# The Experiences of Being a Young Carer to a Parent with Huntington's Disease: A Thematic Synthesis

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## Abstract

**Purpose**: This thematic synthesis explored the experiences of being a young carer to a parent with Huntington's disease.

**Methods**: A systematic search strategy was utilised across eight databases, resulting in 13 papers that met the inclusion criteria. Thomas and Harden's thematic synthesis approach was used to guide the methodological decisions and analyse the data.

**Results**: The analysis resulted in three themes (1) *Lack of awareness, undervalued and unsupported: barriers to young carers accessing support (*2) *Adult responsibilities: impact on developmental stages and worries about the future, (*3) *Engaging with the future or living in the present: managing the impact of being a young carer while at risk of HD*.

**Conclusions**: The experiences of young carers to a parent with HD share some similarities with other young carers to a parent with chronic illness. However, a key difference is the constant reminder of their possibility of inheriting the HD gene and the effects of this on their lives. This makes it difficult for them to envision a future beyond being a young carer.

**Keywords**

Huntington's disease, Young carers, qualitative, systematic review, thematic synthesis

# Introduction

A recent meta-analysis has estimated that between 1% and 12% of young people could be classified as young carers (Lam & Lam, 2024). While the exact figure is difficult to establish due to definitional variation, this does indicate that being a young carer is not an uncommon experience (Lam & Lam, 2024). Young carers are generally defined as individuals aged 25 and under who provide unpaid support to a family member living with a chronic illness, disability or mental health condition (Saragosa et al., 2022). Support can include personal care, household chores or emotional support, without which the supported individual may have difficulty coping (Saragosa et al., 2022). Evidence suggests that young carers experience many common challenges across countries, regardless of differences in economic development or welfare system provision (Becker, 2007; Joseph et al., 2020).

While many conditions present challenges for young carers, caring for a family member with Huntington's disease (HD) is particularly difficult. For example, Parekh et al.'s (2018) meta-synthesis of 12 studies on family carers of all ages emphasised that being a carer in a HD family was unique in its impact on the family system. HD is an incurable, life-limiting disease, clinically diagnosed at the point motor symptoms start, at which point life expectancy is around 20 years (Ramos & Garrett, 2017). As a hereditary condition, with long-term progression affecting numerous domains, it is associated with a number of different psychological challenges (Domaradzki, 2015; Ramos & Garrett, 2017). As the physical and cognitive abilities of the HD-affected individual deteriorate, full-time carer support is needed (Lewit-Mendes et al., 2018).

Family caring for an individual affected by HD has been evidenced to be a stressful experience. Parekh's et al.'s (2018) review concluded that everyday struggles that could normally be managed became overwhelming when coupled with caring responsibilities. Young carers also reported role changes, going from family members to being a carer in a carer-care recipient relationship. Children in HD families often contribute to providing caring support for their HD-affected parent, with one study finding that 83% of young people in an HD family assisted an affected family member (Lewit-Mendes et al., 2018). Although Parekh et al. (2018) found only two studies specifically focused on young carers, they emphasised that the experiences of young carers compared to adult carers were different. They highlighted that a young carer must act like an adult but lacked authority, leading to an inability to coordinate services and the inability to provide care when challenged by the affected parent (Parekh et al., 2018). They also felt that young carers experienced social restrictions, feeling unable to let friends fully into their lives, which could impact the formation of their social identity and understanding of who they were outside the caring role (Parekh et al., 2018).

Young carers in a HD family are not only impacted by the experience of being a carer but growing up in a HD family has been found to be difficult in itself. Research with children aged 18 and under growing up in a HD family has found they can experience a lack of security, stability and experience physical and verbal abuse (Forrest Keenan et al., 2007; Kjoelaas et al., 2022b). Cooper et al.'s (2024) meta-ethnography of 13 studies found that these young people, regardless of whether or not they were young carers, experienced a loss of relationships, loss of sense of self, and loss of transparency within the family system. However, at the same time they wanted to fight to reclaim the aspects of their self and childhood they reported they had lost.

Two recent reviews, Cooper et al. (2024) and Saragosa et al. (2022), have examined respectively the impact and experiences of growing up in an HD family and the unique experience of young carers supporting a parent (including a wide range of health conditions). However, a specific review on the experiences of being a young carer to a parent with HD has not been conducted. Since the Parekh et al. (2018) review, additional studies on young carers in a HD family have been published, rendering a focussed review both timely and feasible. Consequently, this review aimed to answer the following question, ‘What is the experience of being a young carer to a parent with Huntington’s disease?’ To answer this question, a thematic synthesis of qualitative studies was undertaken (Thomas & Harden, 2008), given the focus in qualitative studies on the exploration of human experiences (Tenny et al., 2022). Thomas and Harden’s (2008) **thematic synthesis** method has become a widely recognised and frequently applied approach in qualitative evidence synthesis. It is routinely cited in methodological reviews of qualitative synthesis and has been used as the basis for numerous systematic reviews of qualitative evidence in health and social care, demonstrating both its rigour and utility for integrating findings across diverse qualitative studies (Flemming & Noyes, 2021). It has also been used to synthesise qualitative studies relevant to Huntington’s disease (e.g., Regan, Preston, Eccles & Simpson, 2019).

## Method

The ENTREQ 21-point checklist and PRISMA checklist for systematic reviews was followed to increase the transparency of this review (Page et al., 2021; Tong et al., 2012).

### Identifying relevant papers

Initial scoping searches located three previous reviews on HD families (Cooper et al., 2024; Mahmood et al., 2022 and Parekh et al., 2018). Their included papers a) indicated that the current review was feasible and b) highlighted some “gold-standard” papers which any future search should locate.

A specialist university librarian was consulted to develop the search strategy. This included both free text and subject heading searches and was based upon keywords and functions of specific databases such as “explode”, which allows the inclusion of derivatives, related subject areas and synonyms. The searches combined three concepts: Huntington’s disease, young person and carer. An example search can be seen in Table 1.

After the searches had been completed, forward and backwards citation searches of the included papers were conducted to increase further the chances of locating all relevant studies. This review was pre-registered on PROSPERO accessible at: https://www.crd.york.ac.uk/PROSPERO/view/CRD42025637503. The protocol and complete search strategies for each database are included in the OSF depository accessible at https://osf.io/j9r23/.

The searches were conducted on the following databases: Medline, PsycINFO, Scopus, Embase, CINAHL, Web of Science, Child Development & Adolescent Studies and PubMed. These databases were chosen as they cover psychological research, medical research and research that impacts child development and therefore include the fields relevant to HD and being a young carer.  Due to the sparsity of research, eight databases were searched to increase the likelihood of capturing all relevant data. All searches were conducted on 16/01/2025 and were limited to the English language.  The search strategies were dependent on the database functionality, differences in key terms and the ability to expand such terms.

[Table 1 - about here]

### Inclusion/exclusion criteria

The inclusion criteria were as follows:

The paper must:

- Focus on or have a section dedicated to the experience of being a young carer (an individual aged 25 or under and undertaking caring responsibilities such as chores or direct support to the care recipient) for a parent with HD. This could be current or retrospective experiences.
- Include qualitative data, such as interviews, which were supported by direct quotes from participants to understand their experiences. Mixed methods studies were included where the qualitative section met these criteria.
- Clearly stated that a specific form of qualitative analysis had been used. It must have been evident in the paper that the method had been followed.
- Published in a peer-reviewed journal.
- Be in English

The exclusion criteria were as follows:

- Papers that featured aspects of being a young caregiver for a parent with HD, but the data could not be distinguished clearly, e.g. an account of living in a family with HD that mentioned caregiving, but caregiving was not discussed directly. Similarly, papers that considered multiple conditions, including HD, but where HD could not be differentiated.
- Mixed methods papers where the qualitative and quantitative data were intertwined, so the qualitative data could not be extracted in isolation.

## Analysis

Thomas and Harden's (2008) thematic synthesis framework was used for analysis. This requires immersion in the included studies via multiple full reads. Once immersed in the papers, data relevant to this review's aims were selected. Thematic synthesis is not limited to the study's results but also includes the author's interpretation of the results and their conclusions (Thomas & Harden, 2008). The data from the papers considered relevant were coded line-by-line using NVivo 14 (Lumivero, 2023). Thirty-five codes were created, which were then organised into seven descriptive themes (see Appendix 1).

Analytical themes were created, developing new interpretive findings to increase the understanding of the experiences of the young carers of a parent with HD (See Appendix 2). This resulted in three themes, presented below: (1) *Lack of awareness, undervalued and unsupported: barriers to young carers accessing support* (2) *Adult responsibilities: impact on developmental stages and worries about the future, (*3) *Engaging with the future or living in the present: managing the impact of being a young carer while at risk of HD*. The papers contributing to the themes can be seen in Table 2.

[Table 2 – about here]

# Results

## Search results

The systematic search identified 693 papers. These were uploaded to a systematic review software, rayyan.ai (Rayyan, 2025), which was used to check for duplicates, of which 198 were identified. Rayyan.ai was also used for screening the remaining 495 papers. The title and abstract were screened against the inclusion/exclusion criteria to identify relevancy.

Through this, a further 473 papers were excluded, leaving 22 papers. These 22 papers were reviewed in full, with 11 papers identified as meeting the inclusion criteria. Two additional papers were identified through forward and backwards citation searches, resulting in a total of 13 papers being included in this review. A PRISMA diagram illustrating this process is shown in Figure 1.

To assess the robustness of the screening process, which the first author undertook alone, an inter-rater reliability test was carried out with another researcher. The second reviewer screened a sample of 100 papers (approximately 20%), and a 90% agreement rate was sought and achieved. Complete agreement was sought and achieved after discussion between raters, confirming inter-rater reliability. Additionally, uncertainties within the 22 papers identified in the title and abstract screen were discussed within the full author team before a final decision on inclusion was made.

[Figure 1 – about here]

**Study characteristics**

All 13 studies were conducted in high-income countries: the US (n = 4), Norway (n = 4), the US and Canada (n = 2), the UK (n = 1), Australia (n = 1), and the Netherlands (n = 1). The age range of the participants was 9 to 67 years old. This review defined young carers as 25 years or under; therefore, participants in included studies were within this age range or were retrospectively reflecting on caring within this period. All participants had a biological parent with HD, so they were at risk of inheriting HD at the time of their experiences. It was unclear in the studies if the participants had been tested. Testing is often only available to individuals over the age of 18, so not all studies that included participants over the age of 18 reported the participants' HD status. Studies that included tested individuals did not specify the age at which they were tested, so it was unclear whether they were at risk or had been tested while being a young carer.

Some papers used the same participant sample to explore differing research questions. Kavanaugh et al. (2014), Kavanaugh et al. (2016), and Hendricks et al. (2024) shared one sample. Kjoelaas, et al. (2022a), Kjoelaas, et al. (2022b) and Kjoelaas et al. (2020) shared another sample. Williams et al. (2009) and Sparbel et al. (2008) had another shared sample, meaning the data used in the 13 included papers were derived from eight unique studies. Multiple papers from the same studies were included as the differing research questions resulted in different data extraction covering topics of relevance to this review's research question. Excluding these would have meant missing key experiences of being a young carer to a parent with HD. Sample sizes for the eight studies ranged from 10 to 40, with a total of N = 192 participants, comprising 142 females and 50 males across the eight studies. The main method of data collection was semi-structured interviews (n = 6) with two studies using focus groups. The review included both current and retrospective accounts. Only two papers (Daemen et al., 2024; Røthing, Malterud and Frich, 2014) were fully retrospective. The three Kjoelaas et al. papers and Forrest Keenan et al. (2007) had a mixed sample in terms of providing retrospective and current viewpoints.

A number of qualitative methods were used, including thematic analysis, interpretative phenomenological analysis and content analysis. One study (Daemen et al., 2024) was a mixed-methods study, from which only the qualitative data were extracted for use in this review. Full study characteristics are presented in Table 3.

[Table 3 – about here]

## Quality of the individual studies

The Critical Appraisal Skills Programme (CASP) qualitative studies checklist, a widely used approach to evidencing study quality (CASP, 2023), was applied. After the two screening questions have been administered, the checklist has 10 questions which can be given a ‘yes’, ‘can’t tell’ and ‘no’ rating respectively.  The CASP questions and ratings are shown in Table 4. Overall, the CASP ratings indicated the papers to be of high quality. On only one question, “Has the relationship between the participant and the researchers been adequately considered?”, did the cumulative rating identify a lack of definitive information, with “can’t tell” being appraised in 9 papers.

[Table 4 – about here]

## Analytical Themes

### *Theme 1: Lack of awareness, undervalued and unsupported: barriers to young carers accessing support*

This theme considers the ability of young carers to access relevant and needed forms of support. Participants discussed how the lack of awareness of their caring role caused difficulties in accessing support, including healthcare interventions, being included in decision-making and informational support. Additionally, behaviours of young carers, such as not engaging with difficult emotions and caring experiences and wanting to protect their affected parent, also affected their ability to access support.

The role of young carers appeared to be invisible, with little awareness among the public (Hendricks et al., 2024). In areas where there was awareness of young carers, such as professionals in healthcare and education roles, a lack of recognition of the amount of support they provided or the importance of the role they played was still evident (Hendricks et al., 2024; Kavanaugh et al., 2016; Mand et al., 2015). Young carers felt there was no recognition of their caring responsibilities or their need to be cared for, leading to feeling undervalued and isolated (Daemen et al., 2024; Hendricks et al., 2024; Kavanaugh et al., 2014; Kavanaugh et al., 2016; Kjoelaas et al., 2022a; Mand et al., 2015; Rothing et al., 2014). Even close family members lacked awareness of their caring role:

> "*My aunt, she drove me home to college once, and all she did was tell me how bad she felt for my mom the whole time. And I'm like, "What about me?"* (19-year-old, Kavanaugh, et al., 2015, p. 20).

The lack of recognition was especially difficult for young carers due to the level of additional responsibilities they took on, which was prominent in and impacted all areas of their lives (Hendricks et al., 2024). These responsibilities included household chores such as cooking and cleaning, but also personal care for their parent, looking after younger siblings and being concerned with the household finances (Daemen et al., 2024; Forrest Keenan et al., 2007; Kavanaugh et al., 2016; Kjoelass et al., 2022a; Mand et al., 2025; Rothing et al., 2014; Williams et al., 2009).

Young carers who were minors struggled to access support for themselves and for their affected parent as they did not share the same legal authority to access healthcare support and make caring decisions as adult carers (Williams et al., 2009). Additionally, the nature of HD meant the affected parent might not have recognised they were unwell (Kjoelaas et al., 2022a), thus creating a barrier by either restricting the young carer from accessing support or disguising their symptoms from professionals. As reported: *"It's the most difficult part about this whole thing when you are a young carer who wants help but you are not getting anywhere because your parent is denying that they have a disease"* (Kjoelaas et al., 2022a, p.665)*.* This could lead to fewer healthcare interventions, adding additional responsibilities to the young carer and causing them further emotional distress due to being isolated in managing their responsibilities (Kjoelaas et al., 2022a; Williams et al., 2009).

Young carers were not included in important discussions with healthcare services and within the family unit. Even young carers who were adults could be excluded from medical appointments and end-of-life discussions, with one participant aged 20 in Kavanaugh et al. (2016, p.356) being told: *"it [end of life discussion] is more of an adult thing."* These experiences of being excluded from important discussions furthered the feelings of being undervalued (Kavanaugh et al., 2016). Not being included in important conversations meant they missed opportunities both to support decision-making around their affected parents' care and for them to reach out to access support for themselves. This continued a lack of recognition of their caring role (Kavanaugh et al., 2016; Williams et al., 2009).

Being left out of caregiving discussions also meant the young carers could not access the same informational support as adult caregivers. This hampered their ability to provide care to the best of their capabilities. Across several papers, young caregivers expressed that they wanted more information to support their parent with HD (Dondanville et al., 2019; Hendricks et al., 2024; Kavanaugh et al., 2014). For example, one participant voiced: *"I wish there was more information available. More help for young people trying to care for a parent would be nice" (*Kavanaugh et al., 2014, p.19*)*. Young carers, therefore, received little to no education regarding caring, reporting that they are *"just kind of winging it"* (Kavanaugh et al., 2014, p.19). Young carers reported they learnt to be caregivers via intuition and observation (Hendricks et al., 2024).

Additionally, many young carers did not make an informed decision about becoming caregivers. Young carers often assumed caring responsibilities without being asked, with most young carers feeling obligated to take on the caring role (Mand et al., 2015; Hendricks et al., 2024): *"I just thought of it like, 'This is my duty. This is happening to my mom," (*Dondanville et al., 2019, p.295*)*. Having a more retrospective perspective also allowed some participants to reflect that this sense of duty may have started before more active caring (Kjoelaas, Jensen and Feragen, 2022b, p.217):

> We would be sitting there, having a good time, and my mother would just suddenly start to cry, and I did not understand it at all. And then she would get herself together somehow, disguise it with laughter. It impacted me, like: 'What was that?' And what that did to me? It probably made me feel responsible for her well-being from an early age (Nancy; adult female, mother with HD).

This led to thoughts towards caring for HD as being something young carers just had to "*deal with it"* (Hendricks et al., 2024, p.864). Hendricks et al. (2024) felt that this attitude could be a form of avoidance of engaging with the difficult experiences of caregiving, which negatively impacted young carers in the form of emotional distress, financial concerns and social restrictions. This is supported by Kjoelaas et al. (2022a), who found that some young carers were so emotionally overwhelmed by their difficult experiences that to maintain a sense of self-preservation, they avoided help to avoid engaging with their emotional distress: *"I have plenty of people who have tried to follow up, tried to provide support [...] I just haven't wanted to deal with it, haven't been able to handle it." (*Kjoelaas et al., 2022a, p.667). This may indicate that, on occasions, when support is available, avoidance may be a barrier to accessing it.

The need to protect their affected parent also prevented young carers from accessing support because they concealed when they were struggling (Kavanaugh et al., 2016; Rothering et al., 2014). Often, this was because they felt loyal to the family unit or feared the repercussions of admitting they were struggling. Even when young carers acknowledged they needed support (either at the time or when reflecting later), they sometimes worried this could create conflict within the family or even lead to them facing the possibility of being removed from their parents:

> *"When I look back on the situation today, I think it would have been a very good thing if I had allowed someone to see and take me away, but with children and loyalty, I don't know if that would have worked" (*Kjoelaas et al., 2022a, p.667*).*

In conclusion, the lack of awareness of their role and their caring responsibilities made young carers feel undervalued, leading to emotional distress and feelings of isolation. It resulted in a lack of opportunities to access support, affecting their ability to understand HD, provide the best care possible and reduce their caregiving responsibilities. Additionally, avoiding emotional distress and wanting to protect their family acted as barriers stopping young carers from asking for support.

### *Theme 2: Adult responsibilities: impact on developmental stages and worrying about the future*

This theme explores the process of young carers taking on their affected parent's responsibilities, switching roles and the impact on the young carers. As young carers assumed a parental role, they felt anxious over who would provide support if they were not present, leading to sacrificing social relationships. Furthermore, they were anxious about the future and who would support their parent if they were to leave the family home to pursue their desires. Young carers felt they missed out on typical parent-child relationships.

Young carers experienced taking on the responsibilities of the parent with HD for whom they were caring (Rothing et al., 2014). This started by taking on extra cleaning or household chores that the parent with HD was no longer physically able to do (Daemen et al., 2024; Kjoelaas et al., 2020). However, over time, this increased to taking on a full adult role within the home, such as looking after younger siblings and eventually having to support their parent with HD's personal care and safety needs (Forrest Keenan et al., 2007; Kavanaugh et al., 2016; Kjoelaas et al., 2020). These increased responsibilities did not allow room to be a child, causing young carers to experience a loss of their childhood:

> *"I lost my youth this way. I wasn't given the opportunity to rebel. There was no room for that. I went from being a child to being an adult. Had to take responsibility, take care of myself. And of course, most people can do that, but you sacrifice a lot along the way"*. Evelyn in Kjoelaas et al. (2022b, p. 221)

This transition continued until the roles switched and the young carers considered they were then treating their parent as a child (Mand et al., 2015; Williams et al., 2009). This came with a fear that the parent with HD would hurt themselves, leading to the young carers taking on not only a caring role but a 'protector' mindset. One participant in Williams et al. (2009) described, *"You have to monitor him, like he's your kid or something, 'cause you're watching out for him, 'cause he's making bad decisions."* (Williams et al., 2009, p.7). This fear was apparent even in very young carers. For example, Matthew, aged 13, voiced: *"It's scary not knowing what could happen to mum, she's home by herself a lot and she hurts herself."* (Mand et al., 2015, p.212).

As young carers assumed adult roles, they experienced fear and anxiety about who would support their parent with HD if they were not around (Mand et al., 2015). This led the young carers to prioritise their adult responsibilities and, in turn, make sacrifices in their own lives. One such sacrifice young carers reported was education, with some young carers having to drop out of school to maintain their caring responsibilities (Forrest Keenan et al., 2007; Hendricks et al., 2024; Kavanaugh et al., 2016; Mand et al., 2015). Georgie, aged 17, in Mand et al. (2015, p.212) voiced: *"I don't go to school, I quit in April. I just help dad around the house, he needs it because he works full time and my brother is at school, so I stay home and look after the house"*.

Friendships were also a point of sacrifice for young carers, as they felt they had to refuse social experiences or felt unable to bring their friends home due to feelings of embarrassment and potential stigma towards their family situation (Hendricks et al., 2024; Williams et al., 2009). This made it difficult for young carers to maintain friendships, leading to feelings of isolation (Hendricks et al., 2024; Kavanaugh et al., 2014). Therefore, young carers missed out on peer relationships, vital contributors to social and emotional development. Kavanaugh et al. (2014) believed this might cause them to be perceived as different and experience 'othering' from their peers, furthering feelings of being alone. For those participants who were able to look back at their life from a retrospective position, different attributions were made: 'I used to not want to talk about it, but now I see that I lost contact with a lot of my friends. I think it was largely because I distanced myself like that.' (Kjoelaas et al., 2020, p. 135)

The fear and anxiety young carers experienced extended into the future, where they considered putting their aspirations on hold due to their caring responsibilities: *"Next year I'll be graduating and so… I'm going to be helping out mainly for the next year, but I'm afraid when I leave, I don't know what's gonna happen."* (Sparbel et al., 2008, p.332). Young carers felt they did not progress in line with their peers and missed out on developmental transitions such as completing school, going to higher education or moving out of the family home. At times, this led young carers to be feeling 'stuck' in their families:

*"I'm kind of stuck, like in my family . . . I'm the only . . . like my dad doesn't know everything that I know . . . and then he yells at me, and I'm just saying 'look, I'm trying to help you out.'"* (Williams et al., 2009, p.8).

The sacrifices young carers made meant they experienced feeling that they had missed out on the parent-child relationship: *"The embarrassment I felt, and the feeling that something was missing. I wasn't supposed to be the one supporting her; she was supposed to be the one supporting me."* Lucy, in Kjoelaas et al. (2020, p.134). Taking on the parent's role, making sacrifices towards their current and future lives and missing the parent-child relationship contributed to experiencing a disconnection between who they were and who they wanted to be:

*"I can't really be myself, I have to be [like] an adult…But I want to be a brat [you know], I want to be myself, and I can't."* Sparbel et al. (2008, p.332). This caused resentment towards their parent as they felt that their needs were neglected (Kjoelaas et al., 2022b).

In conclusion, when a child looked after a parent with HD, they moved away from the parent-child relationship. When this occurred at a young age, it supplanted the developmental transitions they would normally go through, via sacrificing social relationships and schooling.

This meant young carers missed chances to explore adolescence and carve out an identity for themselves.

*Theme 3: Engaging with the future or living in the present: managing the impact of being a young carer while at risk of HD*

This theme considers the at-risk status of young carers looking after a parent with HD. Young carers experienced emotional distress from the possibility of having the HD gene expansion but often did not blame their parents. Some young carers found it to be a positive influence, making them more caring, as well as considering how they would wish to be cared for if they had HD.  Other young carers avoided engaging with their HD status, attempting to suppress these thoughts to focus on caring for their parent.

As many young carers were under 18, they were ineligible to be tested, meaning the risk of having the HD gene expansion was ever-present. All included studies highlighted the emotional distress caused by being at risk while providing care (Mand et al., 2015; Williams et al., 2009). They reported anxiety and anger at their potential to have HD and for their potential children to be at risk (Forrest Keenan et al., 2007; Rothing et al., 2014). Some experienced low mood, knowing what they were witnessing could potentially happen to them (Williams et al., 2009).  When young carers reflected on HD's impact on their lives, they experienced feelings of powerlessness (Kjoelaas et al., 2020). These difficult emotions caused young carers to want to escape their situation; for example, Mark in Hendricks et al. (2024, p.859), described wanting to run away which made him feel that he *"really shouldn't feel that way because it's not her [his mother's] fault… It's just a hard situation to deal with."*

While being at risk caused young carers emotional distress, they also reported that they did not blame their HD-affected parent for their potential risk of HD and would still provide care even if they were not at risk (Dondanville et al., 2019; Hendricks et al., 2024). Although young carers did not attribute blame to their parents with Huntington's disease, the caregiving role brought their own risk of developing the condition into sharper focus. Many reported that caregiving heightened anxiety about their own and their siblings' risk of Huntington's disease (Dondanville et al., 2019; Forrest Keenan et al., 2007; Hendricks et al., 2024; Williams et al., 2009).

> *"the worst part [about] caregiving was just getting that anxiety about how it could happen to me or my brother."* Dondanville et al. (2019, p.295).

While being at risk was a source of anxiety, some young carers reported that it had a positive influence. They discussed how it made them empathise more with their parent (Dondanville et al., 2019; Williams et al., 2009). They acknowledged that their parent had no choice in this either; *"it's genetics"* (Dondanville et al., 2019, p.296). They discussed how it made them more caring as they considered how they would like to be cared for in the future (Dondanville et al., 2019; Kavanaugh et al., 2016).

> *"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."* Dondanville et al. (2019, p.295).

Additionally, being a caregiver may have influenced opinions on testing. Some young carers said they wanted to be tested because they had seen and experienced the impact of HD. Many young carers said they wanted to get tested to plan better for the future and to know if HD would impact their relationships, possible children and careers (Dondanville et al., 2019; Hendricks et al., 2024). In contrast, some young carers avoided engaging with the future

(Dondanville et al., 2019; Hendricks et al., 2024; Kavanaugh et al., 2016). Young carers would try to suppress thoughts  - sometimes unsuccessfully - about their potential risk as well as their parents needing end-of-life support, choosing to focus on their caring responsibility and the needs of their parents currently (Dondanville et al., 2019; Hendricks et al., 2024):

> *"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'.* (Dondanville et al., 2019, p.295).

This allowed young carers to live in the present and focus on caring for their parent, reducing anxiety about the future but, as illustrated above, anxious thoughts still occurred. Thoughts suppressed around end-of-life care might also have supported them to engage in their current caring responsibilities by avoiding the emotional distress of contemplating their parents' further deterioration:

> *"I just, I don't know, I just don't really, I try not to picture her, like, getting super sick and terrible. Well, not terrible, but like bad that she would need it [end of life care]. Like, I just don't like picturing that, so I just don't really think about it."* Kavanaugh et al. (2016, p.356).

For those able to reflect back on their life, this provided an ability to evaluate the protective influence of relationships formed in their early years. These pivotal relationships provided a continuous background note of love and care, often demonstrated by memories of such individuals being a presence as opposed to specific actions. These relationships helped mitigate some of the stress and isolation:

> *"I have always been very connected to my grandfather. If he had not been there, I wouldn't be … here … We didn't talk all that much, but at the same time, I always knew he was there*

> *and that he was my protector … He showed me that he loved me just by being there and that I had someone who cared. It was probably what I had been missing the most, but I had him … who made me who I am and gave me the strength to pull through the way I did.”*
>
> *(Tina; adult female, father with HD) Daemen et al. (2024, p.662-663)*

In conclusion, being at risk of HD was a source of emotional distress for the young carers. Distressing thoughts about their at-risk status were elicited by providing care for their HD-affected parent. This would lead some young carers to consider their future and how they wished to be supported, while others felt unable to engage with this, leading to avoidance and suppressing thoughts about their at-risk status.

## Discussion

This review aimed to synthesise qualitative studies exploring the experience of being a young carer to a parent with Huntington’s disease. Thirteen papers were included, derived from eight unique studies, with 192 participants. Generating three independent but related themes, this thematic synthesis found that being a young carer for a parent with HD was a highly challenging and impactful role. The three themes are now further discussed in relation to relevant research and theory.

The first theme highlighted how the lack of recognition of young carers by professionals, the public and sometimes even their own families caused emotional distress and limited their access to support. This finding was not evident in the adult carer section of Parekh et al.’s (2018) review, suggesting that there may be some recognition of the experience of being an adult carer in a HD family but not when children assume caring responsibilities for their affected parent.

Young carers for a parent with HD felt undervalued because they were often excluded from important discussions, which may have affected their access to informational support. The desire for informational support seemed more keenly observed in young carers and children from HD families than in adult carers (Cooper et al., 2024; Parekh et al., 2018). This need for informational support and being excluded from key discussions seems to be a theme among both young carers in general and those caring for a parent with a chronic illness (Stevens et al., 2024; Van der Werf et al., 2022). This need may be linked to confidence and self-identity. Research on young carers indicates that those who receive informational support feel more confident in their abilities and, consequently, in their identity as a carer (Phelps, 2021). Additionally, involving young carers in decision-making has been shown to enhance their well-being (Stevens et al., 2024). When young carers are excluded, their self-identity as carers remains unrecognised, which may make them feel undervalued, affecting well-being (Sharma & Sharma, 2010).

The fear of repercussions often prevented young carers from attempting to access support themselves, particularly from statutory organisations such as social care, and is consistent with findings for young carers generally (Aldridge, 2018). This fear has also been observed among young carers of parents with other (non-HD) chronic illnesses. However, among those participants additional reasons for not seeking support were also highlighted, such as avoiding the stigma of being labelled a young carer and wanting to maintain a self-identity outside of the caring role (Chikhradze et al., 2017; Duzen et al., 2025; Van der Werf et al., 2022). However, these aspects were not evident in this review specifically focusing on HD young carers, which may relate to the pervasiveness of HD on self-identity (Cooper et al., 2024). Hughes (1945) theorised that when a label or role becomes more significant than other aspects of an individual's life, it becomes a 'master' identity. HD is present throughout a young carer's life, in the parent they care for, their at-risk status, and other family members affected by HD; therefore, HD may serve as the master identity rather than that of a young carer. Consequently, Huntington's disease may come to dominate the young carer role, restricting opportunities to envisage alternative futures, as the condition is anticipated to remain a continuing presence in their lives.

Theme two examined the impact of young carers of taking on adult responsibilities and missing key developmental opportunities. While taking on considerable adult responsibilities is not specific to carers in HD families (Saragosa et al., 2022), the range and extent reported in this review is striking. Interventions to reduce caring responsibilities could ease the pressure to give up schooling and social activities. This would enable young carers of an HD-affected parent to provide care while still experiencing key developmental milestones. Evidence in the wider literature, such as Phelps' (2021) study, which examined dedicated young carers' services for general young carers in the UK, observed positive changes in schooling and socialisation following support interventions.

Similar to the findings of this review, research has shown that in general young carers face social and educational disadvantages (Joseph et al., 2020). Young carers have fewer opportunities to attend higher education and fewer employment opportunities (Joseph et al., 2020). Socially, children in HD families are affected by changes in their relationship with their HD-affected parent, which may influence their attachment (see Cooper et al.'s [2024] review). Additionally, young carers might encounter difficulties with peer relationships when at school (Joseph et al., 2020). These are all opportunities that are missed (or negatively impacted) for young carers to develop and expand their self-identities. This may mean that not only is HD their master identity but they also have fewer other identities with which to align, making it difficult to move beyond their role as a young carer. This is supported by Bury's (1982) theory of 'biographical disruption', which explains that chronic illness disrupts one's sense of self and social relationships. Contemporary understanding of biographical disruption suggests that the impact arises from the illness affecting an individual's ability to engage with daily life (Engman, 2019). If this occurs during a key developmental period, such as the transition from adolescence to adulthood, the effects on identity formation can be long-lasting (Grinyer, 2007). The responsibilities of being a young carer to a parent with HD hinder their ability to engage fully with daily life. Therefore, HD young carers are likely to experience biographical disruption in a stage where this has enduring effects on their self-identity. Furthermore, being at risk may also amplify the biographical disruption, meaning that, although they do not currently exhibit symptoms of a chronic illness, they must consider the possibility of developing it in the future, thus extending the biographical disruption beyond their caring role and into the realm of the HD risk.  This may keep the young carer's life centred on HD, potentially increasing feelings of being 'stuck' and intensifying sentiments of resentment and lost childhood (Williams et al., 2009).

The third theme explored two ways of coping with caregiving while being at risk of HD: engaging with the future or living in the present. Living in the present (and not engaging with the future) could be a form of avoidance of the future, raising the concern that young carers are responding only to their immediate experiences rather than developing strategies to manage their emotional difficulties in the long term. This may be attributed to the hereditary nature of HD, where avoidance is not only a way to cope with caregiving-related emotional distress but also their at-risk status, leading them to focus on the present (Cooper et al., 2025).

Preparing for the future seemed to be connected to how they wished to be cared for if they had HD or wanted to get tested (Dondanville et al., 2019; Hendricks et al., 2024). This perspective places HD at its centre and prevents young carers from engaging with what they want from life outside of HD. This contrasts with research on general young carers, where there was a desire to develop a future alongside their caring role (Saragosa et al., 2022). This may again reflect that HD is the master identity, and not that of a young carer. However, both HD young carers and young carers in general hesitated about leaving home to start their own lives, primarily due to concerns about who would care for their parent (Van der Werf et al., 2022). Young carers for an HD-affected parent do share some similarities with general young carers. However, where young carers for a parent with HD clearly differ is their at-risk status, as they are witnessing and providing to a parent with a disease that they may later experience.

## Clinical implications

Globally, there is a need for greater recognition, supported by evidence-based policies, that acknowledge young carers and the responsibilities they undertake. Professionals need to recognise young carers' fear of repercussions, especially regarding social care interventions and that young carers may, therefore, be mistrustful of them. Tact and rapport-building are essential for supporting young carers. One study on young carers' experiences with services found that support is appreciated, particularly when they feel listened to, included in decision-making, and when there is a focus on well-being rather than solely safeguarding (Stevens et al., 2024).

It is crucial to consider all individuals within the family system, especially in the context of HD, where the affected parent's insight may be compromised (Ho et al., 2006). The perspectives of young carers may provide accurate, person-centred information about how the parent with HD presents. This can help provide the best care for the affected parent by ensuring their healthcare team is fully aware of their current difficulties. It would also support the young carer's wellbeing by involving them in decision-making (Phelps, 2021). Having a systemic perspective on chronic illness has also been shown to benefit families in other ways; For example, research on family narratives in the context of chronic illness found that families relied on one another in managing challenges, with positive interactions supporting the maintenance of hope and optimism (Leite et al., 2021).

Support groups can help reduce feelings of isolation and misunderstanding (Hendricks et al., 2024). For example, young carers' services can offer opportunities to connect young carers to foster recognition that they are not alone (Phelps, 2021). Furthermore, this could enhance social experiences and potentially aid in the formation of self-identity.

## Future research

Future research is imperative for us to gain more detailed understanding of and therefore more effective support for young carers of people affected by HD. A potential future research area is whether HD young carers who receive support experience less impact on their educational, social, and emotional development compared to those who do not. Preliminary qualitative research in Phelps (2021) suggests this but specific HD, longitudinal, quantitative studies are lacking. Further research into the concept of self-identity and 'master' identity among HD young carers could offer insights into whether, how and when identity formation is affected. It could also be compared with non-young carers to understand if there are differences in identity development between the groups.

Future research could assess the usefulness of living in the present versus planning for the future, as this could help identify interventions that support young carers in managing emotional distress related to caring for a parent with HD. While currently no individual interventions for young carers in HD families are evidence-based (Zarotti et al., 2020), one potential intervention is Acceptance and Commitment Therapy. This has been shown to support individuals with chronic health issues and their carers (Han & Jenkins, 2021; Konstantinou et al., 2023) with some preliminary work in Huntington's disease (Buswell et al., 2025; Schriger et al., 2025). However, individual therapy is unlikely either to be accessible or accessed by many young people (Zarotti et al., 2022) so systemic solutions and public and health professional education campaigns are likely to be more effective for young carers.

## Limitations

All papers included in this review were from high-income countries, which means the findings cannot be generalised internationally. Welfare and healthcare systems differ, which influences the support and treatment of HD. Additionally, countries have varying cultural beliefs; for instance, HD may be underdiagnosed in Asian countries due to the prevalence of stigma towards genetic illnesses (Papanna et al., 2022). This may mean Asian young carers experience higher levels of stigma, which are not captured in this review. For the purpose of this review, a young carer was defined as being 25 years of age and under; this means that differences between adolescent and adult young carers were not considered. While sufficient studies do not currently exist to support a more granular examination across the age groups, given the significant development individuals experience at this time, differences are likely (Scales et al., 2015). Finally, the CASP identified a lack of reflexivity in the papers, suggesting that the authors' beliefs and experiences may have affected their findings, in turn influencing the results of this review.

## Conclusion

In conclusion, although young carers for a parent with HD face many similarities to young carers of a parent with a chronic illness, societal – and including health and social care professional - awareness of the role played by young carers for a parent with HD is limited. This restricts these young carers' ability to access support and leads to feelings of isolation and being undervalued. Young carers for a parent with HD take on increased responsibilities within the family, impacting their development and future, and often causing them to sacrifice experiences that would support their identity development. Throughout their experiences, these young carers are reminded that they are at risk of inheriting HD, which affects their ability to envision a future beyond caregiving.

## Author Contributions

Authors Lewis Pares, Fiona Eccles, Maria Dale and Jane Simpson all contributed to this work. Lewis Pares as the first author made substantial contributions to the collection, analysis and interpretation of the data. However, this was heavily supported by the other authors. All authors made substantial contributions to drafting the work for publication.

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## Conflict of Interest Statement

The authors report there are no competing interests to declare.

## Data availability statement

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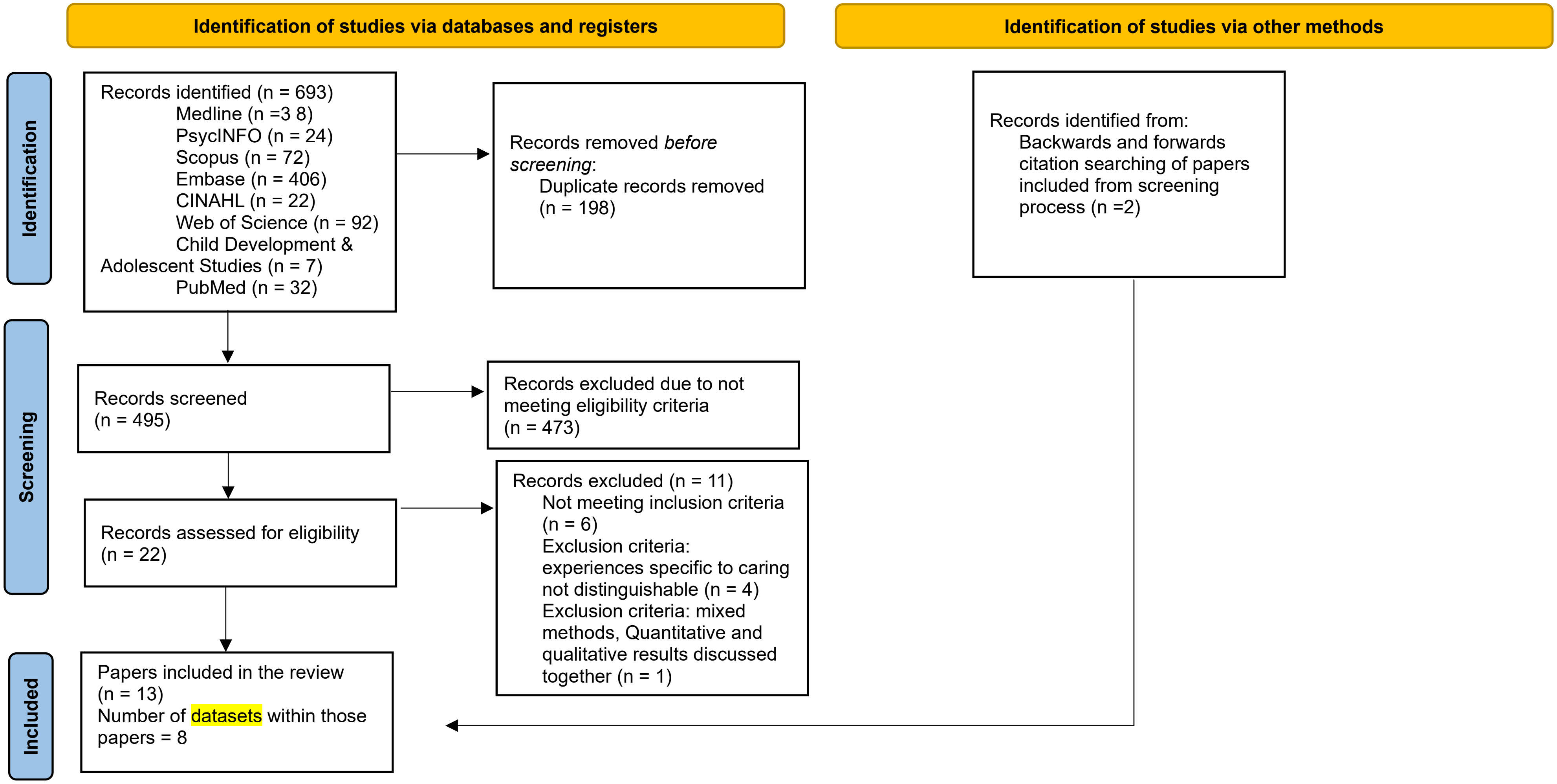
**Figure 1 -** ***PRISMA diagram to outline research paper identification***



Source: Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Clinical research ed.)*, *372*, n71. https://doi.org/10.1136/bmj.n71

Accessible at: https://www.prisma-statement.org/prisma-2020-flow-diagram

**Table 1** - ***Example Systematic Search Strategy (Medline)***

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| (Huntington's Disease) | (MH "Huntington Disease") OR TI Huntington* OR AB Huntington* |
| (young person) | ( (MH "Child+") OR (MH "Adolescent") OR (MH "Adolescent Behavior") OR (MH "Psychology, Adolescent") OR (MH "Only Child") ) OR TI ( children OR adolescent* OR youth* OR child* OR teenager* OR son* OR daughter* OR parentification OR "young person" ) OR AB ( children OR adolescent* OR youth* OR child* OR teenager* OR son* OR daughter* OR parentification OR "young person" ) |
| (Carer) | ( (MH "Caregiver Burden") OR (MH "Caregivers") ) OR TI ( carer* OR caregiver* ) OR AB ( carer* OR caregiver* ) |
| (combining searches) | S1 AND S2 AND S3 |

Please note that searches differed depending on the search functions of the databases.

**Table 2 -** ***Contribution of individual papers to analytical themes***

| Analytical Themes | Daemen et al., 2024 | Dondanville et al., 2019 | Forrest Keenan et al., 2007 | Hendricks et al., 2024 | Kavanaugh, Noh and Studer, 2014 | Kavanaugh, Noh and Zhang, 2016 | Kjoelaas, Jensen and Feragen, 2022a | Kjoelaas, Jensen and Feragen, 2022b | Kjoelaas, Jensen and Feragen, 2020 | Mand et al., 2015 | Røthing, Malterud and Frich, 2014 | Sparbel et al., 2008 | Williams et al., 2009 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Theme 1** | X | X | X | X | X | X | X | N/A | N/A | X | X | N/A | X |
| *Theme 2** | X | N/A | X | X | X | X | N/A | X | X | X | X | X | X |
| *Theme 3** | N/A | X | X | X | X | X | N/A | N/A | X | X | X | N/A | X |

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*Theme titles:

Theme 1: *Lack of awareness, undervalued and unsupported, barriers to young carers accessing support*

Theme 2: *Adult responsibilities: impact on developmental stages and worrying about the future*

Theme 3: *Engaging with the future or living in the present, managing the impact of being a young carer while at risk of HD*

**Table 3 -** ***Study Characteristics***

| Author | Title | Country of Origin | Participants | Methodology | Aims | Findings |
|---|---|---|---|---|---|---|
| Daemen et al., 2024 | Through their eyes: A retrospective mixed-methods study on the experiences and support needs of children growing up with a parent with Huntington's disease | Netherlands | 13 individuals aged 18-35, 1 male and 12 females, recruited from specialised HD clinics and social media | focus group with a semi-structured topic list<br>Inductive thematic analysis with a descriptive phenomenological approach | This study aims to offer an in-depth understanding of the multifaceted impact of growing up with a parent with HD, examining the needs for professional guidance on emotional and social aspects, and identifying specific areas where support can be | Three main themes;<br>1) Experiences and impact of growing up with a parent with HD, 2) Experiences gained with help and support, 3) |

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| | | | | | improved to better aid them. | Advice and support needs |
| Dondanville et al., 2018 | “This could be me”: exploring the impact of genetic risk for Huntington’s disease young caregivers | USA | 13 individuals aged 15-25, 2 males and 11 females, recruited from Huntington's disease Youth Association and Huntington's disease society of America | semi-structured interviews<br>An inductive data-driven approach for analysis with the goal of generating representative themes from the data gathered | To understand; (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? | Two main themes;<br>(1) caregiving evokes thoughts and emotions related to the caregiver’s personal genetic risk and<br>(2) caregiving impacts young caregivers’ |

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| | | | | | | perceived opinions towards pursuing genetic testing. |
| Forrest Keenan et al., 2007 | Young people's experiences of growing up in a family affected by Huntington's disease | UK (Scotland) | 33 individuals aged 9-28, 21 females and 12 males, recruited from genetic clinics and the Scottish Huntington's Association | semi-structured interviews<br>Thematic analysis | This study aims to describe the experiences of YP in families affected by HD and to use the findings to inform the development of effective strategies to help potentially vulnerable YP. | Four main themes;<br>1)<br>YP as carers, 2) Worried well, 3) Those who cope. 4) At risk/in need |

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|  |  |  |  |  | Specifically, we explored (1) how participants found out about in the family; (2) their perceptions of their own risk; (3) any protective or risk factors they encountered; (4) any caring activities they under-took; and (5) the impact of HD on their relation-ships with siblings, parents, extended family |  |

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|  |  |  |  |  | members, and the wider community |  |
| Hendricks et al., 2024 | “Man, this Isn’t easy”: exploring the manifestation of parentification among young carers of a parent with Huntington’s disease | USA | secondary data analysis; N=40 in the original study recruited from the Huntington's Disease Society of America, but a sample of 28 (aged 10-20, 22 females | Secondary data analysis of semi-structured interviews<br>content analysis | To explore the manifestation of parentification among young carers of a parent with HD. | Three main themes:<br>1) Being a young carer, 2) Living with a new normal, 3) Facing HD as a young carer |

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| | | | and 6 males) were chosen for this, including only those who had consented and been audio recorded | | | |
| Kavanaugh, Noh and Studer, 2014 | “It’d be nice if someone asked me how I was doing. Like, ‘cause I will have an answer”: exploring support | USA | 40 individuals aged 10-20, 31 females and 9 males, recruited from the Huntington's | interviews,<br>conventional content analysis | This study aims to seek answers to two exploratory research questions: (1) what types of social support are viewed helpful by young carers in caring | Three main categories: 1) Instrumental support, 2) Emotional Support, 3) Personal needs |

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| | needs of young carers of a parent with Huntington’s disease | | Disease Society of America directly and their conventions | | for their parent with HD, and (2) what support do they feel they need but do not have. | |
| Kavanaugh, Noh and Zhang, 2016 | Caregiving youth knowledge and perceptions of parental End-of-life wishes in Huntington’s disease | USA | 40 individuals aged 10-20, 31 females and 9 males, recruited from Huntington's Disease Society of America | interviews, conventional content analysis | The purpose of this study is to provide an initial exploration into what caregiving youth know about their parent’s advance care planning and their experiences with having | Two main categories: 1) Reasons to want or not want EOL discussion with the parent, 2) Reasons to not want discussion |

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| | | | directly and their conventions | | EOL discussions with the parent. | with the parent about possibility of death |
| Kjoelaas, Jensen and Feragen, 2022a | Social support experiences when growing up with a parent with Huntington's disease | Norway | 36 participants, aged 13-65, 26 females and 10 males, recruited via genetic clinics, genetic counselling services, social media and the | semi-structured interviews<br>thematic analysis | This study aimed to investigate what current and past experiences young people who grow up with a parent with HD have with social support outside the parent–child context. | Five main themes:<br>1) I felt connected to someone, 2) I learned how to cope, 3) I got a break from reality, 4) My needs for support were |

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|  |  |  | Norwegian Association for Huntington's Disease |  |  | not understood, 5) I did not know if involving others would help |
| Kjoelaas,Feragen and Jensen, 2022b | ‘I knew it wasn’t normal, I just didn’t know what to do about it’: adversity and caregiver support when growing up in a family with Huntington’s disease | Norway | 36 participants, aged 13-65, 26 females and 10 males, recruited via genetic clinics, genetic counselling services, social | semi-structured interviews<br>Interpretative phenomenological analysis (IPA) | This study aimed to explore adverse childhood experiences (ACEs) of individuals who grew up with a parent with HD and their perceptions of caregiver support. | six main themes"<br>1) I never knew what to expect, 2) You lose them over and over again, 3) I was scared all the time, 4) I had to take care |

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| | | | media and the Norwegian Association for Huntington's Disease | | | of myself, 5) Nowhere to turn, 6) Having a lightning rod |
| Kjoelaas, Jensen and Feragen, 2020 | The ripple effect: A qualitative overview of challenges When growing up in families affected by Huntington’s disease | Norway | 36 participants, aged 13-65, 26 females and 10 males, recruited via genetic clinics, genetic counselling services, social | semi-structured interviews<br>thematic analysis | This study explored the risks of growing up in a family affected by HD, and provided a participant-generated overview of the main challenges the participants experienced, in order to enhance awareness and | Four main themes:<br>(1) family functioning, (2) emotions and reactions, (3) social functioning, and (4) public |

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| | | | media and the Norwegian Association for Huntington's Disease | | promote more youth-focused support. | and care services |
| Mand et al., 2015 | “I’m scared of being like mum”: The experience of adolescents living in families with Huntington disease | Australia | 10 individuals aged 13-20, 6 females and 4 males, recruited from a genetic centre | semi-structured interviews<br>thematic analysis | This study explores the psychosocial context of young people living in families affected by HD, to better understand their experiences and the specific challenges they face. | five main themes:(1) Impact of an unwell parent; (2) Complicated families; (3) Being a teenager living in a family |

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| | | | | | | affected by HD; (4) The experience of living at risk; (5) Thoughts concerning predictive testing. |
| Røthing, Malterud and Frich, 2014 | Caregiver roles in families affected by Huntington's disease: a qualitative interview study | Norway | 15 individuals aged 20-67, 12 females and 3 males, recruited from hospitals and | semi-structured interviews<br>systematic text condensation (STC), a method for cross- | The objective of this study was to explore family caregivers' experiences with the impact of Huntington's disease (HD) on the | Three main themes:<br>1) Transitions of family members' roles and changes in relationships, 2) |

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|  |  |  | a HD organisation | case thematic analysis | family structure and roles in the family. | Family caretakers must adjust to mixed feelings, 3) The family network becomes vulnerable and fragmented |
| Sparbel et al., 2008 | Experiences of teens living in the shadow of Huntington disease | US and Canada | 32 participants, aged 14 to 18, 23 females and 9 males, recruited from HD centres | 6 focus groups.<br>Narrative analysis | The purpose of this study was to explore the experiences of teens living in families with HD by asking them, while they were still teens. | Four main themes:<br>(1) watching and waiting; (2) alone in the midst of others; (3) family life is |

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|  |  |  |  |  |  | kind of hard; and (4) having to be like an adult |
| Williams et al., 2009 | Caregiving by teens for family members with Huntington disease | US and Canada | 32 participants, aged 14 to 18, 23 females and 9 males, recruited from HD centres | 6 focus groups.<br>descriptive analysis | The purpose of this report is to examine caregiving responsibilities assumed by teens in families of persons with HD. | Four main themes: 1) Tasks and Responsibilities, 2) Subjective Burden, 3) Caregiving in the Context of Personal Risk for HD 4) |

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| | | | | | | Decisional<br>Responsibility |

**Table 4 -** ***CASP results***

| CASP Questions | Daemen et al., 2024 | Dondanville et al., 2019 | Forrest Keenan et al., 2007 | Hendricks et al., 2024 | Kavanaugh, Noh and Studer, 2015 | Kavanaugh, Noh and Zhang, 2016 | Kjoelaas, Jensen and Feragen, 2022a | Kjoelaas, Jensen and Feragen, 2022b | Kjoelaas, Jensen and Feragen, 2020 | Mand et al., 2015 | Røthing, Malterud and Frich, 2014 | Sparbel et al., 2008 | Williams et al., 2009 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Was there a clear statement of the aims of the research? | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |

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| Is a qualitative methodology appropriate? | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |
| Was the research design appropriate to address the aims of the research? | yes | can’t tell | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |

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| Was the recruitment strategy appropriate to the aims of the research? | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |
| Was the data collected in a way that addressed the research issue? | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |

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| Has the relationship between researcher and participants been adequately considered? | can't tell | can't tell | can't tell | yes | can't tell | can't tell | yes | yes | yes | can't tell | can't tell | can't tell | can't tell |
| Have ethical issues been taken into consideration? | yes | yes | yes | can't tell | yes | yes | yes | yes | yes | yes | yes | yes | yes |

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| Was the data analysis sufficiently rigorous? | yes | can’t tell | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |
| Is there a clear statement of findings? | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |
| How valuable is the research? | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes | yes |

**Appendix 1 - *Descriptive themes with codes***

| Descriptive Themes | Codes |
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| Barriers to support | A lack of informational support for young carers<br>A lack of recognition or understanding of how much support young carers provide<br>Difficulty recognising the need or asking for support<br>Not enough time to provide support<br>The importance of social support<br>unable to access support due to being a child<br>Useful information for professionals when they are assessing caregiving<br>Support can make young carers feel not normal |
| Caring responsibilities | Caring responsibilities |
| Communication within the family unit | A need for patience from young carers as communication is difficult for parent with HD<br>Conversations around the end of life were not had<br>Less openness, resulting in emotional conflict<br>Not included in decision-making as they are not adults<br>Taboo to discuss testing within the family |

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| Effects of being at risk while caregiving | Being at risk made caregiving harder<br>Being at risk made young carers more caring<br>Caregiving causes emotional distress about being at risk<br>It influences testing<br>Not placing blame on parent with HD<br>Suppressing thoughts about the future<br>The young carer empathises with the parent |
| Impact of being a young carer | Being at risk of harm or neglect<br>Concealing their difficulties from others<br>Difficulties getting their own needs met<br>Effects of parent being stigmatised<br>Financial strains on the whole family unit<br>Impact on attending school or completing schoolwork<br>The emotional impact of providing care<br>Feeling that they were not normal<br>How they coped with being a young carer<br>Thoughts about end-of-life care<br>The impact on friendships |
| Parentification of the young carer | Lack of a traditional parent-child relationship<br>Learning to be a carer<br>No room to be a child |

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| | Protecting the parent |
| Positive aspects of caregiving | How I can be helped in the future<br>If it were not genetic, they would still provide care<br>Maturity-Resilience |

**Appendix 2** - ***Development of Analytical themes from Descriptive themes***

| Analytical Themes | Descriptive Themes |
|---|---|
| *Lack of awareness, undervalued and unsupported, barriers to young carers accessing support* | Barriers to support<br>Caring responsibilities<br>Communication within the family unit |
| *Adult responsibilities: impact on developmental stages and worrying about the future* | Caring responsibilities<br>Parentification of the young carer<br>Impact of being a young carer |
| *Engaging with the future or living in the present, managing the impact of being a young carer while at risk of HD* | Effects of being at risk while caregiving<br>Positive aspects of caregiving |