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ORIGINAL ARTICLE

"This could be me": exploring the impact of genetic risk for Huntington's disease young caregivers

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Abstract

Huntington's disease (HD) is a predominantly adult-onset, genetic, neurodegenerative condition. Children of affected individuals have a 50% risk of inheriting HD and often assume caregiving roles for their parent. Studies specifically focused on HD young caregivers have proposed that the genetic risk component of HD "exacerbates" the caregiving experience and identified common responsibilities, burdens, and support needs, but none have explored the relationship between the caregiving role and perception of genetic risk. In an attempt to understand this relationship, we conducted a qualitative study to explore the interaction between a young caregiver's perception of genetic risk, the caregiving experience, and thoughts about and plans for predictive testing. Thirteen individuals between 15 and 25 years who provided care for a parent with HD were recruited from two HD youth groups and local support groups. Interviews were recorded, transcribed, and analyzed thematically. Two themes emerged: (1) caregiving and thoughts about risk and (2) caregiving and perceived opinions towards genetic testing. Our findings suggest that the genetic risk colors the caregiving experience by evoking feelings about the future and a potential diagnosis of HD, in addition to impacting plans for predictive testing. Genetic counselors can use these findings to inform their understanding of caregiver experiences, which can aid them when helping patients explore their motivations for testing during a genetic counseling session. Future studies should explore the extent to which health care providers acknowledge the work of young caregivers in the home and provide support to these individuals.

Keywords Young caregiver · Young carer · Huntington's disease · Genetic risk · Genetic counseling · Predictive testing

Introduction

Huntington's disease (HD) is a predominantly adult-onset, genetic, neurodegenerative disorder, affecting nearly 30,000 individuals in the USA (Bates et al. 2002). It has been characterized as the quintessential family disease; the nature of its autosomal dominant inheritance leaves over 200,000 children of affected individuals at a 50% risk of carrying the gene expansion and thus having HD (Huntington's Disease Society of America 2016; Kavanaugh 2014). As a progressive disorder, symptoms are complex, affecting motor, behavioral, and psychological capabilities (Nance et al. 2011). Without a cure or treatment to slow the progression of the disease, symptoms typically appear between the ages of 30–50 years and worsen over a 10- to 20-year period.

It is estimated that for every HD patient, there are 20 people who suffer the consequences of HD (Hayden et al. 1980). These consequences may largely be attributable to the dependence on caregivers in the later stages of the disease and/or the genetic inheritance (Aubeeluck and Moskowitz 2008). The caregiving role usually becomes the responsibility of family members (Aubeeluck and Moskowitz 2008). Further, due to the relatively young age of onset, the complexity and length of expression of symptoms, and the possibility that the well parent will have to work to support the family, children and adolescents are often involved in providing care to the parent with HD (Kavanaugh 2014). In such cases, the consequences

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of HD are compounded for these youth, who are impacted both by the dependence of their parent and their biologic risk.

A few studies have looked at the specific caregiving tasks performed by children and adolescents who care for a parent with HD, who are often designated in the literature as "young caregivers" or "young carers" (Forrest Keenan et al. 2007; Kavanaugh 2014; Kavanaugh et al. 2014; Røthing et al. 2014; Williams et al. 2007; Williams et al. 2009). Young caregivers are typically defined as children and young persons under the age of 18 who provide, or intend to provide, care, assistance, or support to another family member, assuming a level of responsibility that would normally be associated with an adult (Frank and Slatcher 2009). These studies highlight that young caregivers in this setting are involved in substantial caregiving tasks that include direct physical care of the parent with HD, housework, and sibling assistance. In addition to physical tasks, young caregivers promote a supportive environment for the person with HD and others in the family by accommodating other family member's needs, expressing empathy, and devising solutions to caregiving problems (Williams et al. 2009).

These studies also note caregiver burdens and strains. Kavanaugh (2014) assessed the relationship between caregiving, parent-child conflict, school problems, and psychological well-being of child/adolescent caregivers, utilizing the Stress Process Model as guidance (Pearlin et al. 1990). This model provides a conceptual framework that has been used in the adult caregiving population to understand caregiver stressors. Kavanaugh's findings demonstrated a relationship between caregiving, parent-child conflict, and problems with caregivers' school performance. Additionally, she found that often, these young caregivers have minimal social and school support, limiting the available resources to mitigate these household strains (Kavanaugh 2014). Williams et al. (2009) found subjective caregiver burden in their youth cohort, a term defined as the physical, psychological, social, and financial impact on the caregiver caused by feelings and appraisals of the objective caregiving role (Dulin and Hill 2008). Subjective caregiver burden has been reported in adult caregiver populations and the categories of emotional distress, social restrictions, and financial concerns were also found in the experiences of teen caregivers (Williams et al. 2009).

Despite the many responsibilities that these young individuals fulfill, they also described the lack of recognition, or the feeling of invisibility, by family and health care providers (Williams et al. 2009). There are many reasons young caregivers remain hidden and unsupported, which may include the structure of the family, the nature of the illness, and reluctance to tell outsiders about the situation (Frank and Slatcher 2009). Specific to HD, the stigmatizing nature and the overarching secrecy surrounding the disease further contribute to the youth's inability to be seen and heard (Kavanaugh et al. 2014; Williams et al. 2013). The invisibility of caregivers in general, and young caregivers in particular, is a key problem; since they often go unnoticed, so do many of their needs (Howatson-Jones and Coren 2013).

While the discussions of these papers focused on separate youth caregiver issues, multiple authors have called attention to one crucial and understudied piece of the youth caregiving experience in HD families. As a genetic disease, HD fosters a unique caregiving context, especially for the young individuals who are caring for a parent and for a disease for which they themselves are at 50% risk. As such, they face daily reminders of their own risk (Williams et al. 2009). The impact of the young caregiver's awareness of this genetic risk on all aspects of the caregiving experience is unknown and an important topic for exploration (Kavanaugh 2014; Williams et al. 2009).

To understand this impact, we conducted a qualitative study to explore the two-pronged research question: (1) what is the interaction between a young caregiver's perception of genetic risk and the caregiving experience and (2) does the caregiving experience impact thoughts about and plans for predictive testing? Information from this study will contribute to the limited literature that exists about young individuals who care for a parent with HD, specifically providing insight about the impact of the caregiving experience on motivations and plans for predictive testing. It will also provide genetic counselors with valuable insight into this experience, so that they can best meet the clinical and psychosocial needs of these individuals in a genetic counseling session.

Methods

Participants

Study participants included English-speaking males and females between the ages of 13–25 years who self-identified as a caregiver for a parent with HD. Caregiving tasks included the following: (1) assisting the parent with daily tasks, e.g., eating, dressing, and walking; (2) doing tasks to help the family as a whole, e.g., grocery shopping or caring for a younger sibling; and (3) other companionship duties, e.g., providing emotional support or promoting a supportive family environment. The typical age range of young caregivers in the literature extends from 5 to 18 years (Bauman et al. 2006; Gates and Lackey 1998; Jacobson and Wood 2004; Kavanaugh 2014). However, young adult caregivers between the ages of 18 and 25 also assume considerable caregiving responsibilities and are largely ignored in the literature (Levine et al. 2005). For that reason, we widened the definition of "young" in our study to include participants up to the age of 25 years.

Eligible participants were providing care at the time of data collection or had provided care up until the recent passing (i.e., within the last 18 months) of his/her parent with HD. Eligible participants were aware of the inheritance risk associated with HD, as assessed by a five-question questionnaire about the

genetics of HD, and had not previously undergone predictive testing. Participants were assigned pseudonyms, which are linked to their demographic characteristics (Table 1**).**

Recruitment

Multiple methods were employed to recruit participants and are detailed in Fig. 1. Information about the research project and contact information were posted on the Facebook pages of the Huntington's Disease Youth Organization (HDYO) and its Youth Camp. HDYO is an international non-profit organization that provides information, education, and support to young people impacted by HD. Research project fliers were disseminated at three Regional Youth Retreats sponsored by the Huntington Disease Society of America (HDSA) National Youth Alliance (NYA) during the summer of 2016 in Pittsburg, Iowa City, and Denver. Retreats were open to individuals between the ages of 12–22 years who have a family member with HD. Research flyers were also circulated at several HDSA support groups in Northern California. Lastly, the study information was posted on HDSA's HD Trial Finder webpage, under "Quality of Life Studies."

Interested individuals directly contacted the first author, D.S.D, by email, who screened potential participants for caregiving status and parent status (e.g., alive or deceased) and whether or not the participant had undergone predictive genetic testing. Nineteen individuals who met eligibility requirements were emailed consent forms; five did not return consent forms and/or were lost to follow-up.

Parents of participants under 18 years of age and participants 18 years or over signed consent forms; participants under the age of 18 years signed assent forms. All consents were collected prior to scheduling the interview. All participants were offered a $20 Amazon gift card as compensation for their participation. The study was reviewed as an expedited protocol and approved by the Stanford University Institutional Review Board.

Data collection

A semi-structured interview guide was created to explore four domains. The domains and associated sample questions are provided in Table 2. Participants were encouraged to discuss issues and experiences that they felt were important to their caregiving experience. The interview guide was created by D.S.D and reviewed by J.H.F. It was then pilot tested with an individual who was a prior caregiver for her mother with HD, but at the age of 34, was not eligible for the project.

All interviews (14) were conducted by D.S.D, utilizing BlueJeans, a secure application for the purpose of accessibility and digital recording. Participants were given the option of in-person, phone, or video conferencing based on personal comfort level and preference. Closed-ended questions were used to capture demographic information and knowledge about the genetic basis of HD (Fig. 2). Support resources provided by D.S.D were available, specifically the names and contact information of a HD youth worker and genetic counselor, should the participant demonstrate or express emotional uneasiness due to the nature of the interview questions. However, none of the participants demonstrated or expressed distress during the interview process. As such, support resources were not utilized.

One interview was not included in the study because of a poor internet connection. The remaining 13 interviews were transcribed verbatim by D.S.D for data analysis. All identifying information from participants was removed to ensure confidentiality.

Table 1 Demographic characteristics of young caregiver cohort ($N = 13$)

Pseudonym	Age	Gender	Caregiver education	Parent with HD	Parent status	Who else cares for the parent?
Kristin	15	Female	High school	Mother	Alive	No one
Kylie	15	Female	High school	Father	Alive	Sibling, medical aid
Patrick	15	Male	High School	Mother	Alive	Other parent, grandparent
Jackie	16	Female	High school	Mother	Alive	Other parent
Charlie	17	Male	High school	Father	Alive	Sibling, medical aid
Elizabeth	17	Female	High school	Mother	Alive	Other parent, grandparent
Samantha	17	Female	High school	Mother	Alive	Other parent
Shannon	20	Female	College	Mother	Alive	Medical aid
Gabrielle	21	Female	College	Mother	Deceased	Other parent, sibling, and medical aid
Lindsey	23	Female	College	Mother	Deceased	Other parent, sibling
Beth	24	Female	Out of school	Father	Deceased	Other parent
Annie	25	Female	Graduate school	Mother	Alive	Other parent, sibling, and medical aid
Haley	25	Female	Out of school	Mother	Deceased	Other parent, sibling

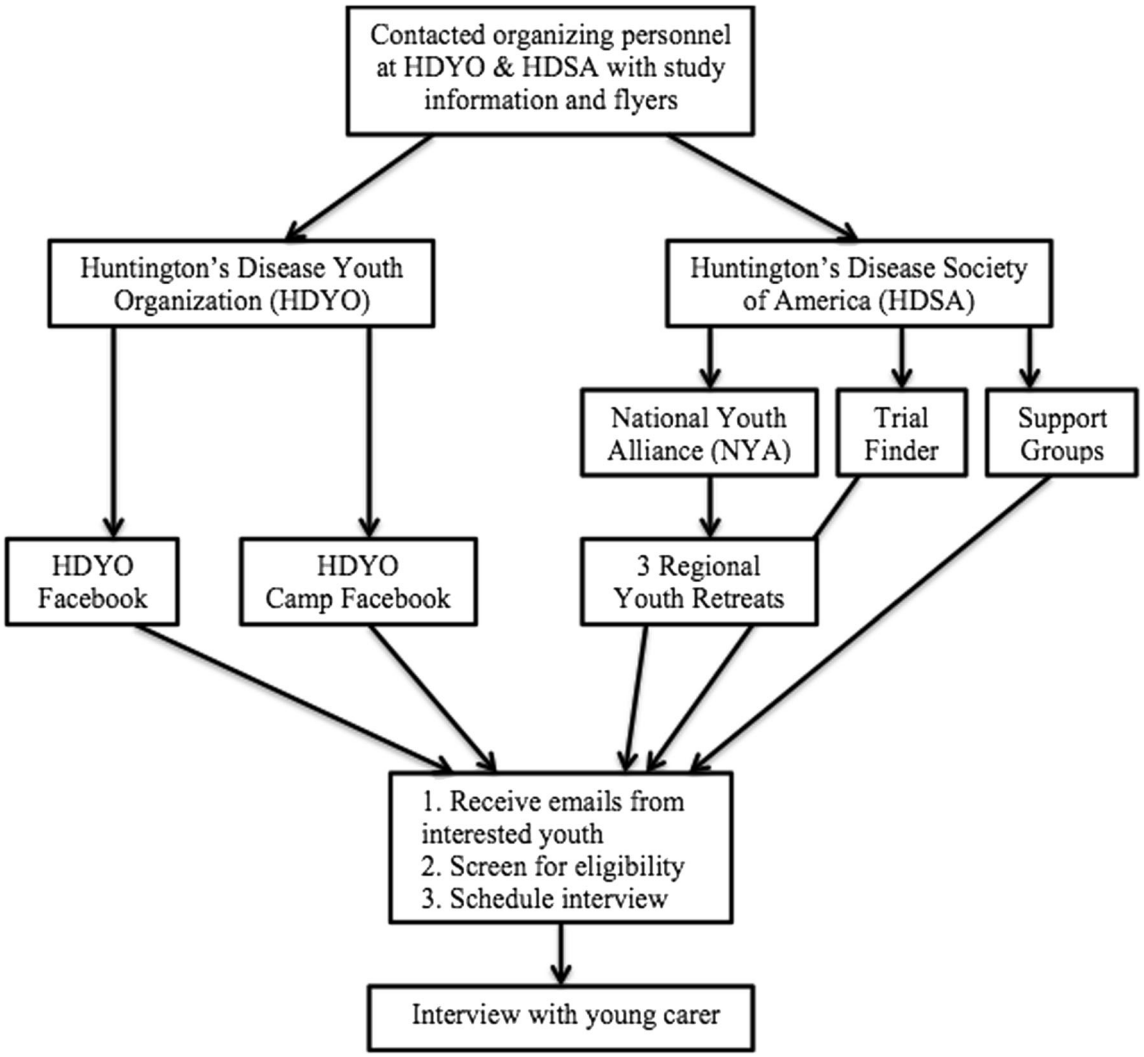

Fig. 1 Data collection flow chart

Table 2 Interview guide domains and sample questions

Domain	Sample questions
Learning about the diagnosis and genetics of HD	1. When did you learn about your parent's diagnosis of HD? What was that like for you?
	2. When did you learn about the genetics/inheritance of HD? What was that like for you?
Caregiving role	1. Explain your role as a caregiver for your parent with HD.
	2. What has this experience been like for you?
Genetic risk and caregiving	1. Does knowing about your genetic risk impact your caregiving?
	2. Does the act of caregiving impact how you feel about your genetic risk?
Genetic risk, caregiving, and predictive genetic testing	1. Have you heard about predictive genetic testing?
	2. Have you thought about predictive testing for yourself? If so, what are your thoughts/plans?
	3. Do you think your caregiving experience has impacted how you feel about testing and your plans to pursue (or not pursue) testing?

1. Is HD a genetic disease? Y N
2. How is Huntington's disease inherited?
   a. Autosomal dominant
   b. Autosomal recessive
   c. X-linked
   d. Sporadic (randomly)
3. If a parent has HD, the chance for each child to inherit HD is:
   a. 25%
   b. 50%
   c. 75%
   d. 100%
4. HD affects all ethnicities. TRUE FALSE
5. HD affects both sexes (males and females). TRUE FALSE

Fig. 2 Interview guide—HD genetics questionnaire

Data analysis

We utilized an inductive data driven approach for analysis with the goal of generating representative themes from the data gathered (Hanson et al. 2011; Thomas 2006). Coding was completed in phases using Dedoose (2016). All transcripts were reviewed for familiarity. D.S.D independently coded two interviews to produce a preliminary draft of the codebook. A Master's student colleague, Aiste Nerkeviciute, independently coded one transcript. D.S.D and A.N. came to a consensus agreement on code definition and usage, identified missing codes, and added the necessary codes to fill the identified gaps. A final version of the codebook was then applied by D.S.D to the complete set of transcripts. All authors contributed to the final analysis and validation of findings. Codes were sorted into overarching themes.

Results

Cohort demographics

Demographic data for the 13 participants are reported in Table 1. All participants identified as being caregivers for a parent with HD. One participant identified as being the sole caregiver. Twelve participants indicated caregiving assistance from the other parent ($N = 9$), sibling ($N = 6$), grandparent ($N = 2$), and/or from a professional medical aid ($N = 5$). Eleven participants were female; two were male. Ages of participants ranged from 15 to 25 years. Ten participants chose video conferencing, two chose phone conferencing, and one chose an in-person interview.

Two main themes that relate to the original research question emerged from the data: (1) caregiving evokes thoughts and emotions related to the caregiver's personal genetic risk and (2) caregiving impacts young caregivers' perceived opinions towards pursuing genetic testing.

Caregiving and thoughts about genetic risk

"**This could be me**" All participants acknowledged their 50% risk of developing HD in the future. However, many expressed that they attempt not to think about their risk while providing care for their parent. They mentioned suppressing thoughts about their own genetic risk by thinking about the parent and what he/she is going through before thinking about oneself. However, despite their efforts to avoid these thoughts, there were times when the act of caregiving prompted thoughts about one's genetic risk. Elizabeth (17) discussed how she typically does not think about her own risk to develop HD while caregiving for her mother. However, when her mother is "behaving in a way [she] doesn't like," Elizabeth described triggered thoughts:

> I would sort of sit back and think, "I really hope I'm not like this if I do test positive." I really hope that I'll be better, that I'll be different, or that I wouldn't be putting a child of my age or loved ones in a similar situation that we are in for my mother.

Similarly, when asked whether the act of caregiving evoked certain thoughts or emotions about one's future, Annie (25) said it went in phases:

> A lot of the time, I just thought of it like, "This is my duty. This is happening to my mom," and I didn't try and loop it back to me. But there are obviously times where I've thought, "Oh my God, this could be me."

These "this could be me" thoughts and related emotions were expressed, in some form, by every participant. One participant, Kylie (15) put it plainly, "the worst part [about] caregiving was just getting that anxiety about how it could happen to me or my brother." While caregiving for her father, she described being glad to help out, but often she would have these anxiety-provoking thoughts afterwards. Similarly, Gabrielle (21) illustrated how caregiving prompted lingering thoughts about her 50% risk and the feeling that she has already seen her future, what she is going to "become," and what people will have to do for her, if she tests positive. Charlie (17) described how he was able to identify positive aspects of the situation:

> For me, when I take care of my dad, I sometimes go, "This could be me." So I figured I might as well learn what's good, so if I do develop symptoms and if I decided I wanted to have kids, I could teach them the best ways to [take care of me] and things like that.

Likewise, other participants were able to identify positive aspects of the caregiving experience, which included an increased sense of emotional maturity and independence, and strengthened family ties.

Not placing blame because "it's genetics" While the "this could be me" thoughts often promoted distressing thoughts about their genetic risk, the participants, more often than not, did not place blame on their parent with HD for "putting" them at risk. Patrick's (15) mother was adopted and had no prior knowledge about a family history of HD. When asked if he thought awareness of his risk affects the way he cares for his mother, he replied that he did not think so because he acknowledged that she had no control:

> There's no reason that it should make me upset or make me not want to help her or make me angry at her or anybody. Because it's genetics…I can't be mad at her because she was dealt the same cards...We are in different roles, but I can't be mad at her any more than I can be mad at my dad; he had no control [either].

Similarly, when asked if things would be different if HD were not a genetic disease, participants thought that they would be less concerned for their own future but imagined doing the same physical caregiving duties. Shannon (20) replied:

> If I didn't have a chance to get [HD], I mean she's still my mom regardless, I'm still going to love her and care for her as much as I can because she's the only mom I've got.

Some stated that, if anything, they were more invested in the act of caregiving:

> [Given] the possibility that I could have it definitely made me a little bit more caring. Because it's like...what would I want someone to do for me if I were in this situation? (Haley, 25)

Overall, caregiving for a parent with HD triggered self-reflection about the caregiver's personal genetic risk. Thinking about one's risk often evoked unfavorable feelings, such as uneasiness, frustration, anxiety, fearfulness, anger, and sadness. Some were able to balance one or more of these unfavorable emotions with positivity and an attempt to live in the moment. In addition, the caregivers did not feel that the emotional aspects of being at risk negatively impacted how they provided care for their parent with HD. While many felt they would be doing the same duties for their parent regardless of whether or not they were at risk for this disease, a few participants actually felt like they did more because of their personal connection to the disease.

Caregiving and perceived opinions towards genetic testing

Plans for testing None of the participants had undergone predictive testing, as specified by the eligibility requirements and thus were not aware of whether or not they had inherited HD from their parent. However, all participants indicated that they had heard about the option of predictive testing. The amount of information a participant knew about the details of testing depended on his/her age, degree of involvement in youth groups, and whether or not the participant had gone to HDSA conferences. None had met with a genetic counselor or clinical geneticist to discuss testing. However, multiple participants mentioned meeting genetic counselors at the camps or hearing a genetic counselor present at a conference.

When asked about plans to pursue testing, all but one participant said they had plans to test at some point in their future. Each participant had a different timeline for pursuing testing, some waiting to become legally of age to pursue testing and others waiting for certain life milestones, e.g., finishing school or getting involved in a serious relationship. Motivations for testing were not explicitly asked about, but participants often alluded to their rationale for testing and justifications for why the current time was not the appropriate time to test. Motivations for testing included preparing for the future, making decisions (e.g., insurance, career romantic relationships, and childbearing), and relieving the feeling of uncertainty. Justifications not to pursue testing at the current time included not wanting the result to limit one's future, feeling unsure how one would respond to results, recognizing that one's genetic status was not going to change, and being too scared to know whether HD would manifest in their future. Only one participant indicated not having given thought about plans to test. Shannon (20) described thinking about testing more frequently in the past year but does not know if it is the best time to do so while in college:

> I want to get tested but it's hard right now with school because if it's positive, should I continue my schooling? Should I live a normal life? There's a whole "what if" part of it.

She expressed that she thinks about the "what if" part often. She hopes that by having a result, whether positive or negative, she will be better able to cope than with the uncertainty of not knowing. Samantha (17) learned about the genetic testing process at the HDYO youth camp and through her cousin's experience, which has prompted more thought about the subject. She described her plans for testing:

> As of now I don't think that I want to know until later. I think that I want to have the right reasons to know. So I think that I'll wait. But I am interested in getting tested some day.

When asked what the "right" reasons are for pursuing testing, she described wanting to know her results when deciding on

plans for the future, such as if and when to start a family and what career to pursue.

Our study found that there was minimal understanding amongst friends and those outside of the household regarding HD and its implications, making it difficult for caregivers to discuss their thoughts about and plans for testing with these individuals. Further, discussion about testing was often seen as "taboo" within the family unit. Not only did participants mention that it was often a difficult subject to broach with family members, but two participants also stated they would keep positive results from their family members. One participant only intended to test after her mother had passed away. These participants were concerned about the emotional consequences of a positive result on other family members, as illustrated by the following quote:

> Part of the reason I've been waiting to test is I don't necessarily know if I would want my dad or siblings to know the result 'cause I think that'd be harder on them. I don't want to talk about it with them 'cause even though they love me and support me, I feel like it would crush them, maybe even more than it would crush me, if it was positive. (Annie, 25)

Impact of caregiving When asked whether or not their caregiving experience has impacted their thoughts about genetic testing, 12 participants agreed that their experience had played a role in how they felt about testing. For those who had older siblings who did not participate in caregiving or had moved out of the house before the onset of the parent's symptoms, participants noted differences between how they felt about testing and how their sibling(s) felt. Several participants with plans to pursue testing noted that their non-caregiver siblings had not tested nor were many inclined to test. One participant did not see a connection and believed that she would feel the same way about testing regardless of the caregiving experience.

Participants who agreed that their caregiving experience had an impact on testing decisions thought so for various reasons. Some felt that witnessing the disease so closely and being involved in caregiving for the illness made them more curious about the possibility of HD in their own future. Annie (25) contrasted her experience as a caregiver to that of someone who may not have had an active role in caregiving and may not have seen the impact of HD. This "wider" perspective about the implications of the disease has prompted her desire to test:

> I think it's being in that situation where you see just how it spreads to every facet of that affected person's life and the family's life. It just widens your perspective about the implications, more than it would for someone else who hadn't necessarily seen those things…which inclines me to want to test because it would be harder for me to accept someone, like my daughter, giving me the type of care I provide my mom.

Annie later mentioned wanting to know her test result before thinking about having children. Shannon (20) also compared her experience to that of her sister, who removed herself from the caregiving role:

> I think that does have an impact on why she doesn't want to get tested because she has tried to block out the caregiving, and so now she's trying to block out whether or not this is going to happen to her as well. So if I didn't have to care for my mom then honestly, I don't know if I would get tested because it's like I'm not watching someone decline from it. So... why would I even want to know?

Others mentioned wanting to know so that they could prepare themselves and others. Elizabeth (17) felt that her mother did not have enough time to prepare for the disease, as she tested after the onset of symptoms. Watching the progression of the disease and wanting to be able to prepare for the potential onset of symptoms has impacted her thoughts about testing:

> For the longest time I have [wanted to get tested], just so I can prepare for my future better and know if I do test positive, maybe I should think about this and that… like children, maybe have a secure plan with a doctor, already speak with a doctor to see what we can do early on.

Her experience of the stress associated with caregiving has also "scared her" into wanting to test, so that if she is positive, she would be in a different situation than her mother and not put the burden of stress on someone else. This sentiment of fear made one participant less inclined to test. Beth (24) stated that she would only test if she fell in love with someone and they were discussing whether or not to have children. She expressed that witnessing the effects of HD from such a young age has impacted this decision:

> You see this person and you take care of this person and knowing that you could or could not end up exactly like that is scary and knowing so young too. The fact that I could go and get tested today and find out…after seeing just the horrible pain and suffering that HD patients go through, it's really tough to think about for yourself at such a young age.

Haley (25) felt that seeing the disease firsthand had not changed her thoughts about and plans for testing. She indicated that she is taking it year-by-year and not making any decisions until she is ready. She felt strongly that the caregiving experience had not changed that plan.

Discussion

This study provides insight into the experiences of young individuals, between the ages of 15 and 25 years, who provide care for a parent with HD. By giving the option of in-person, phone, or video conferencing, this study provided participants with a flexible research opportunity that served their individual comfort level and preference. It also provided extended access to youth individuals in various physical locations. Our findings build on prior research that has identified caregiver burden in this population, exemplifying genetic risk as a factor that compounds the emotional distress felt by young caregivers (Williams et al. 2009). Our findings also highlight the impact of the caregiving experience on the caregiver's thoughts about and plans for the future, including plans for predictive testing. This is valuable insight for genetic counselors, who may provide services to individuals who are or were young caregivers.

The relationship between caregiving and genetic risk

It became evident that youth in this setting performed substantial physical and emotional caregiving duties for their parents with HD. By performing these roles, the participants described actively interacting with the disease progression and bearing witness to its affects. The caregiving tasks, coupled with the awareness of genetic risk, appeared to compound the emotional complexity of the situation. The emotional complexity seemed to stem more from the impact of the caregiving experience on the caregiver's perceived genetic risk and less so from the impact of genetic risk on the act of caregiving. The youth in this study described how the caregiving experience either made the 50% risk heightened, or "scarier," as they bore witness to the devastating effects of the disease, or lessened, due to an increased sense of control and preparedness. The perceived impact of how each participant's 50% risk would play out in their future differed amongst participants.

While participants described feelings of anger, frustration, and resentment about their situation, they did not feel that being aware of their genetic risk impacted their physical caregiving actions or made them less likely to perform certain tasks. They did not blame their parent for putting them in this situation, revoke assistance, or refuse the role as a caregiver. Instead, they often empathized with their parent. It was common for the participants to reflect upon the possibility of HD manifesting in their future and imagine themselves in their parent's situation, or "shoes," as the participants often phrased it. They recognized that they may one day be the recipient of care, putting others in a caregiving situation, specifically siblings, future spouses, and even future children.

Study participants grappled with these "this could be" thoughts, acknowledging their attempt to suppress these thoughts and feelings while performing caregiving tasks for their parents. However, these thoughts were often instigated by moments of difficulty while caregiving for the parent with HD, and based on the frequency of these types of responses from the participants, they appeared to be inevitable during the course of caregiving. If not during the caregiving routine, reflective "this could be me" thoughts occurred during times of contemplation about one's past, present, or future. They described ways of coping with these thoughts, which included taking personal time away from the sick parent, seeking support from HD youth groups, and planning for the future. These are similar to the problem-focused and emotion-focused strategies described by Forrest Keenan et al. (2007) and highlight the successful coping abilities of young individuals growing up in a family with HD.

Our findings underline the pervasiveness of HD in the lives of the young caregivers, which is paralleled by prior research. Williams et al. (2009) similarly focused on sentiments stemming from "the potential to become the patient" (p. 284). They acknowledged the potentially unrecognized influence of biologic risk on the responsibilities assumed by these teens, the meaning of caregiving to these teens, and the ways in which they balance multiple challenges (Williams et al. 2009). In her research, Kavanaugh (2014) posited that this awareness of one's genetic risk may exacerbate the level of parent/child conflict, which she demonstrated to be present for young caregivers involved in numerous caregiving activities. The findings from our study not only paralleled these prior findings, but also suggest an additional area impacted by the awareness of genetic risk; the results from our study indicate that one's experience of caregiving for a parent for a disease that they themselves are at 50% risk to develop impacts the young caregivers' thoughts about and plans for predictive genetic testing.

Caregiving, experiential knowledge, and predictive testing

Whether it made them more or less likely to pursue testing in the future, many participants reflected upon the impact of their caregiving experience on their plan. By being so close to the manifesting symptoms, they felt like they knew what was potentially "down the line," intensifying the perceived weight of this decision. The impact was further exemplified by the contrast in opinions between these youth caregivers and their non-caregiver siblings. Aside from being an interesting topic for a follow-up study, this lends support to the impact the caregiving experience may have on this decision. While our study focused on the impact of caregiving on predictive testing opinions, it should be noted that there are likely other factors that play a role in this decision. An individual's personality and temperament, perceived ability to cope with the result, overall experience of living with HD, knowledge about and availability of testing, psychological support, and/or family attitude may also motivate or demotivate individuals from pursuing testing, aside from, or in conjunction with, the impact of the caregiving experience (Rivera-Navarro et al. 2015).

Commentary concerning testing has predominantly focused on the potential consequences for the individual, "each considered as if they were a blank slate, with little consideration of the influence of prior lived experiences in determining areas of vulnerability or resilience" (Mand et al. 2013, p. 646). However, a key finding from Mand et al. (2013), which was supported by our data and others (Forrest Keenan et al. 2015; Sparbel et al. 2008), is that life before testing influences one's decision to pursue testing.

It has been suggested that developmental factors and experiential knowledge are of greater importance than age in assessing competence and resilience to undergo predictive testing (American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors 1995; Binedell et al. 1996; Mand et al. 2013; Sparbel et al. 2008). It should not be overlooked that the young caregivers within this study varied in ages. While age does not directly correlate with one's development, it is certain that the participants differed in their degree of physical, intellectual, social, and emotional development. Between the ages of 15 and 25, our participants were facing different developmental issues and milestones at the time of this study, which was often illuminated during interview discourse. While an examination of developmental stages in the context of decision-making is beyond the scope of this paper, it can be assumed that one's developmental life stage may impact how he/she views and prioritizes testing amongst other life tasks and decisions, an area that warrants further study. While we were unable to assess the direct impact of one's development on predictive testing opinions, we did assess the use of experiential knowledge. Abel and Browner (1998) differentiate between two types of experiential knowledge: embodied and empathetic. The former refers to personal perceptions of bodily experiences and sensations, e.g., perception of being positive for HD. The latter refers to knowledge derived from close association with others living the particular experience, e.g., caregiving for a parent with HD (Abel and Browner 1998). Researchers have suggested various ways in which experiential knowledge can be defined, acquired, and used. Despite these differences, Boardman (2014) highlights agreement that experiential knowledge is drawn upon in the context of decision-making and risk assessment.

The vast majority of study participants indicated that their experience of being a caregiver for a parent with HD has impacted their thoughts about and plans for predictive testing in the future. In the context of decision-making about whether or not to pursue predictive testing, participants confirmed the use of their experiential knowledge as a factor in this decision, consistent with Boardman's (2014) findings above. This suggests that the experience of being a caregiver for a parent with HD may motivate or demotivate youth from pursuing genetic testing, independently or perhaps in conjunction with some of the other factors listed above. However, it is worth noting that while most of participants in this cohort indicated that they had plans to test, prior studies highlight that a substantial number of at-risk individuals do not actually pursue testing until symptomatic (Baig et al. 2016; Morrison et al. 2011). As we are not able to follow these participants longitudinally, it is unclear whether the caregiving experience impacts adherence to proposed testing plans in addition to impacting their perceived opinions.

Implications for genetic counselors

Given that genetic counselors are often involved in both predictive and diagnostic testing for at risk or symptomatic individuals, they are likely to come into contact with individuals who are or were young caregivers for a parent with HD. Similarly to how we have explored the intricacies of this experience for the 13 participants in this study, we recommend genetic counselors to do the same in a genetic counseling session. These youth are not seeking genetic counseling as "blank slates," as may have been previously thought; their lived experience as a young caregiver has impacted who they are, how they feel about HD, and how they imagine HD manifesting in their future. It would be important for genetic counselors to be aware of this fact when determining competence and resilience of these youth to undergo predictive testing. In addition, inquiring about caregiver roles may shed light on the individual's experiential knowledge that he/she may utilize to make decisions about predictive testing.

In 1994, the International Huntington Association and the World Federation of Neurology Research Group on Huntington's Chorea produced guidelines for predictive testing for HD. While revisions have since been made, the original aims remain, which set minimum standards for predictive testing, protect at-risk individuals, and provide a reference point to help with ethical and clinical dilemmas as they arise (Macleod et al. 2013). In order to ensure informed consent and minimize adverse psychosocial outcomes, the most recent recommendations include an in-depth telephone conversation, during which information about the testing process, costs, and risks are disclosed, followed by in-person pre-test counseling as well as post-test counseling (Huntington's Disease Society of America 2016). During the pre-test counseling, the genetic counselor will often explore the applicant's experience with HD and perceptions of the disease and discuss how the test results may impact not only the individual's life and future plans, but also family ties (Nance et al. 2003).

From this study, we found that youth in this setting consider the implications of testing long before they actually plan to pursue or not pursue testing, consistent with prior literature (Forrest Keenan et al. 2015; Sparbel et al. 2008). Without the aid of facilitation by a genetic counselor in a pre-test setting, participants had already considered the impact of both a positive and negative result, not only on their future, but also on the lives of and relationships with their family members. Many have witnessed the HD symptoms and disease progression and have

an idea of what the disease requires in terms of resources and care needs. While young caregivers are likely knowledgeable about the progression of the disease and their risk status, what they may be lacking is the ability to talk through their decision with someone who is equally knowledgeable about the condition, both on a clinical and psychological level.

This last point is supported by our data that highlights the minimal understanding of HD and its implications amongst those outside of the home. We also found that it is often "taboo" to discuss predictive testing within the household. Whether they turn to friends outside of the home or to family within the home, these young caregivers are faced with limited social support to discuss the disease and to talk through momentous testing decisions. Prior studies have illuminated similar feelings of isolation amongst a HD young caregiver cohort (Forrest Keenan et al. 2015; Kavanaugh et al. 2014; Korer and Fitzsimmons 1987; Sparbel et al. 2008; Tyler et al. 1983). In addition, the authors utilize this finding as evidence to support a "call to action" for anyone encountering these young individuals, especially health care providers and genetic counselors who typically focus only on patients with HD and adult caregivers (Sparbel et al. 2008). Along similar lines, genetic counselors can draw upon their clinical knowledge about genetic disease and from their experience with working with other individuals under the stressor of genetic risk, to provide empathy and anticipatory guidance to these individuals (Accreditation Council for Genetic Counseling 2015). With young caregivers who are likely knowledgeable about HD and its implications, compared to someone without that experience, genetic counselors may shift the focus of a pre-test counseling session. They may concentrate less on the details of the disease and more on facilitating testing decision-making, assessing support needs, and making proper referrals, when necessary.

None of the participants in this study had met with a genetic counselor in a formal clinical setting. Thus, we were unable to ask them directly about aspects of a genetic counseling session that would best serve their clinical and psychosocial needs. Further, because very few of the participants attended medical appointments with their parent with HD, it was not possible to discern whether medical professionals asked about the needs of these young caregivers. Prior research has defined the instrumental support, emotional support, and personal needs of this group and a clinical assessment tool, the HD-Teen Inventory, has been created (Driessnack et al. 2012; Kavanaugh et al. 2014). However, even with this available information and clinical resource, it still appears as though young caregivers are under-acknowledged and under-supported. Future research could focus on young caregivers who have pursued predictive testing, examining how the predictive testing protocol met or fell short of their needs. In addition, future studies should establish if and when health care providers are acknowledging and inquiring about the work of young caregivers in the home so that additional assistance can be offered, when needed.

Study limitations

While attempts were made to include both male and female caregivers, our study population is predominantly comprised of a small cohort of self-selected, primarily female, young caregivers. Participants were primarily recruited from two large HD youth organizations. Their experiences may differ from those who have no interaction with these organizations or other similar youth support resources. Therefore, the experiences conveyed may not be representative of HD young caregivers as a whole. With our recruitment modalities and during the time frame of this project, we were unable to recruit enough eligible participants to reach data saturation. It may be that there are young caregivers with experiences that differ from those in our cohort, lending to varying opinions about predictive testing. Lastly, the experiences described by a few participants were retrospective, as they reflected upon their caregiving experience when their parent with HD was still living, and are thus vulnerable to recall bias.

Conclusion

This study qualitatively explores the lived experiences of young individuals providing care to a parent with HD. Prior caregiver studies specifically focused on HD young caregivers have identified common responsibilities, burdens, and support needs. Our findings support those of prior studies, specifically, that many young caregivers perform significant physical and emotional caregiving tasks for their parent with HD. Our findings suggest that that genetic risk colors the caregiving experience by evoking feelings about the future and a potential diagnosis of HD. The 50% risk of inheriting HD exacerbates the emotional dimensions of the caregiving experience, eliciting "this could be me" thoughts. Further, the youth caregivers draw on this experience when thinking about their plans for predictive testing. This study contributes to the limited literature that exists about youth who care for a parent with HD, and its findings may be used by genetic counselors to tailor the support and counseling needs of these individuals in a pre-test genetic counseling session.

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Compliance with ethical standards

Study with human subjects This project was approved by the Institutional Review Board of Stanford University. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2005 (5). Informed consent was obtained from all patients for being included in this study.

Conflict of interest Andrea Hanson-Kahn facilitates a support group for individuals with HD for which she receives a stipend from the HDSA. Authors Danielle S. Dondanville, Joanna H. Fanos, Melinda S. Kavanaugh, and Carly E. Siskind declare that they have no conflict of interest.

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