]

- 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]
- Valiakalayil A, Paulson L, Tibbo P. Burden in adolescent children of parents with schizophrenia: The Edmonton project. *Social Psychiatry and Psychiatric Epidemiology*. 2004; 39:528–535. [PubMed: 15243690]
- Van der Meer L, Timman R, Trijsburg W, Duisterhof M, Erman R, Elderen T, et al. Attachment in families with Huntington disease: A paradigm in clinical genetics. *Patient Education and Counseling*. 2006; 63:246–254. [PubMed: 16427763]
- Vamos M, Hambridge J, Edwards M, Conaghan J. The impact of Huntington's disease on family life. *Psychosomatics*. 2007; 48:400–404. [PubMed: 17878498]
- Walsh, F. Strengthening family resilience. 2nd. New York: Guilford; 2006.
- 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; 12:655–664.
- Williams, JK.; Barnette, JJ.; Reed, D.; Sousa, VD.; Schutte, DL.; McGonigal-Kenney, M., et al. Development of the Huntington disease family concerns and strategies survey from focus group data. Manuscript submitted for publication; 2008.
- Williams JK, Hamilton RJ, Nehl C, McGonigal-Kenney M, Schutte DL, Sparbel KJH, et al. "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:636–641.
- Williams, JK.; Paulsen, JS.; Schutte, DL.; Tripp-Reimer, T. [Retrieved April 21, 2009] Family health after predictive HD testing (Grant NR07970). 2001. from <http://crisp.cit.nih.gov>
- Williams JK, Skirton H, Paulsen JS, Tripp-Reimer T, Jarmon L, McGonigal-Kenney M, et al. The emotional experiences of family carers in Huntington disease. *Journal of Advanced Nursing*. 2009; 65:789–798. [PubMed: 19228233]
- Woodgate RL. Siblings' experiences with childhood cancer. *Cancer Nursing*. 2006; 29:406–414. [PubMed: 17006115]
- Young Carers. 2007 Nov. from <http://www.healthyb.dal.ca/young.html>.

Biographies

Janet K. Williams, RN, PhD, PNP, CGC, FAAN, is the Kelting Professor of Nursing, Director of the Clinical Genetic Nursing Research postdoctoral training program in the College of Nursing at The University of Iowa. Her program of research focuses on psychosocial responses to genetic testing and family management of inherited conditions by adults and teens. Her recent publications include "I'm Like You": Establishing, Confirming and Contesting Common Ground In Focus Groups With Huntington Disease Caregivers" in *Journal of Research in Nursing* (2007), "The Emotional Experiences of Family Carers in Huntington Disease" in *Journal of Advanced Nursing* (2009), and "Teens' Experiences Living With Huntington Disease" in *Journal of Genetic Counseling* (2008).

Lioness Ayres, RN, PhD, is an assistant professor in the College of Nursing at The University of Iowa. Her research interest is families' response to chronic illness across the lifespan. She is currently in the second year of a federally funded study of young adults with impaired mobility and the way they and their families manage their transition to adulthood. Her recent publications include "I'm like you": Establishing, Confirming and Contesting Common Ground in Focus Groups With Huntington Disease Caregivers" in *Journal of Research in Nursing* (2007), "The Best of Both Worlds: The Interdependence of Software and 'people-ware'" in *Research in Nursing & Health* (2008), and a five-part series on

designing qualitative health research in the *Journal of Wound, Ostomy, and Continence Nursing*.

Janet Specht, RN, PhD, FAAN, is an associate professor in the College of Nursing at The University of Iowa. Her research interests are on urinary incontinence in persons with dementia, and their caregivers. She is the principal investigator on a federally funded project to introduce evidence-based practice for urinary incontinence and for pain in 50 nursing homes. Her recent publications include “Interventions for Residents With Dementia and Their Family and Staff Caregivers: Evaluating the Effectiveness of Measures of Outcomes in Long-Term Care” in *Journal of Gerontological Nursing* (2005), “Research-Based Model Home for Persons With Dementia: Policymaking and Regulatory Constraints on Nursing Innovation” in *Nursing and Health Policy Review* (2004, with M. L. Maas), and “Partnering for Care: The Evidence and the Expert” in *Journal of Gerontological Nursing* (2009).

Kathleen Sparbel, RN, PhD, APRN, BC, is a postdoctoral Clinical Genetics Nursing Research Fellow at The University of Iowa, and a clinical instructor, University of Illinois College of Nursing, Quad Cities Regional Program. Her program of research focuses on patient decision making regarding genetic testing, implementation of genetic testing in primary care, and patient and family responses to genetic information and conditions. Her recent publications include “Teens’ Experiences Living With Huntington Disease” in *Journal of Genetic Counseling* (2008) and “‘No One Else Sees the Difference’: Family Members’ Perceptions of Changes in Persons With Preclinical Huntington Disease” in *American Journal of Medical Genetics* (2007).

Mary Lou Klimek, RN, MA, is a genetic research nurse in the Movement Disorders Program and Ocular Genetics, at the University of Calgary. She is the site coordinator for the Huntington Study Group, University of Calgary, and Board Member of the Southern Alberta Chapter Huntington Society of Canada.

Caregiving Youth Research

Table 1

Report	Location	Method	Sample	Age (Years)	Family
Banks, et al. (2002)	U.K.	Survey and focus groups	31	11–17	Sibling or parent with mental or physical disability
Gates and Lackey (1998)	U.S.	Phenomenology	11	10–19	Adult with cancer
Forest Keenan et al. (2007)	Scotland	Interviews	33	9–28	Family with HD
Jacobson and Wood (2004)	U.S.	Survey of adults	15.7%, 51 adults ($n = 8$) young caregivers	5–18	Adult with diabetes
Kelley, 2005	St. Lucia	Ethnography	45	3.5–16	Frail elders in community
National Alliance for Caregiving (2005)	U.S.	Telephone interviews	213	8–18	Family member with Alzheimer disease, disease of heart, lung, or kidneys, arthritis, or diabetes
Sislowski (2006)	U.S.	Survey of public school children	6,210	6–12 grade	Family member in need of special medical care
Valiakalayil et al. (2004)	Canada	Semistructured interview	13	13–18	Parent with schizophrenia

Table 2

Tasks in Caregiving Youth Literature

	Cook	Errand Shop	Comfort	Med Glucose	Drive	Bathe, Dress	Help With ADL	Read	Manage House	Talk HCP	Pay Bills
1	1	1	1						1		
	2	2	2				2				
							3		3		
5	5	5	5	4	4						
	6	6	6	6			6		6	6	
	7					7	7	7	7		
8	8				8				8		8

Note: ADL = activities of daily living. HCP = health care provider. 1 = Banks et al. (2002); 2 = Gates and Lackey (1998); 3 = Forest Keenan et al. (2007); 4 = Jacobson and Wood (2004); 5 = Kelley (2005); 6 = National Alliance for Caregiving (2005); 7 = Sislowski (2006); 8 = Valiakalayil et al. (2004).