Child & Youth Care Forum (2024) 53:849–870
https://doi.org/10.1007/s10566-023-09775-4

ORIGINAL PAPER

“Man, This Isn’t Easy”: Exploring the Manifestation of Parentification Among Young Carers of a Parent with Huntington’s Disease

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Accepted: 16 October 2023 / Published online: 8 November 2023

Abstract

Background Due to the progressive deterioration of motor, cognitive, and psychological function, individuals with Huntington’s disease (HD) rely heavily on family caregivers, including children in the home. This “young carer” role can result in responsibilities that are inappropriate for the child’s age and abilities. Also referred to as parentification, this experience can result in both positive and negative outcomes for the child, spanning multiple domains of health and well-being.
Objective To explore the manifestation of parentification among young carers of a parent with HD.
Method Directed content analysis, guided by a literature-derived framework of parentification, was utilized for this qualitative study. Participants included 28 young carers (mean age of 16.6 (±2.6)) who self-identified as engaging in caregiving activities related to HD with the majority providing care for 1–3 years (53.6%)- averaging 25.4 h of care per week.
Results Three main themes with subthemes emerged: (1) being a young carer [perceptions of caregiving, learning to be a caregiver, caregiver burden, coping], (2) living with a new normal (school and friends, feeling unheard/alone, support system, personal growth), and (3) facing HD as a young carer (stigma and isolation, parent/child relationship, end of life, genetic risk).
Conclusions Young carers in the context of HD experience many attributes and consequences of parentification generally present among young carers of ill parents. However, HD specific findings emerged from this study that can be used to inform clinicians and direct future research aimed at guiding policy and developing tailored support services.

Keywords Young carers · Parentification · Huntington’s disease · Directed content analysis

Introduction

Huntington’s disease (HD) results in the progressive deterioration of the brain’s nerve cells, resulting in diminished motor, psychiatric, and cognitive function (Huntington’s Disease Society of America [HDSA], 2011; Nance et al., 2011). These symptoms progress

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Extended author information available on the last page of the article and worsen following clinical diagnosis, until the individual's death, typically 10–25 years later. (HDSA, 2011; Nance et al., 2011). There is currently no cure for the disease and children of parents with HD have a 50% chance of inheriting the disease themselves (Walker, 2007). In the United States, there are approximately 41,000 people with HD and an additional 200,000 who are at risk of inheriting it (HDSA, 2011; Rawlins et al., 2016). In the early stage of HD, individuals remain functional and can continue living independently (HDSA, 2011; Kirkwood et al., 2001). The symptoms are often minor and include slight involuntary movements, subtle loss of coordination, and difficulties with complex thought (Kirkwood et al., 2001; Nance et al., 2011). In the intermediate stage, individuals with HD are able to continue carrying out activities of daily living (ADLs) with minimal assistance, but they often require assistance with instrumental activities of daily living (IADLs) due to worsening symptoms affecting problem solving, balance, coordination, and voluntary motor movements (HDSA, 2011; Nance et al., 2011). In the late stage of HD, individuals need assistance with most ADLs and IADLs as symptoms progress to the point that individuals are often nonverbal and bedridden (Nance et al., 2011).

Caregiving Associated with Huntington's Disease

As symptoms progress, care needs also increase. Because HD is an illness with debilitating symptoms that affect the diagnosed individual for many years, it often falls on the family to provide care in the home (HDSA, 2011; Kirkwood et al., 2001). Diagnosis can occur anywhere from age two to 80, but most frequently occurs between the ages of 30 to 50 (HDSA, 2011). Consequentially, symptoms often manifest at a time when there are children living in the home (Kavanaugh et al., 2016). While a spouse or other adult is typically the primary caregiver in these situations, families also rely on the help of secondary caregivers, such as the children in the home acting as young carers (Blum & Sherman, 2010; McNamara & Rosenwax, 2010). Ultimately, HD affects not just the diagnosed individual, but also the family, who provide extensive care (HDSA, 2011; Kavanaugh et al., 2016). The long-term nature of HD, where symptoms progressively worsen for years following diagnosis, means that the necessity for caregiving often lasts the entirety of a child's time living at home (Kavanaugh et al., 2016). The symptoms are also stigmatizing, which can lead to feelings of isolation and secrecy for families dealing with HD (Dondanville et al., 2019; Kavanaugh, 2014). This combination of prolonged disease trajectory, complicated symptomology affecting a variety of functions, and the stigma associated with HD, all contribute to difficulties in providing care, especially for young carers.

Young Carers

Young carers are largely unacknowledged in the United States (Hendricks et al., 2021b; National Alliance for Caregiving, 2005). It is estimated that there are more than 5.4 million young carers providing care for family members who have a chronic illness, disability, or other health condition that requires assistance (Armstrong-Carter et al., 2021; AARP & National Alliance for Caregiving, 2020). While the term "young carer" often refers to children and adolescents aged 18 and younger, the term can also encompass emerging young adults up to age 25 (Hendricks et al., 2021b). In addition to variations in age range, varying terminology for this group also exists, with "young carers" being used most often internationally and "caregiving youth" or young caregivers" being alternatively used in the United States. (Hendricks et al., 2021b). But regardless of terminology, these individuals adopt a caregiving role while simultaneously dealing with responsibilities related to family, school, and work (McGuire et al., 2012). They do this without the education, support, and/or acknowledgement provided to their adult caregiving counterparts (Hendricks et al., 2021b). As young carers, these youth provide both instrumental (e.g., cleaning, cooking, feeding, dressing, administering medications, and/or assisting with transportation/mobility) and emotional support (e.g., keeping their parent company) (Boumans & Dorant, 2018; Khafi et al., 2014). The frequency, duration, and type of care varies based on the child themselves, the family, available resources/support, and the ill parent's care needs (Blum & Sherman, 2010; Kavanaugh et al., 2016; McNamara & Rosenwax, 2010). The care needs may also change due to disease progression and worsening symptoms (HDSA, 2011).

Parentification

Because these young carers are taking on roles and responsibilities typical of an adult, there is a potential for parentification to occur (Hooper & Doehler, 2012). Parentification refers to the alteration of the implied and obvious rules/expectations that exist within familial relationships which occurs when youth take on responsibilities that are inappropriate for their age and abilities. While parentification results in outcomes that affect multiple domains of health and well-being, it should not be viewed as purely pathological (Earley & Cushway, 2002; Hooper & Doehler, 2012; Khafi et al., 2014). There are negative consequences, such as stress, anxiety, poor school performance, and altered peer relationships, but also positive consequences, such as an increased maturity, confidence, and responsibility (Hendricks et al., 2021a; Hooper et al., 2008; Kelley et al., 2007; Khafi et al., 2014). Because of the multidimensional nature of the concept of parentification and its bimodal outcomes, whether or not parentification occurs and how it manifests varies based on the individual and their unique context (Hooper et al., 2008; Khafi et al., 2014; McMahon & Luthar, 2007; Williams & Francis, 2010). Since parentification is more frequently explored within the contexts of parental neglect, parental substance abuse, and parental mental illness, less is known about parentification among young carers with chronically ill parents (Earley & Cushway, 2002). In HD specifically, little is known about the experiences of young carers and how parentification manifests in this context, where a combination of degenerative, complicated symptoms occur over a long disease trajectory with a large genetic component. Research is needed to not only address this gap, but to provide foundational knowledge, which can inform practitioners (clinicians, researchers, social workers, educators) of the challenges facing children in families affected by HD and direct future research aimed at guiding policy and developing targeted support services for this vulnerable population.

Study Objective

The aim of this study was to explore the manifestation of parentification among young carers of a parent with HD through a secondary qualitative analysis. We hypothesized that attributes and consequences of parentification generally present among young carers of ill parents would also be evident in this population of young carers; however, we also hypothesized that the progressive, debilitating symptoms of HD and related caregiving needs, would result in a manifestation of parentification with emergent components relevant to youth caring in the context of HD.

Method

A secondary analysis of qualitative data from a parent study (Kavanaugh et al., 2015) was conducted using a directed content analysis approach and reported on following the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Hsieh & Shannon, 2005; Tong et al., 2007).

Participant Recruitment

Participants were purposefully recruited from local chapters of the Huntington's Disease Society of America (HDSA) representing 18 states (Kavanaugh et al., 2015). The strategy for recruitment through the HDSA included contacting the HDSA boards in Missouri, Wisconsin, Iowa, Illinois, Minnesota, and Indiana for permission to advertise for the study. In addition, chapter social workers were contacted to send flyers and permission was obtained to advertise at national HDSA conventions (Kavanaugh et al., 2015). After permission was obtained, (a) flyers were mailed to families on the HDSA list, (b) ads were placed in chapter newsletters and websites, and (c) information about the study was posted to state websites, Facebook, and the national HDSA website (Kavanaugh et al., 2015). A call or email was then received from the parent or participant if over the age of 18. Further recruitment details are reported in the parent study (Kavanaugh et al., 2015).

Data Collection

Prior to the start of the interview, parents of children under age 18 and participants over age 18 signed consent forms, while participants under the age of 18 signed assent forms. All interviews were conducted with the participants only and were completed in a single session at a location of the participant's choice (Kavanaugh et al., 2015). The interviews lasted between 30 and 55 min and each interview was audiotaped and transcribed verbatim by a professional transcriptionist. Participants in the study had to be aged 10–20 years old, have a parent with HD, and self-identify as engaging in caregiving activities (Kavanaugh et al., 2015).

The in-person interview involved the primary investigator of the parent study asking youth to respond to items in the investigator created survey, *"Child caregivers of a parent with HD"* (Kavanaugh et al., 2015). The questions asked about overall caregiving experiences and tasks, interactions with the parent, impact of caregiving, school, life satisfaction, physical health, depression, and social support (Kavanaugh et al., 2015). The items included a combination of yes/no and Likert-like scale items, in addition to three open ended questions (Table 1). These open-ended questions were utilized to gain further insight into participant experiences that could not be adequately captured with closed-ended responses and to allow participants an opportunity to voice experiences/concerns that may not have been addressed in the other items. The interview transcriptions provided qualitative data through responses to the three open-ended questions, but also elaborated responses to the closed ended questions. An example of this elaborated response is seen here where one of the youth responded to a closed ended question with "*2 = neither agree or disagree*", but offered further elaboration saying *"I didn't wanna help her that much because I was a kid and I did wanna go have friends and play outside and stuff."* These elaborated responses, in addition to the responses of the open-ended questions, were analyzed using a qualitative directed content analysis approach (Hsieh & Shannon, 2005).

Table 1 Summary of interview questions

Section	Topic of questions	response type
1. Caregiving	Frequency of care, type of tasks, education related to tasks, frequency and duration of care, other persons to help	Likert Scale (0–2), Y/N, Open-Ended (1)
2. Interactions with Parent	How well they get along with their parent who has HD	Y/N
3. Impact of Caregiving	How they feel about helping their parent, activities they did before caregiving that they no longer do	Likert Scale (0–4)
4. School	Experiences at school as a result of caregiving	Likert Scale (1–3)
5. Life satisfaction	How they feel about life overall	Likert Scale (0–4)
6. Physical Health	How they feel physically	Likert Scale (1–5), Y/N
7. Depression	How they have been feeling the past two weeks, mood	Children's Depression Inventory (CDI) items
8. Social Support	Family and friends, persons who provide support, frequency of support provided	Likert Scale (0–5), Y/N, Open-Ended (2)

Study Participants

A sample of 40 individuals participated in the parent study. For the present study, a subsample of 28 was drawn from the original sample. This subset of 28 participants included only the participants who consented to audio-recording and transcription of their interviews. The protocol for the parent study was approved by the University of Wisconsin-Milwaukee IRB and this secondary analysis was approved by the University of Alabama at Birmingham IRB.

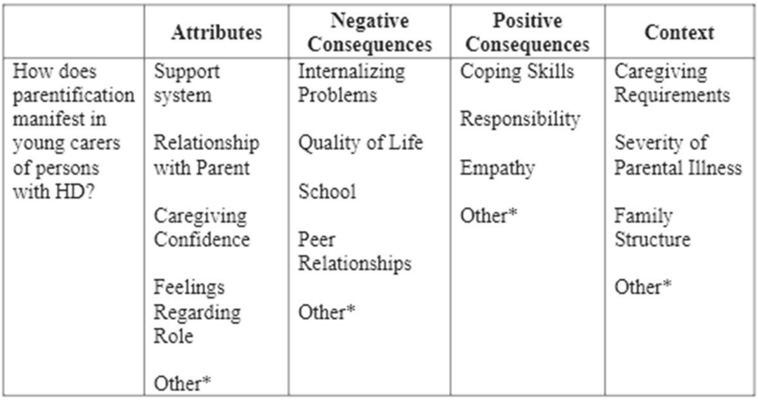
Guiding Framework

The framework guiding this study was a conceptual framework of parentification among young carers created by Hendricks et al. (2021a). To date, this is the only conceptual framework of parentification in the context of youth caring for chronically ill family members. This conceptual framework provides an overview of the phenomenon including its antecedents, attributes, and consequences. According to the framework, the antecedents of parentification among young carers are the development of a dependency condition by the care receiver and the adoption of a caregiving role by a child due to care receiver dependency (Hendricks et al., 2021a). This antecedent appears in the context of HD, where youth adopt the young carer role due to their parent's illness and related care needs. Concept attributes listed in the framework include the perception of fairness, felt obligation, resiliency, confidence in performing care tasks, family system functioning, family resources, the caregiver-care receiver relationship, and awareness by the care receiver of the young carer's needs. This framework also reflects the bimodal outcomes of parentification, listing both positive (responsibility, maturity, coping skills, empathy, life skills, autonomy) and negative consequences (stress, compulsive caretaking, internalizing problems). This conceptual framework guided the initial coding structure during data analysis as the manifestation of parentification was explored in the context of HD.

Analysis

A directed concept analysis approach was used to perform a secondary qualitative analysis of the data (Hsieh & Shannon, 2005). Directed content analysis is a deductive approach that uses an existing theory or framework as guidance for the initial coding structure to be expanded upon throughout the coding process (Hsieh & Shannon, 2005). This initial coding structure was outlined in a formative categorization matrix (Fig. 1) informed by the conceptual framework of parentification among young carers (Hendricks et al., 2021a). Analysis began with data immersion where transcripts were read in their entirety by the PI and an audit trail was maintained to record phrases, ideas, and/or key concepts that occurred while reading (Creswell & Poth, 2016). The data was then broken down into meaning units (words, phrases, or sentences that contain some insight) and labeled with codes referenced in the formative categorization matrix (Bengtsson, 2016; Erlingsson & Brysiewicz, 2017).

This list of initial codes evolved as analysis continued. The resulting themes and subthemes were compared to the initial categories (themes) outlined in the categorization matrix and were either nested within a pre-existing main category or a new category



	Attributes	Negative Consequences	Positive Consequences	Context
How does parentification manifest in young carers of persons with HD?	Support system Relationship with Parent Caregiving Confidence Feelings Regarding Role Other*	Internalizing Problems Quality of Life School Peer Relationships Other*	Coping Skills Responsibility Empathy Other*	Caregiving Requirements Severity of Parental Illness Family Structure Other*

Fig. 1 Formative categorization matrix. *Other inductively emergent categories

was created (Assarroudi et al., 2018). Thus, the categorization matrix was continually being revised and updated based on themes generated from the analysis. Lastly, the resulting themes and subthemes were compared to the guiding conceptual framework to determine similarities and differences (Hsieh & Shannon, 2005). It is important to note that this analysis process allowed for the emergence of new themes and subthemes during the coding process that were not initially reflected in the categorization matrix. Data was analyzed using the qualitative analysis software, NVivo.

Validity and Reliability

Various strategies for ensuring reliability and validity of the study were implemented. Adequate engagement of the researcher was achieved by allowing for the potential emergence of new categories resulting from analysis of the data, even if the categories were not present in the original guiding framework. For the purposes of this study, the researcher's prior experience as a young carer could have led to potential biases and assumptions, therefore, a reflexivity statement was included to address this (See Fig. 2). Peer examination occurred through meetings scheduled on a regular basis with a small group of impartial researchers and clinicians with relevant expertise. During these collaborative meetings, methodology, findings, and interpretations were examined to enhance credibility, ensure validity, and increase reflexivity (Spall, 1998). An audit trail was also kept which provided a detailed account of how the study was conducted and provided a running record of the researchers' interactions with the data. The authors of this study declare no conflict of interest.

Findings

The sample (N = 28) had a mean age of 16.6 (± 2.6). The majority were female (78.6%), caring for a mother with HD (71.4%), and had been acting as a young carer for 1–3 years (53.6%) (Table 2). The predominantly female sample reflects the current literature which indicates that girls in the family, are more likely, just like their adult counterparts, to adopt a caregiving role (Becker, 2007; Boyle et al., 2023; Revenson et al., 2016). Participants reported an average of 25.4 h per week providing care and 67.9% reported

Fig. 2 Reflexivity statement

As a child with a parent who had a terminal illness, I somewhat understand and am aware of the roles, responsibilities, and difficulties faced by young carers. However, I lack understanding as to what this experience is like in other disease contexts, such as in HD. I undertook this study to better understand what this experience is like for young carers especially given the unique symptomology of HD, the prolonged and worsening trajectory, and the potential for genetic transmission of the disease.

Table 2 Demographics and care tasks reported by young carers

Sample Demographics (N = 28)	*N (%)*	Care Tasks Completed in Last Month	*N (%)*
Caregiver age (years)		Clean other rooms in house	26 (92.9)
12–14	7 (24.9)	Keep parent company	26 (92.9)
15–17	11 (39.3)	Do dishes	25 (89.2)
18–20	10 (35.7)	Help parent walk/get around	23 (82.2)
Mean age	16.6(±2.62)	Cook meals	21 (75)
Gender		Laundry	21 (75)
Female	22 (78.6)	Grocery shopping	20 (71.5)
Male	6 (21.4)	Help parent write	16 (57.2)
		Help parent with appearance	14 (50)
Parent with Huntington's		Help parent eat	13 (46.4)
Mother	20 (71.4)	Work part time	12 (42.9)
Father	8 (28.6)	Drive parent places	12 (42.9)
		Make phone calls for parent	12 (42.9)
Duration of caregiving		Talk to Dr for parents/go to appointments	10 (35.7)
1–3 years	15 (53.6)	Help parent undress	10 (35.7)
4–6 years	8 (28.6)	Decorate rooms	9 (32.1)
7–10 years	5 (17.8)	Help parent with medication	7 (25)
Who else cares for parent?		Watching siblings with another adult around	5 (17.8)
No one	9 (32.1)	Take siblings to school	4 (14.3)
Other parent	14 (50)	Help parent toilet	4 (14.3)
Sibling	4 (14.3)	Clean up accidents (incontinence)	4 (14.3)
Grandparent	1 (3.6)	Pay bills	3 (10.7)
Receive care education		Help parent bathe	3 (10.7)
No	20 (71.4)	Brush teeth	3 (10.7)
Yes	8 (28.6)		
Hours per week caring	$M = 25.4$		

that they were not the only person providing care to their parent with HD. The most frequently reported care tasks were keeping the parent company (92.9%), helping parent walk/get around (82.2%), cooking (75%), and grocery shopping (71.5%) (Table 2). More than half of the participants (71.4%) reported that they received no education or instruction related to their role.

Themes

The qualitative analysis resulted in three main themes, each with four subthemes. The themes included (1) being a young carer, (2) living with a new normal, and (3) facing HD as a young carer (See Fig. 3). Pseudonyms are used for reporting of the data, but reported ages are accurate. Table 3 provides a visualization of variability of subthemes among participants and the total number of codes for each.

Theme 1: Being A Young Carer

This theme dealt with the thoughts and feelings that a child had about taking on the role of young carer due to their parent's diagnosis with HD. There were four subthemes: a) perceptions of caregiving, b) learning to be a caregiver, c) the burden of caregiving, and d) coping.

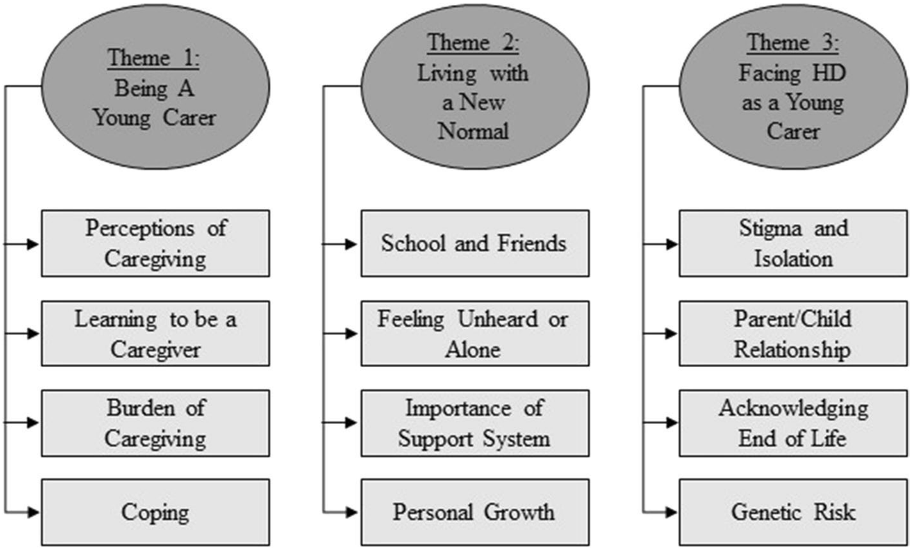


Fig. 3 Map of qualitative themes and related subthemes

Table 3 Coding overview

Subthemes	Number of participants	Number of references
Perceptions of caregiving	12	24
Learning to be a caregiver	17	21
The burden of caregiving	13	19
Coping with the role	5	6
School and peer relationships	16	32
Feeling unheard and alone	9	12
Importance of social support	16	33
Personal growth	8	20
Stigma and isolation	11	18
Parent–child relationships	11	18
Acknowledging end of life	14	19
Genetic risk	7	8

Bold values subthemes fall under Theme 1: Being a Young Carer, Italic values subthemes fall under Theme 2: Living with a New Normal, and Roman values subthemes fall under Theme 3: Facing HD as a Young Carer

Perceptions of Caregiving

All participants acknowledged that adopting the young carer role was a necessity due to their parents HD diagnosis, but they differed in their perceptions regarding taking on the role. Twelve of the 28 participants discussed this at length. For many they saw the caregiving role as something that was just a part of their life, while others had overtly positive or negative feelings regarding the role. Most viewed the role of young carer as a normal part of their life, and for many it had been a part of their life for a number of years. When asked how he felt about taking care of his parent, Matthew (age 19) said: *"I just try not to make it a huge part of my life."* and *"I feel like in every family there's always something, you know, that's not normal or, or just wrong... and Huntington's disease is ours."* Alicia (age 20) discussed a similar attitude regarding the role saying: "*I don't really think about it...I just, I do it."* Others, like Samantha (age 20), viewed taking on the caregiving role as something positive. She said that she started out doing things just to make things easier for her mom, but she does not think of it as a chore or a "*bad thing*." Instead, she said, *"I'm not upset that I have to do it because I just feel like, you know, I was a baby, she took care of me. She did everything for me, so it's just like giving back what she did for me."* Sarah (age 13) similarly said that *"[she] is happy to do it*" because she felt that what she is going through *"seems kind of trivial compared to what [her mother] is going through."* Not all participants viewed taking on the caregiving role this way. For some, taking on the role proved to be a difficult experience. Michael (age 17) shed light on the genetic component of HD when he said that sometimes when he helps his mom, he asks "*Why am I fueling what gave the disease to me?"*.

Learning to Be a Caregiver

Of the 28 youth interviewed, 17 specifically discussed the experience of learning to be a caregiver. Though 8 (28.6%) of the 28 participants in this study indicated that they had someone explain to them how to do a specific task(s), none of the participants indicated that they had every task explained to them. For these unexplained tasks regarding HD or the caregiving role, they had to learn on their own. Many stated that their caregiving knowledge came from observation. Erin (age 12), when asked how she knew what to do, said: *"watching I guess."* Similarly, Katie (age 14) said *"[she] just learned."* Some of the youth, used their past experiences to guide them on what to do. Alicia (age 20) said that she knew what to do from "*past experiences helping, just normal things around the house, and stuff like that.*" Alternatively, they learned to be a caregiver through common sense or intuition. Jennifer (age 16) drew parallels between caring for herself and caring for her mom saying, *"helping my mom take showers…it's just like bathing myself."* Sarah (age 13) said that she did not know where she learned about what to do. She said: "*I just do. I don't know. Most of it seems like kind of common sense.*" For some, they were able to sense what needed to be done. Ellie (age 17) learned this way, saying, "*I guess just picking up on little things she needed help with. Noticing."* Jacob (age 15) also felt this way. He said: "*it just seemed like that's what you should do."* Some, like Madeline (age 20) felt that it "*just came naturally,"* while Hallie (age 17) said "*you just know. You know what's good for people."*

The Burden of Caregiving

Thirteen youth reported that the caregiving role placed a burden on them. This burden referred to the all-encompassing challenges felt by the participants related to their new role of being a young carer. For some, simply being around their parent with HD was too much and they felt like they had to escape home in order to get away. For example, Abigail (age 20), said that *"the only time [she] could escape was when [she] had to go to school."* Isabelle (age 20) said similarly that she *"just didn't wanna go home, but there was nowhere else [she] could go."* Mark (age 17) elaborated on this feeling of wanting to get away, saying he *"really shouldn't feel that way because it's not her fault… It's just a hard situation to deal with."* Susan (age 15) also expressed this difficulty saying that it "*definitely gets hard sometimes*." Pairing the negative with the positive, Maria (age 16) stated that while it made her feel good to help, it also took "*a big, big toll*." Ellie (age 17) also spoke to this idea saying that "*as much as [she] loves her mom and loves being able to help her, some days it's a little much."* Ellie (age 17) summarized these feelings when she said, "*it's a lot harder than what people see."*

Coping with the Role

Coping with the role is also something that was discussed by several of the youth. While many simply said that they did or did not participate in some form of coping, there were others who elaborated on what worked best for them. Some, like Mark (age 17), felt that they *"always had to deal with it.*" Regardless, he said that "*even just getting out sometimes helps a lot because you don't always have to be in the midst of HD*." Maria (age 16) also mentioned that she liked to cope by "*going outside a lot*" just to be away from her mom with her friends. For Ellie (age 17) her main source of coping was singing or journaling; in addition, she said that she has "*people that'll listen to [her] vent about anything.*" In contrast, Michael (age 17) felt that he always "*dealt with it on his own.*"

Theme 2: Living with A New Normal

The second theme, dealing with it, related to the situations that youth have to face after taking on a caregiving role. This included the four subthemes of (a) school and peer relationships, (b) feeling unheard and alone, (c) the importance of a support system, and d) personal growth.

School and Peer Relationships

Sixteen of the participants discussed how HD and their caregiving role impacted their relationships with their friends and school. For many they had difficulties doing their homework at home because of their responsibilities or the behavior of their parent with HD. Abigail (age 20) said "*I'd be trying to do my homework and I'd have to go in my room and shut the door or go in the basement.*" Sometimes, she said she would just "*stay at school in the library*" because she would not be able to get her work done at home. Isabelle (age 20) similarly said that she "*couldn't get any of [her] homework done*" because her father always wanted help with what he was doing. For some, school was a place where they could go to escape the difficulty of their role. This idea was expressed by Isabelle (age 20) who said that at school, "*where there's just kids like you and its normal. You can be normal.*"

Aside from the difficulties related to completing schoolwork, many youth also experienced difficulties making and maintaining friendships with their peers. Hannah (age 20) said that "*it was lonely and alienating in grade school and high school*" because she could "*never, ever go to anything.*" Katie (age 14) similarly said that it kept her *"from doing other stuff and stuff that [she] wants to do."* Jennifer (age 16) explicitly stated that she did not want to help her mom as much as she did because she was a kid and she just wanted *"to go have friends and play outside.*" She elaborated on this feeling saying: "*I kinda missed out on all the kid things that you normally go through as you're growing up. I was more of, like, one of the adults at the age of what, like, thirteen?".*

Feeling Unheard and Alone

A third of the youth discussed the fact that they felt alone, unheard, and misunderstood by their peers, teachers, and family. For many, their friends were unable to relate to their situation of being a caregiver of a parent with HD. Abigail (age 20) said that none of her friends had anything like that going on in their life so she "*felt like [she] was an outcast.*" Jennifer (age 16) elaborated on this by discussing her belief that they "*can't really fully understand 'cause they've never really been through it.*" She said that even when "*you're getting your feelings out to a friend, deep down you know that they, they're really not gonna feel the way you feel and understand it 'cause they've never been through it.*" For Susan (age 15) she also felt that the teachers never understood what was going on, saying, "*teachers don't know about it and that's hard just like it is with friends. Because, like, sometimes we expect adults to know more than the kids do and they don't.*" In response to their feelings of being unheard, alone, and misunderstood, many discussed the desire to have a supportive friend who understood what they were going through. Susan (age 15) said "*I kind of need a friend who supports me more with it because a lot of my best friends just don't get it and that's hard*." Alicia (age 20) said she just "*needs someone to talk to*." More broadly speaking they also discussed the fact that family and outsiders did not understand the impact that being a young carer had on them. Isabelle (age 20) elaborated by saying that her family asked about how her mom is doing, but no one asked how she was doing. She said: *"What about me?… I'm dealing with it too."* Many simply wanted recognition and acknowledgement. Carmen (age 17) said, "*just recognize that I do it,"* while Isabelle (age 20) got to the root of the problem saying, "*It's tough… nobody kind of really ever acknowledges that teenagers are involved or kids."*

Importance of Social Support

Besides finding awareness and understanding for their role, participants also discussed the type of social support they had and/or the difficulties in getting social support. Sixteen of the youth discussed social support during the interview. For Abigail (age 20), she said she asked people for advice but felt like "*they didn't really want to get involved*." She lamented that people always say they want to help, but it was difficult to accept the help because *"[they] don't really know how they could help."* Mark (age 17) recalled that he had "*a pretty good support system,"* but luckily did not have to use it all that often. Michael (age 17) said that despite having friends that were pretty understanding, they were "*kind of blankly supportive*" because "*they can't really understand*" and they *"don't completely comprehend everything that is involved*." For some, they had specific people that they relied on. Jennifer (age 16) recalled a friend who, "*didn't really understand, but [she] took the time to try to understand."* Wendy (age 15) discussed the fact that her mom tried to make her life "*as normal as it can be*." Sadly, for some, they lacked a good support system or simply did not know how to ask for what they needed. This was expressed by David (age 13) who said, "*I could have asked [for help], but no one seemed to care."*

Personal Growth

A third of the participants reported experiencing some sort of personal growth as a result of their caregiving experience, whether through an increase in maturity, responsibility, self-confidence, or fortitude. Brenda (age 18) said it "*made [her] a lot more mature*" because she "*pretty much raised [herself]"* since the eighth grade. She said: *"I'm strong enough I guess to, like, take care of her and also, like, grow from it.*" Jennifer (age 16) felt like what happened to her "*made [her] stronger"* and that she could "*do more things*" and "*had more confidence."* Mark (age 17) believed he "*matured at a super early age because of Huntington's disease*" so he has already learned to "*cope and deal with this kind of stuff and other people haven't*" and Jennifer (age 16) said it "*made [her] more responsible*" because she "*became more of an adult at a younger age*" and "*had to be responsible and stuff*." She therefore said she had "*grown up faster than the normal person."* Others more broadly discussed their personal growth. Isabelle (age 20) said that her experience as a young carer "*molded [her] into the person [she] is today*" and Alicia (age 20) said it "*inspired [her] to keep going no matter what life throws at you*." She said: "*you keep going, and you take it, and you use it, and you go on."* Halle (age 17) believed that there was always something to be positive about, saying: *"it's hard, but there's always something to smile about."* Some of the youth also discussed the experience in a reflective capacity, looking back on who they used to be. Michael (age 17) said that when he was a young child, he "*always thought his life would be better off had [his] mom not had Huntington's disease, so [he] could have been a normal kid,*" but "*without that experience…[he] definitely wouldn't be the person that [he is] today.*" Holly (age 16) offered a similar sentiment saying that "*it definitely makes you grow up.*"

Theme 3: Facing HD as a Young Carer

The third theme dealt with the specifics of being a young carer to a person with HD. The subthemes were a) the stigma and isolation surrounding HD, b) the difficulty in dealing with the prognosis and progression of HD, and c) facing the risk of inheriting HD.

Stigma and Isolation

Eleven participants in the study discussed embarrassing situations or feelings of awkwardness related to their parent having HD. Isabelle (age 20) recalled the time that a neighbor saw her father "*get the mail in his underwear*" and that she was "*never allowed to play [with the neighbor's child] again.*" Jennifer (age 16) recalled the time that they went out to eat and everyone "*was laughing at [her mom] and it made [her] really mad.*" For some, they learned to cope with the embarrassment and are now less worried about it. Mark (age 17) said that when he was younger "*it was kind of embarrassing*" but now most of his friends know about it and "*they're not judgmental or anything.*" Many, like Sarah (age 13) stated the fact that they just wanted to be treated normally. She said that when it comes to her mom "*don't treat her like an alien… just act like she's a normal person.*" Alicia (age 20) similarly said "*We're just a normal family. There's nothing different about us than the family next-door; we just have different issues to deal with.*" Some of the youth also expressed the desire for people to better understand what was going on for them. Abigail (age 20) said that "*no one knows exactly what to do with Huntington's disease 'cause it's so different for everybody*" and Wendy (age 15) simply requested that people "*just try to understand how it is with Huntington's.*"

Parent–Child Relationships

Eleven of the 28 interviewed youth discussed their relationship with their parents. For some, they never got to have a relationship with their parents before they became symptomatic and for others the relationship changed dramatically after diagnosis. Many discussed the fact that they treated their parent more like a child than an adult. Isabelle (age 20) said that her family treated her father "*like a little brother*" because "*he's like a child.*" Maria (age 20) also said that talking to her mother was *"like talking to a seven-year-old sometimes.*" Alicia (age 20) offered a unique perspective saying that while she "*treats [her father] more like a child now*", their relationship has gotten closer since diagnosis because "*he has a lot more fun with them…. he just kind of really just gets to be himself.*" For many they felt that they never got to have a relationship with their parent because of HD and wish that they could have. Abigail (age 20) said that her and her dad never really talk and that "*he [isn't], like a father figure*" Mark (age 17) said: "*I can't remember my mom before Huntington's disease at all,*" and Mathew (age 19) similarly said: "*I can only kind of remember her beforehand.*" Caitlin (age 18) discussed the difficulty with this lack of relationship when she said: "*It's just been hard for me because I never really had that* *emotional bond or connection towards her."* She said that *"if I would have had a relationship with her to bond it would be easier to take care of her."* Wendy (age 16) similarly discussed difficulties with not having a relationship with her mom when she said that her mom "*doesn't understand [her]*" likely because she never got to know her and her siblings before she became symptomatic.

Acknowledging End of Life

The fact that HD is incurable and has a long prognosis with increasingly worsening symptoms is something that was discussed in different ways by 14 participants in the study. For some, like Erin (age 12) they "*don't always like to talk about that 'cause sometimes [they] just don't like to think about it."* Samantha (age 20) tried not to "*picture [her mom] getting super sick and terrible*" because she *"[doesn't] like picturing it"* and she does not "*really like to think about it"*. Alicia (20) said that she just "*doesn't like focusing on [her dad's disease progression].*" In addition to the progression of the illness, many also discussed the future death of their parent due to HD. For some, like Jennifer (age 16), they expressed understanding the fact that their parent would die, even though they felt upset about the outcome. She reported that she knows everybody is going to die but said: "*my mom is gonna die more than likely way before the average person… knowing that each day she's, like, getting worse and worse…it just…It makes me upset."* Susan (age 15) felt similarly and said: *"It's hard knowing that I'm almost powerless and that I can't do much to help her because there is no cure…she's still going to die."* Others discussed the situation in a way that framed their parent's death as something that just goes with dealing with HD, even though they are sad about it. Mark (age 17) said "*[he's] pretty much come to accept it."* He recalled that *"it was emotional but not overwhelming*" and that it was just "*part of the whole thing of accepting Huntington's disease."* Matthew (age 19) similarly said that even though "*sometimes it can be depressing… you can't avoid it so it's not something to worry about."* He said: "*I realize my mom's probably going to die I don't know, within a couple years,"* but *"that's what Huntington's does."*

Genetic Risk

While also struggling with the progression and prognosis of their parents' diagnoses, they also worried about their own genetic risk and whether they wanted to be tested. Some are always worrying about HD like Abigail (age 20) who said: "*I worry about, like, you know, having kids and, like, my job – like, how far can I get before something happens."* She discussed the fact that despite "*always worrying about having Huntington's*" she still felt apprehensive about being tested because "*it's too much to think about right now.*" For Isabelle (age 20) she wants to get tested "*so [she] can plan [her] life out,"* but shared that that was not always her feeling regarding testing. She said that thinking about it used to make her "*really depressed,"* but now she says *"I wanna know how much time I have left."* Mark (age 17) said he planned to get tested after high school, but now he is "*not so sure*" after finding out his brother tested positive, but *"[he] still wants to know."* Matthew (age 19) similarly said he wants to get tested because it would "*let [him] know how [he's] gonna plan [his] future.*" He said that if he gets tested and has Huntington's it "*will just let [him] know that [he] has to live [his] life out to the fullest before then.*" Jennifer (age 16) simply stated: *"Sometimes I think about what it's gonna be like if I have it. And how my life is gonna change."*

Discussion

Multiple components of the guiding framework of parentification among young carers were reflected in this study in addition to new components specific to HD that emerged from the data. As the original framework relates to parentification among young carers in a broad sense and is not disease specific, this study provides a clearer picture of the unique manifestation of parentification among young carers in the context of HD and shows how the original framework can be expanded upon for different disease contexts.

Components Reflected in Guiding Framework

The components of the guiding framework of parentification among young carers (Hendricks et al., 2021a) that were discussed among participants in this study included confidence in performing care tasks, the effect on school and peer relationships, importance of a good support system, coping, and positive outcomes of the role. Most of the youth reported having little to no education regarding their caregiving role and the majority said that they learned from observation or intuition. Kavanaugh et al. (2019) discussed similar findings in their study which showed that many young carers did not receive specific training, but instead relied on the care recipient for guidance and learned through watching and observing, common sense, or trial and error. The participants in this study also reported a desire to better understand HD in order to help care for it. In 2015, Kavanaugh and colleagues similarly found that youth wanted more information and advice about HD (Kavanaugh et al., 2015).

With regards to coping, similar to the feelings related to taking on the caregiving role, many felt that it was just something they had to deal with and did not discuss specific coping mechanisms or difficulties with coping. While there were some who discussed specific coping methods, the majority felt that it was just something that they had to get through. This may be indicative of avoidance or a felt obligation to take on the role. McDougall et al. (2018) discussed a similar finding saying they found young carers managed the role primarily with solitude. This may also be tied to caregiving burden. While caregiving burden was not something that was presented in the original framework for parentification among young carers, it is likely a component that should be considered in the future as it was very prevalent among the youth interviewed. McMahon and Luther (2007) found that child caretaking burden was positively correlated with psychological distress among young carers and Williams et al. (2009) similarly found that caregiving caused a burden for young carers in the form of emotional distress, social restrictions, and financial concerns. In the present study the burden of caring was also discussed by participants related to emotional distress and social restrictions. This may be due to their feelings related to just "getting through" the experience and potential avoidance or felt obligation.

The impact of the young carer role was discussed at length by the participants. With regards to school and friends, many discussed the idea that they were unable to complete their schoolwork at home because of the behavior of their parent with HD or their caregiving responsibilities. This finding was something similarly discussed by Kavanaugh et al. (2014) who found that there was a relationship between the parent with HD being difficult to get along with and school problems. Assaf et al. (2016) likewise found that caregiving youth made personal and academic sacrifices to act as caregivers. Participants in this study also discussed the impact of caregiving on their relationships with friends. They felt that they were unable to bring their friends to their home or were unable to go out with their friends due to their parent having HD. They felt a disconnect with their friends, because they were unable to fully understand their unique situation. These feelings of loneliness and being unheard were also reported in other studies. McDougall et al. (2018) found that young carers felt lost in the system and Kavanaugh et al. (2015) reported that youth said they needed friends who understood their caregiving situation.

Some participants felt they had a good support system even though the people in their support system did not know how to help or the family was unsure of asking for the help they needed. There were participants, however, that felt that they did not have a good support system or that the support being provided to them was not effective. The importance of a good support system for young carers was discussed by Keenan et al. (2007) who found that a good support system and strong relationships were protective against negative outcomes. Participants in this study reported that they wished people would acknowledge them and their role. Kavanaugh et al. (2015) similarly found that youth needed to be asked how they are doing, not just about how their parent is doing, while Rothing et al. (2014) found that youth felt their own needs were put aside for their parent's. This idea is summed up by Van Parys et al. (2013) who reported that the participants in their study simply longed for recognition and permission regarding their role. Participants in this study also discussed the positive side of taking on the role of young carer in their discussions of personal growth. For many, they felt that they had experienced increased maturity and self-confidence related to the caregiving role and that their experience in the role did ultimately have a positive impact on their life. This idea of personal growth and positive experiences is also reflected in the study by McDougall et al. (2018) who found that some carers experienced positives from their role and by Hooper et al. (2008) and Keigher et al. (2005) who both found that parentification among young carers is not always a purely negative experience.

Emergent Components

With regards to the young carer experience as it relates specifically to HD, some themes and subthemes arose from the data that were not reflected in the original framework including stigma and isolation surrounding the illness, parent–child relationship changes, end of life, and genetic risk. These emergent components would be beneficial to include in future iterations of the framework as they are reflected in the experience of young carers in the context of HD, but may also be evident in other disease processes.

The first pertains to the idea of stigma and isolation related to HD. Multiple youth discussed experiences of embarrassment when they were out in public with their parent that resulted in other people laughing or looking with disdain upon their parent. They discuss their desire to have people treat them as a normal family. Kavanaugh and colleagues (2015) also found this desire among young carers of a parent with HD.

Another component of being a caregiver of a person with HD is the fact that the parent–child relationship changes as a result of the illness or is in fact something that has never formed because of the parent's diagnosis occurring so early in the child's life. For many, they discuss the fact that they never really knew their parents before HD and their parent likewise never got to know them. As a result, they felt they did not have a strong relationship with their parent, and many wished that they had the opportunity. The importance of the relationship these children are lacking was highlighted by Bauman et al. (2006)

who reported that an important predictor of child mental health was a strong parent–child relationship.

Discussions regarding disease progression and end of life were found to be especially pertinent to the experience of being a young carer to a parent with HD. These youth discussed that it was hard to watch their parent deteriorate due to the illness, but many also expressed, that despite their realization that their parent would die and that even though it is hard, it was something that they understood and acknowledged. Kavanaugh et al. (2016) discussed a lack of knowledge surrounding end of life in young carers of a parent with HD. While participants in this study stated that they understood that their parent was going to die, further discussions/education surrounding end of life may have been beneficial.

Lastly, a large component of caring for a person with HD that was discussed by participants is the potential genetic risk. The difficulty in caring for someone with the same illness that you are potentially at risk for and the need to plan for the future was reported frequently by participants. Many wanted to know whether or not they were positive for HD so that they could plan out their future with regards to loved ones, school, and careers. But many also discussed feeling apprehensive about being tested. Similar results were found by Williams et al. (2009) and Keenan et al. (2007) who reported that young carers were worried about getting HD. Dondanville et al. (2019) also found the genetic risk compounded the emotional distress felt by young carers.

Implications

This study provides foundational knowledge to inform practitioners (clinicians, researchers, social worker, educators) of the challenges facing children in families affected by HD, which can help guide their decision making when interacting with this population. Knowing how challenging caregiving can be in the context of HD, especially for youth, and knowing the specifics of that caregiving experience, can enable practitioners to ensure that families are receiving adequate support when available. It is important for practitioners working with people diagnosed with HD to inquire about the children and family at home and take steps to promote their well-being. Furthermore, children should be included in the conversation, not just the patient. This whole family approach allows practitioners can engage with children and provide them with available support to meet their specific needs.

However, there is a lack of targeted interventions for young carers, especially in specific disease contexts such as HD. Compared to other developed countries' awareness and support for young carers, the United States is behind, as there is little public awareness, a limited research base, no specific legal rights, and few dedicated services or interventions (Leu & Becker, 2017). Young carers in the United States remain an understudied and under resourced population, both in policy and research. Compared to the research being done for adult caregivers, there is very little being done for the population under age 18 (Hendricks et al., 2021b; Kavanaugh et al., 2016). This is true not only for HD, but for all families who are dealing with serious illness and have a child who may potentially be taking on a caregiving role. In the future this may be even more important as there will likely be more of a need for children to adopt the role of young carer due to a declining caregiver support ratio (Reinhard et al., 2015). It is important for healthcare providers, researchers, and educators to acknowledge that young carers do exist and make a point to include them in future research, policy, and support services. They must also engage with HD clinics and organizations to ensure these targeted services and programs are being developed with implementation in mind.

Lastly, this work provides a foundation from which future research can be built upon. The guiding framework of parentification among young carers can be expanded upon to reflect caregiving in different disease contexts. Findings from this research indicated that there are some framework components that could be added to the existing framework that also reflect the experience of caregiving of young carers outside of HD. Future research is needed which focuses on young carers in different disease contexts, the long-term impact of the role through longitudinal work, more diverse studies to explore the impact of culture and SES on the role, and work to develop targeted interventions for young carers.

Limitations

Limitations of the present study primarily deal with the fact that secondary data was utilized. Because the data was collected at an earlier timepoint, it is possible that the findings of the current study do not reflect of the context surrounding participants in the present day (Ruggiano & Perry, 2019). Perhaps the greatest limitation of secondary data analysis is that because the data was previously collected, questions pertaining specifically to parentification were not asked of participants, so the exploration of this concept in the analysis is done through questions addressing similar topics. While attempts were made to include a diverse sample reflecting all races and ethnicities, only one participant identified as other than white, thus limiting our understanding of the potential differences by race or ethnicity. While HD predominately affects people of European descent, it can affect people of all races/ and ethnicities; therefore, including a more diverse sample and exploring differences based on these factors is an important focus for future research of young carers who care for a parent with HD.

Conclusion

A HD diagnosis affects not only the individual diagnosed, but the entire family. In families with children, they may need to take on the role of young carer and aid in providing care for their ill parent. This role can conflict with other family, home, work, and school related responsibilities and can result in potential consequences such as parentification. Using directed content analysis to explore the manifestation of parentification among young carers of a parent with HD, we found that many of the components reflected in the original guiding framework were also reflected in this HD-specific sample. However, HD specific themes and subthemes also emerged from the analysis and presented new categories that were not reflected in this original framework. Therefore, these new components of the young carer experience should also be considered when addressing young carers of persons with HD. The findings of this study are supported by similar findings from previously conducted studies exploring young carer experiences and outcomes. In providing further knowledge related to the experience of young carers and the manifestation of parentification in the context of HD, the intention is that this study will inform future studies that will increase research, policy, and support for these unacknowledged and underserved children.

Funding This work was funded by the Robert Wood Johnson Foundation Future of Nursing Scholars Program.

Declarations

Conflict of interest We have no conflict of interest to disclose.

References

AARP & National Alliance for Caregiving. (2020). Caregiving in the U.S. 2020. AARP. https://doi.org/10.26419/ppi.00103.001

Armstrong-Carter, E., Johnson, C., Belkowitz, J., Siskowski, C., & Olson, E. (2021). The United States should recognize and support caregiving youth. *Social Policy Report, 34*(2), 1–24. https://doi.org/10.1002/sop2.14

Assaf, R. R., Springe, J., Siskowski, C., Ludwig, D. A., Mathew, M. S., & Belkowitz, J. (2016). Participation rates and perceptions of caregiving youth providing home health care. *Journal of Community Health, 41*(2), 326–333. https://doi.org/10.1007/s10900-015-0100-7

Assarroudi, A., Nabavi, F. H., Armat, M. R., Ebadi, A., & Vaismoradi, M. (2018). Directed qualitative content analysis: The description and elaboration of its underpinning methods and data analysis process. *Journal of Research in Nursing, 23*(1), 42–55. https://doi.org/10.1177/1744987117741667

Bauman, L. J., Foster, G., Johnson Silver, E., Berman, R., Gamble, I., & Muchaneta, L. (2006). Children caring for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies, 1*(1), 56–70. https://doi.org/10.1080/17450120600659077

Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family. *Global Social Policy, 7*(1), 23–50. https://doi.org/10.1177/1468018107073892

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open, 2*, 8–14. https://doi.org/10.1016/j.npls.2016.01.001

Blum, K., & Sherman, D. W. (2010). Understanding the experience of caregivers: A focus on transitions. *Seminars in Oncology Nursing, 26*(4), 243–258. https://doi.org/10.1016/j.soncn.2010.08.005

Boumans, N. P. G., & Dorant, E. (2018). A cross-sectional study on experiences of young adult carers compared to young adult noncarers: Parentification, coping and resilience. *Scandanavian Journal of Caring Science*. https://doi.org/10.1111/scs.12586

Boyle, G., Constantinou, G., & Garcia, R. (2023). Does gender influence children's and young people's caring? A qualitative, systematic review and meta-ethnography. *Children & Society, 37*(2), 404–423. https://doi.org/10.1111/chso.12598

Dondanville, D. S., Hanson-Kahn, A. K., Kavanaugh, M. S., Siskind, C. E., & Fanos, J. H. (2019). "This could be me": Exploring the impact of genetic risk for Huntington's disease young caregivers. *Journal of Community Genetics, 10*(2), 291–302. https://doi.org/10.1007/s12687-018-0395-z

Earley, L., & Cushway, D. (2002). The parentified child. *Clinical Child Psychology and Psychiatry, 7*(2), 163–178. https://doi.org/10.1177/1359104502007002005

Erlingsson, C., & Brysiewicz. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine, 7*(3), 93–99. https://doi.org/10.1016/j.afjem.2017.08.001

Hendricks, B. A., Kavanaugh, M., & Bakitas, M. A. (2021b). How far have we come? *An Updated Scoping Review of Young Carers in the U.s. Child and Adolescent Social Work Journal*. https://doi.org/10.1007/s10560-021-00783-8

Hendricks, B. A., Vo, J. B., Dionne-Odom, J. N., & Bakitas, M. A. (2021a). Parentification among young carers: A concept analysis. *Child and Adolescent Social Work Journal*. https://doi.org/10.1007/s10560-021-00784-7

Hooper, L. M., Marotta, S. A., & Lanthier, R. P. (2008). Predictors of growth and distress following childhood parentification: A retrospective exploratory study. *Journal of Child and Family Studies, 17*(5), 693–705. https://doi.org/10.1007/s10826-007-9184-8

Hooper, & Doehler. (2012). Assessing family caregiving: A comparison of three retrospective parentification measures. *Journal of Marital and Family Therapy, 38*(4), 653–666. https://doi.org/10.1111/j.1752-0606.2011.00258.x

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Huntington's Disease Society of America. (2011). *A caregiver's guide to Huntington's disease*. http://hdsa.org/wp-content/uploads/2015/03/A-Caregivers-Guide-to-HD.pdf

Kavanaugh, M. (2014). Children and adolescents providing care to a parent with Huntington's disease: Disease symptoms, caregiving tasks and young carer well-being. *Child & Youth Care Forum, 43*(6), 675–690. https://doi.org/10.1007/s10566-014-9258-x

Kavanaugh, M. S., Cho, C. C., & Howard, M. (2019). “I just learned by observation and trial and error”: Exploration of young caregiver training and knowledge in families living with rare neurological disorders. *Child & Youth Care Forum, 48*(4), 479–492. https://doi.org/10.1007/s10566-019-09490-z

Kavanaugh, M., Noh, H., & Studer, L. (2015). “It’d be nice if someone asked me how I was doing. Like, ’cause I will have an answer”: Exploring support needs of young carers of a parent with Huntington’s disease. *Vulnerable Children and Youth Studies, 10*(1), 12–25. https://doi.org/10.1080/17450128.2014.980370

Kavanaugh, M., Noh, H., & Zhang, L. (2016). Caregiving youth knowledge and perceptions of parental end-of-life wishes in Huntington’s disease. *Journal of Social Work in End of Life & Palliative Care, 12*(4), 348–365. https://doi.org/10.1080/15524256.2016.1252828

Keenan, K., Miedzybrodzka, Z., van Teijlingen, E., McKee, L., & Simpson, S. A. (2007). Young people’s experiences of growing up in a family affected by Huntington’s disease. *Clinical Genetics, 71*(2), 120–129. https://doi.org/10.1111/j.1399-0004.2006.00702.x

Keigher, S., Zabler, B., Robinson, N., Fernandez, A., & Stevens, P. E. (2005). Young caregivers of mothers with HIV: Need for supports. *Children and Youth Services Review, 27*(8), 881–904. https://doi.org/10.1016/j.childyouth.2004.12.010

Kelley, M. L., French, A., Bountress, K., Keefe, H. A., Schroeder, V., Steer, K., & Gumienny, L. (2007). Parentification and family responsibility in the family of origin of adult children of alcoholics. *Addictive Behaviors, 32*(4), 675–685. https://doi.org/10.1016/j.addbeh.2006.06.010

Khafi, T. Y., Yates, T. M., & Luthar, S. S. (2014). Ethnic differences in the developmental significance of parentification. *Family Process, 53*(2), 267–287. https://doi.org/10.1111/famp.12072

Kirkwood, S. C., Su, J. L., Conneally, P. M., & Foroud, T. (2001). Progression of symptoms in the early and middle stages of Huntington disease. *Archives of Neurolog, y, 58*, 273. https://doi.org/10.1001/archneur.58.2.273

McDougall, E., O’Connor, M., & Howell, J. (2018). “Something that happens at home and stays at home”: An exploration of the lived experience of young carers in Western Australia. *Health & Social Care in the Community, 26*(4), 572–580. https://doi.org/10.1111/hsc.12547

McGuire, D. B., Grant, M., & Park, J. (2012). Palliative care and end of life: The caregiver. *Nursing Outlook, 60*(6), 351–356. https://doi.org/10.1016/j.outlook.2012.08.003

McMahon, T. J., & Luthar, S. S. (2007). Defining characteristics and potential consequences of caretaking burden among children living in urban poverty. *American Journal of Orthopsychiatry, 77*(2), 267–281. https://doi.org/10.1037/0002-9432.77.2.267

McNamara, B., & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science & Medicine, 70*(7), 1035–1041. https://doi.org/10.1016/j.socscimed.2009.11.029

Modi, J. & Maldonado, A. (2022). What are the five stages of Huntington’s disease?

Nance, M., Paulsen, J., Rosenblatt, A., & Wheelock, V. (2011). *A physician’s guide to the management of Huntington’s disease* (3rd ed.). Huntington’s Disease Society of America.

National Alliance for Caregiving. (2005). *Young Caregivers in the U.S.: Report of Findings September 2005*. https://www.caregiving.org/data/youngcaregivers.pdf

Polit, D. F., & Beck, C. T. (2017). *Nursing research : Generating and assessing evidence for nursing practice* (10th ed.). Wolters Kluwer Health.

Rawlins, M. D., Wexler, N. S., Wexler, A. R., Tabrizi, S. J., Douglas, I., Evans, S. J. W., & Smeeth, L. (2016). The prevalence of Huntington’s disease. *Neuroepidemiology, 46*(2), 144–153. https://doi.org/10.1159/000443738

Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015, July). Valuing the invaluable: 2015 update. AARP Public Policy Institute: Insight on the Issues. https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf

Revenson, T. A., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., Vilchinsky, N., & Hagedoorn, M. (2016). Gender and caregiving: The costs of caregiving for women. *Caregiving in the Illness Context*. https://doi.org/10.1057/9781137558985_5

Ruggiano, N., & Perry, T. E. (2019). Conducting secondary analysis of qualititative data: Shoud we, can we and how? *Qualitative Social Work, 18*(1), 81–97. https://doi.org/10.1177/1273325017700701

Saldana, J. (2009). *The Coding Manual for Qualitative Researchers*. SAGE Publications.

Spall, S. (1998). Peer debriefing in qualitative research: Emerging operational models. *Qualitative Inquiry, 4*(2), 280–292. https://doi.org/10.1177/107780049800400208

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Van Loon, L. M., Van de Ven, M. O., Van Doesum, K. T., Hosman, C. M., & Witteman, C. L. (2017). Parentification, stress, and problem behavior of adolescents who have a parent with mental health problems. *Family Process, 56*(1), 141–153. https://doi.org/10.1111/famp.12165

Van Parys, H., Smith, J. A., & Rober, P. (2014). Trying to comfort the parent: A qualitative study of children dealing with parental depression. *Journal of Marital and Family Therapy, 39*(3), 330–345. https://doi.org/10.1111/j.1752-0606.2012.00304.x

Walker, F. O. (2007). Huntington's disease. *The Lancet, 369*(9557), 218–228. https://doi.org/10.1016/S0140-6736(07)60111-1

Williams, J. K., Ayres, L., Specht, J., Sparbel, K., & Klimek, M. L. (2009). Caregiving by teens for family members with Huntington disease. *Journal of Family Nursing, 15*(3), 273–294. https://doi.org/10.1177/1074840709337126

Williams, K., & Francis, S. (2010). Parentification and psychological adjustment: Locus of control as a moderating variable. *Contemporary Family Therapy, 32*(3), 231–237. https://doi.org/10.1007/s10591-010-9123-5

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