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Retrospective meaning-making of multifaceted care among Finnish former young carers

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ABSTRACT

This article analyzes experiences of caring in the accounts of Finnish former young carers. The data consists of retrospective interviews (N = 23) with people aged 20–49 whose childhoods have been shadowed by a parent's mental health disorder and/or substance abuse issues. The research questions of this article are: (1) How do former young carers describe the care they have given during childhood and adolescence? (2) How do they reframe these experiences in the present? Our interpretative analysis combines thematic and narrative methods and focuses on responsibilities embedded in caring, forms of emotional care, and the ways the research participants retrospectively constructed meaning and made sense of their experiences. Our analysis shows how emotional care expands beyond the dyadic relationship between the child and the ailing parent, to the ways in which the former young carers perform emotion work in relation to themselves, other family members, and broader social surroundings. Interviewees reframed their experiences through the epistemic dimension (characterized by limited knowledge, understanding, awareness, and language to make sense of and articulate their experiences as they were unfolding), the moral-affective dimension (including moral obligation, family loyalty, and fear), and the structural-practical dimension (marked by a care void within the family).

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Care; Finland; former young carers; retrospective interviews; young carers

Introduction

This article focuses on the experiences of caring in the accounts of Finnish former young carers. 'Young carers' are a group of children and young people who provide care, support, help, and/or assistance to a family member or kin on a regular basis. They can be either supportive or main carers, and their caring roles can include domestic tasks as well as intimate and emotional care (Kennan et al. 2012). What is characteristic of young carers and distinguishes them from other children and young people, is that these caring responsibilities affect their lives in a significant way (Kennan et al. 2012;

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Aldridge & Becker 1993, 2003), as the caring provided by young carers entails significant temporal, physical, mental and/or emotional demands.

Research on young carers has been conducted for over 30 years, with seminal research by Aldridge and Becker (1993) considered as the starting point. There is a growing body of research on young carers, which has recently focused on issues such as the life-course impacts of caring (Silverman et al. 2020), wellbeing and perceived stress (Wepf & Leu 2022), and mental and physical health (Robison et al. 2020) of young carers. However, there is less research on former young carers, even though the recent decade has seen progress in research focusing on those recalling their caring childhoods (Szafran et al. 2016; Nagl-Cupal et al. 2015; Roling et al. 2020; MacDonald & McLaughlin 2024). Furthermore, only a few of these studies have focused on the experiences of former young carers of parents with mental health disorders and/or substance abuse issues (MHD/SA) (c.f. Yuan & Ku 2024a; 2024b; Blake-Holmes 2020).

Until recent years, current and former young carers have remained a largely invisible social group in Finland (Sihto & Hokkila 2021, 2023, Helenius et al. 2024). Leu and Becker (2017) and Leu et al. (2023) have analyzed the level of awareness and policy responses to young carers in different countries, using a scale from one (sustainable) to seven (no response). In 2017, Finland was classified as a level six country, which was just awakening to the issues concerning young carers (Leu & Becker 2017). In 2021, Finland had progressed to a level five country, characterized as 'emerging' with a small but growing research base, some local projects and service pilots, and NGOs working to raise awareness (Leu et al. 2023). However, Finland still lacks specific legislation, policies, and targeted support and services for young carers, even though the number of young carers in Finland bears resemblance to other countries in which around 2–8% of minors can be considered young carers (Joseph et al. 2020). According to a nationally representative School Health Promotion Study conducted in 2023, 2.8% of eighth and ninth graders (aged 14–16) in Finland provide care on a daily or near-daily basis for a family member or kin, and 6.3% have at least weekly caring responsibilities (Helenius et al. 2024).

In this article, we analyse retrospective interviews with Finnish former young carers who have cared for a parent with MHD/SA. We decided our focus mainly for three reasons: (1) the prevalence of MHD/SA in Finland. Around 8.7% of Finnish minors have at least one biological parent with a serious substance abuse problem before the child turns 18 (Raitasalo 2024). It has been estimated that around 20% of children have a parent that has received specialized psychiatric care during their childhood or adolescence (Ristikari et al. 2016). (2) Research on care and young carers still has quite a heavy focus on caring for people with somatic illnesses or physical frailty. (3) Focusing on caring for a person with MHD/SA gives the opportunity to explore the particularities of these caring situations and relationships in more depth. As noted by Joseph et al. (2020), much of the existing literature on young carers merges their experiences into a single framework, failing to provide a nuanced understanding of caregiving for different types of illnesses and other care needs.

In our analysis, we adopt a broad understanding of the concept of 'care' (see Tronto 1993), which does not limit care to private, instrumental, or individual acts, but further emphasizes its social and relational dimensions. This article also sheds light on the situation of Finland, which is still in an emerging phase regarding policy attention and support measures concerning young carers (Leu et al. 2023). Our study contributes to the conceptual discussion of care provided by adolescents and produces one of the first insights into care provided by minors in Finland.

Caring for a parent with mental health disorder and/or substance abuse issues

The research on former young carers has largely focused on the consequences of caring for the later lives of former young carers. According to these studies (e.g. MacDonald & McLaughlin 2024), some of the consequences of being a carer during childhood and adolescence are reflected positively into adulthood, with former young carers emphasizing resilience, self-growth, and close ties with family members. However, research has also highlighted the adverse consequences of caring, such as negative school experiences, mental strain, and social withdrawal (e.g., Roling et al. 2020; Szafran et al. 2016).

Some studies have analyzed the experiences of young adults who are currently caring for a parent with MHD (e.g. Blake-Holmes 2020), while other studies (Yuan & Ku 2024a; 2024b) have taken a retrospective perspective. Among young carers, those who care for a parent with MHD/SA are in a particularly vulnerable position. This group of young carers faces many of the same challenges as other young carers, such as not being recognized and not receiving adequate forms of support. However, when caring for a parent with MHD/SA, some of these challenges are intensified. Due to the pronounced stigma related to MHD/SA, these young carers often remain largely hidden from the service system, their social surroundings and even to themselves, and thus face a high risk of being marginalized across various life domains (Yuan & Ku 2024a; 2024b). Children of parents with MHD do not necessarily see themselves as carers, and neither do the parent(s) acknowledge that their child has become their carer (Cooklin 2010). Consequently, due to this extreme invisibility, understanding the experiences of this group and providing support and services for them is essential (see Yuan & Ku 2024b).

As noted by Blake-Holmes (2020) and Moore et al. (2011), quantifying care in the context of caring for a parent with MHD/SA can be difficult. One quantifying measure has been the MACA-YC18 (Joseph et al. 2009), an 18-item self-report measure that is used to provide an index of the total amount of caring provided by a young person. The MACA-YC18 divides the caring tasks done by young carers into six domains: (1) personal care; (2) sibling care; (3) domestic chores; (4) emotional care; (5) household management; and (6) financial/practical support. For young carers, personal care such as bathing or dressing the other person are often seen as the most difficult caring tasks, whereas domestic chores are the most time-consuming tasks (Lackey et al. 2001). Typically, these more practical forms of care are easier to measure (for example in terms of weekly hours devoted to care), when compared with emotional care, which in the MACA-YC18 includes aspects such as keeping an eye on someone you live with to make sure that they are alright (Joseph et al. 2009).

However, it could be argued that young carer’s emotional care is a more complex and multidimensional phenomenon, extending beyond what can be captured with the MACA-YC18. Prior research (e.g. Berardini et al. 2021; Chikhradze et al. 2017; Aldridge 2008; Szafran et al. 2016) implies that young carers often employ challenging emotional strategies to maintain family stability and show compassion to the family member with care needs – forms of emotion work that can lead to long-term emotional exhaustion, internalized stigma, and difficulties in self-expression during adulthood. At the same time, this emotion work may cultivate young carers' resilience and empathy, highlighting its ambivalent impact (Joseph et al. 2009). Given these complex and lasting effects, further research is crucial to unpack how young carers navigate and make sense of their emotional responsibilities. Taking into consideration the often-unpredictable nature of parental MHD/SA (e.g. Muir et al. 2023; Yamamoto and Keogh 2018), this offers a relevant context for an in-depth exploration of emotional care and the emotion work carried out by young carers.

Following the definition by Hochschild (1979, 561), in this article we understand emotion work as 'the act of trying to change in degree or quality an emotion or feeling', either in relation to self or others. When defining care, we follow the broad definition proposed by Tronto (1993, 103), who defines care as 'everything we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment'. Relying on this definition (Tronto 1993), we aim to shed light on the more invisible aspects of care and caring. However, we simultaneously remain cautious about the use of the concept, and wary of labeling all interactions or forms of reciprocity between humans as 'care'.

In this article, we analyze the experiences of caring in the accounts of Finnish former young carers. Our research questions are: (1) How do former young carers describe the care they have given during childhood and adolescence? (2) How do they reframe these experiences in the present? By analyzing evolving meanings relating to care experiences, we aim to gain a deeper insight into sensemaking processes regarding childhood caregiving experiences and their perceived impact. Given Finland's inadequate recognition of minor's caregiving roles, it is important to provide a deeper understanding of the societal meaning making processes of these experiences, in order to guide the development of policy and services for young carers.

Data & methods

The data of this article consists of retrospective interviews (N = 23) conducted in 2021. Interviewees were recruited through an online and social media call originally made for a non-fiction book by the second author and her collaborator, focusing on childhood affected by a parent's serious illness or death. At a later stage, the interviewees were informed about the second author's research for her doctoral dissertation and asked whether they would give their consent for the interviews to be used for this purpose as well. All the interviewees gave their informed consent.

Given the lack of awareness concerning young carers in Finland (Leu et al. 2023), using the term 'young carer' in the call would likely have made it more difficult to reach potential interviewees. The original call was more broadly directed at individuals who had experienced being children as next of kin (Järkestig Berggren & Hanson 2016). However, we chose to focus specifically on descriptions of care in the interview accounts. Consequently, we excluded interviews where care was not a prominent theme. It is also important to note that a parent's MHD/SA does not automatically result in children assuming a caring role. As proposed by Aeyelts et al. (2016), we understand minors becoming carers for a parent with MHD/SA as often being triggered by a combination of disorder(s) and/or addiction with a lack of support from society, community, and/or other family members and kin.

We also excluded from our data the interviews where somatic illnesses (SI) were the primary concern. While seven of the participants in our data had a parent that also had somatic issues, their interviews were included in the analysis as their care narratives explicitly centered on parental MHD/SA. This determination was also guided by open-ended scoping questions in the beginning of the interview to detect the main care narrative such as: *Could you describe your childhood/adolescence? What kinds of things burdened it and in what ways?*

The included participants were aged between 20 and 49. Information on the interviewees can be found in Table 1. Some of the interviewees were still caring for their parents, although in many cases, the parent's MHD/SA had eased over time, or the parent had passed away. However, for all interviewees, the caring relationship with the parent had seen some kind of change over time.

Our approach is retrospective, where the interviewees are 'looking back' at their childhood experiences, offering the interviewees an opportunity to reflect on their childhood, adolescence, and present. Remembering one's childhood and adolescence in adulthood can facilitate the integration of past experiences and memories into a wider context of one's life course (McAdams 2001). Children growing up with parental MHD/SA are known to be reluctant to disclose their experiences and their caring roles due to the secrecy of the familial situation (Aldridge & Becker 2003; Murphy et al. 2017). Also, from a development point of view, it can be easier to reflect and articulate experiences at an older age than during childhood or youth (McAdams et al. 2006; Kaimal & Beardslee 2010). Moral and normative understandings concerning family relationships evolve alongside age and maturity, as individuals (re)interpret their past experiences from new

Table 1. Information on the interviewees.

Pseudonym	Age group	Gender	The ailing parent(s) and the care needs
Daniel	25–29	M	Father with MHD/SA
Kristina	20–24	F	Mother with SA
Olivia	20–24	F	Mother with MHD/SA
Helena	45–49	F	Father with MHD/SA
Linda	45–49	F	Father with MHD/SA (+ SI) and mother with MHD
Anna	40–44	F	Mother with MHD/SA (+SI)
Emma	35–39	F	Mother with MHD/SA
Erika	40–44	F	Mother with MHD
Maria	30–34	F	Mother with MHD/SA
Sofia	30–34	F	Mother with MHD/SA (+ SI) and father with SA
Noora	20–24	F	Mother with MHD/SA (+ SI)
Julia	20–24	F	Mother with MHD/SA
Vanessa	45–49	F	Mother with MHD
Stella	20–24	F	Mother with MHD/SA
Elisa	35–39	F	Mother with MHD (+ SI) and the father with MHD
Ella	35–39	F	Father with MHD/SA (+ SI)
Mikael	30–34	M	Father with SA and mother with MHD
Heidi	25–29	F	Mother with MHD
Johanna	30–34	F	Father with MHD
Leo	35–39	M	Father with MHD and mother with SA
Stella	40–44	F	Mother with MHD
Amanda	40–44	F	Mother with MHD
Sara	30–34	F	Father with MHD/SA (+ SI)

perspectives informed by cognitive, emotional, and social development (Killen & Smetana 2006). This temporal and psychological distance allows for reflexivity, enabling individuals to articulate the significance of past events in ways they might not have been able to do at the time these events were unfolding.

The interviews were biographical in the sense that they covered the interviewees' whole life course. The interview themes explored interviewees' descriptions of their childhood circumstances, their roles in relation to their family members, their school, social relationships, family, and career trajectories, and the perceived impacts their childhood and youth have had on them. To guide the interview, we used open-ended questions such as: *Could you describe your family relationships and close circle? What kind of relationship did you have with your parents? How would you describe your role in your childhood family? How would you describe your everyday life; being at home, going to school, hobbies, friends, etc.?* Follow-up questions were asked to clarify their descriptions and reflections and explore the experiences the interviewees brought up. The interviews were audiotaped and transcribed verbatim. The transcripts were cleaned to remove personally identifiable information, and interviewees were assigned pseudonyms to protect their identity.

Our analysis includes only descriptions of events that, according to interviewees' recollections, occurred when they were minors. However, determining the exact age at which caregiving took place is challenging, as many participants experienced prolonged burden throughout their childhood and adolescence. We made a choice to start our interpretative analysis by first concentrating on the narratives of care with the question 'what' is told about care, applying the 'Trontoan' perspective of care. Accounts that we understand as describing the ways their 'world' was maintained, continued and/or repaired in their everyday lives with parental illness were in focus. The data was first analyzed thematically, inductively identifying unifying themes and patterns (Braun & Clarke 2006) concerning the experiences and meanings we understood as attached to care. This allowed us to consider multiple cases concerning this phenomenon and search and code identifying themes to formulate common retrospective stories (Riessman 2008) about care. This phase meant reading and re-reading the data set and coding the emerging themes.

Secondly, we analyzed the data set by focusing more deeply on 'how' interviewees narrated and made sense of their care experiences (Riessman 2008), paying attention to temporal shifts in perspective. Rather than treating narratives as fixed or focusing on their form, we examined how individuals (re)interpret and (re)frame past care experiences over time. We became attentive to how participants positioned (Bamberg 2004) their childhood selves in narrating and making sense of their care experiences. Applying an experience-centred narrative approach also allowed us to gain insight into the societal underpinnings that shape these interpretations (Squire 2008). Drawing on these narrative approaches, we aimed at gaining a deeper understanding of how interviewees made sense of their childhood and youth retrospectively, and how they perceive the consequences of these experiences.

Our interpretative approach acknowledges that the experiences described by our interviewees do not solely reflect 'the reality out there', but more 'the reality inside' in the interviewees' constructions of themselves. From a realist standpoint, one could say that retrospective accounts represent how, in the case of this study, adults remember their past as the child of an ailing parent, which inevitably differs from how a child, or an adolescent would narrate their experiences with an ailing parent as the situation is unfolding. As noted by Scott and Alwin (1998), memories of the past, and the explanations and justifications given to the past, are likely to be influenced by subsequent outcomes and present circumstances. However, we argue that our findings also reveal something important about young carer's realities 'out there' that need to be acknowledged and used to inform the development of support and services for them.

Results

The main findings of the analysis include (1) the multifaceted nature of care, which extends beyond the dyadic relationship between the child and the ailing parent to include other family members and the social environment. While participants described taking concrete responsibility for others and themselves, (2) emotional care emerged as a central and complex phenomenon. (3) In adulthood, the interviewees reframed their experiences as shaped by necessity, loyalty, fear, and stigma, retrospectively recognizing the personal cost of their caregiving roles.

Multifacetedness of care

Caring had taken on many forms in the interviewees' adolescence. The nature of the caring relationship, as well as the duration and intensity of caring varied. Caring did not necessarily only include caring for the ailing parent but also caring for siblings and often also caring for the healthy, but burdened, parent. Caring was also directed at one's social surroundings and 'keeping up appearances', taking actions to ensure that the family situation is not revealed outside of the family – which we understand as aiming to 'maintain, continue and repair' the 'world' (Tronto 1993, p. 103) of our interviewees.

Descriptions of concrete, practical caring activities (*caring for*) performed in relation to the ailing parent were less common than descriptions of emotional care (*caring about*), containing significant amounts of mental and emotional work. This was due to the interviewees' parents primarily having MHD/SA, and thus not necessarily needing physical forms of care. This was also reflected in how the interviewees described their roles and actions in relation to their families. Only a few of them used the direct Finnish word for care (*hoiva*) which is usually used to refer to physical forms of care. Instead, the interviewees used Finnish phrases for *taking responsibility, looking after,* or *being on one's guard*.

Taking concrete responsibility

Interviewees frequently described themselves as the only reliable or functioning person in their childhood family, which meant they took significant responsibility for other family members and themselves. The descriptions of practical ***caring for the ill parent*** took many forms. In the most extreme examples, interviewees described caring as trying to keep their suicidal parent alive. Some of the interviewees described practical caring activities such as helping the parent with their medication, or making sure the parent took care of their own responsibilities; for example, going to get the parent from a bar so that the parent would be able to go to work the next day. Concrete activities also involved taking care of daily chores. As described by Noora:

> There have been kinds of days that my mom has been so hung over that I have had to go do the groceries, and I have had to do everything, I have made sure that my mom gets food that day as well.

Especially in situations where the parent's MHD/SA was associated with violent or threatening behavior, the interviewees described their concrete actions to ***protect younger siblings***, whose safety and wellbeing they felt responsible for. Sofia described this as follows:

> I never let her [Sofia's mother] get past me. Like, if she did manage to get past, I remember many times grabbing her from behind or something like that – because I felt that in those moments, it was justified to use physical force. That somehow, it was okay then. That I was allowed to grab her hand and pull her away when she was going after my sister.

Several interviewees described how they had been ***responsible for taking care of themselves*** in ways that they now interpreted to be rare for minors, for example carrying more responsibility for their schooling and everyday lives than their peers did. Maria described this responsibility as 'being the kind [of responsibility] that it is normal for parents to do, support their children in schooling, hobbies, emotional skills, in life'. Consequently, bearing the responsibility for oneself included concrete tasks such as learning to prepare food for oneself or getting to school on their own, but also less concrete issues such as learning emotional skills or coping with the responsibilities of school by themselves.

Interviewees also provided extensive descriptions of their concrete actions to keep the family situation hidden from outsiders, especially from the authorities. This entailed demanding and carefully planned concrete actions to ***perform*** 'normality' as described by Emma:

> When she [child protection worker] said she was coming over, we cleaned the place up – usually me and my brother – and we baked cinnamon buns. […] And then I'd sit there and, even from a really young age, I already knew how to talk, like, 'Everything's fine, things have been really nice for us'.

Emotional care

Interviewees provided extensive descriptions about the mental and emotion work required from them to maintain 'balance' in the family, to make family members feel safe, and not to cause additional 'burden' at home. The distinction between emotional and concrete care was that emotional care was often directed not only at the ailing parent, but at the healthy parent as well.

The interviewees often described ***emotional care for the ailing parent.*** This entailed listening, consoling, and cheering up the parent. Several interviewees described how they as adults have realized that the parent's condition had blurred the parent's understanding of what is suitable for parents to share with children. The interviewees also described taking self-initiated strategic actions to prevent the parent's mental state from deteriorating. This was also seen as a means to protect themselves and other family members, as the ailing parents' worsened mood could mean threatening or unpleasant situations in the family. The interviewees described relying on tacit knowledge when aiming to 'read' (Hämäläinen 2022) their ailing parents' moods, mental states and wellbeing, and attuning themselves accordingly. Here, tacit knowledge refers to 'gut feeling', where the carer is not necessarily able to fully explain how (s)he makes certain observations or draws certain conclusions (ibid.). As described by Mikael:

> I learned already when I was very young to interpret my dad. If he called me on the phone, I could recognize from the first word whether he had drunk or not. You become a master at knowing and reading the parents' signals.

Helena described how she had tried to ***alter the moods and feelings of others*** in her family, 'to keep the atmosphere nice at home, so that nobody will get in a bad mood'. She described providing emotional care for her healthy mother as follows:

> When I was school age, I remember dad's situation taking a turn somehow for the worse, and after that it became … I think that I have consoled and calmed my mom a lot, and listened, and taken on that kind of role, as I guess all of us siblings have.

Many of the interviewees described ***managing their own feelings and needs***, and the display of their feelings and needs, in order to avoid causing additional worry or burden at home, also when help and support from family members would have been available. This was described as one way to emotionally care for family members. Sara described significant amounts of emotional work when altering her own moods so that she would not demand too much from her parents: 'I didn't rebel in my teens – I thought I couldn't do that to my parents'. Some of the interviewees expressed suppressing their own feelings because there was nobody capable of helping them with their worries, or as described by Elisa, to 'mirror their feelings'. As told by Mikael:

> Maybe it's also a kind of taking responsibility, that I was left alone with those things. Like, when I was a teenager and went through bodily changes and teenage anxiety, there was no one – I couldn't talk to anyone, I had to grow myself up alone.

One form of emotion work was aiming to ***control how one presents one's needs outside the family.*** Several interviewees described how they had hoped someone would notice their distress, but simultaneously, they had aimed at controlling their own behavior so as not to raise concern among those outside their family. In practice, this meant controlling the display of their own negative thoughts and feelings, in order to avoid questions or outside interference:

> Anna: I've always, in a way, made sure that nothing I do would cause trouble. I didn't want to be the one who gets the wrong kind of attention. Actually, I didn't want to be the one who gets any attention at all.
>
> Interviewer: Why?
>
> Anna: Well, let's just say there was already more than enough hiding going on at home. Like, if I had acted out at school – started skipping classes or talking back to teachers or not doing my homework – then people would've immediately started asking questions, like 'Why are you feeling so bad? Is everything okay?'

Emotional burden of caring

Several of the interviewees' accounts contained descriptions of parentification – the reversal of roles between the child and the parent, where the child becomes 'parent-like' (Burnett et al. 2006). In some cases, the role reversal was more permanent, whereas in others, interviewees recounted alternating between assuming a parental role and being parented, depending on the parent's condition (see also Aeyelts et al. 2016). Interviewees often described the ***temporal unpredictability and fluctuation*** of these roles. During easier phases, the parent(s) could fulfill their roles and support their children. However, at other times, they could be completely dependent on others, and in some cases even threatening or violent. These changes were often abrupt and unexpected. As noted by Moore et al. (2011), periods of parents' good health can still involve constant monitoring and preparing for the parents' health to get worse. Several interviewees described ***constant mental work*** and cognitive burden, where there was never time off from worrying about the parents' wellbeing (see also Chikhradze et al. 2017). Anna described the situation with her mother as follows: 'There is not even one second when you can trust that now everything is okay, that I can just sit here and take a breath.' Her account illustrates how caring situations are not necessarily either-or situations (caring/not caring); and even when spending time on activities other than concrete caring, the cared for persons' wellbeing could still be constantly on one's mind, and affect the choices made in everyday life (see also Moore et al. 2011).

Reframing the caring experiences

When analyzing how the interviewees narrated their childhood experiences from an adult point of view, it was apparent that they evaluated their experiences as being 'wrong' and exceeding children's capabilities and the norms regarding children's responsibilities. Hence, the interviewees' narratives contained explicit ***attempts to make sense*** of their own actions during childhood that for their adult selves seemed irrational, considering how caring and protecting others had caused harm to themselves. The interviewees also implicitly construct complex and conflicting positions regarding their roles within the family – what felt natural or inevitable at the time is now seen as situational and unjust.

The narrations reveal how they as adults reframe their experiences and see their roles in childhood as being shaped by obligation, loyalty and necessity. They reflected on the feeling that there were no other alternatives and the fear of outside interference stemming from their past selves' limited understanding of what would happen if their family situation was revealed.

Based on their retrospective reflections, it can be stated that the interviewees' caring had arisen from the need to fill the ***care void*** in their families. Several of the interviewees described their parents being unable to bear their responsibilities, leading to parentification. The narrations reveal that the caregiving roles are reflected not as a conscious choice, but as something relationally forced on them. Julia reflected on necessity being the reason for taking on the caring role: 'I guess it probably comes from having taken on the role that was available there'

However, necessity was not the only reason for taking on significant responsibilities. Some of the interviewees reflected on their younger selves' actions as stemming from a sense of ***moral obligation.*** Care was reflected as an internalized responsibility, and as a norm that was abided by without conscious reflection or negotiation, even if it meant doing this at the expense of one's own needs and well-being. As described by Anna:

> [I]f something happens to her [Annas' mother], then it's on me. It's my responsibility. It's my fault. And I guess that's probably the reason why I didn't feel anger back then – because I felt it was just as much my job to take care of her as anyone else's. […] it just felt automatic, and it never even crossed my mind that this wasn't something kids are supposed to do.

The interviewees described a tension between hoping for recognition and simultaneously concealing the caregiving situation. Sometimes this was due to ***family loyalty,*** with the interviewees wanting to 'keep the family together' (see Metzing-Blau & Schnepp 2008) and the fear of the family being separated. As narrated by Sara, seeking help for oneself was not done because it would have been considered as disloyal (see also Cooklin 2010), 'a big crime against the family', reinforcing a sense of moral obligation to uphold familial unity at personal cost.

The interviewees also described ***fear*** of the consequences that would fall on themselves and others, especially the ailing parent, if they disclosed their situation to 'outsiders'. These fears were not necessarily related to what would happen to the family unit as a whole, but rather what would happen to its individual members. Olivia described the reasons for hiding the situation as follows:

> I was afraid. I wanted to protect my mother. I didn't know what the consequences would be. I thought she would go to jail. […] These kinds of things have upheld the secrecy, I didn't know what would happen, where would I go.

Olivia's narrative reveals the fear stemming from ***limited knowledge and understanding***. She positions her younger self as someone who had internalized an exaggerated sense of risk and fear of adverse consequences. The interviewees often described a simultaneous desire for freedom and a fear of unknown results, positioning themselves in a complex role with their agency constrained by uncertainty. Secrecy was thus reframed as a logical response to a world that they could not yet totally understand.

Some interviewees also made sense of their actions through considering the role of ***shame and stigma.*** They considered the stigma associated with MHD/SA in general, but also to themselves to be different from other children. Helena's narration from the position of an adult indicates how she is able to recognize that the stigma was learned based on observations of other people's behavior: 'I specifically remember how, at that point, I had somehow internalized that it was something incredibly shameful and embarrassing and awkward if people would find out that my dad is like that.'

In some cases, the interviewees described that they had not questioned their situation or reached out for help because they had not even realized that something was wrong or out of the ordinary in their childhood and adolescence. Elisa pondered her own childhood experiences as follows:

> If someone would have asked me while I was in elementary school 'hey, can I help you, is something wrong?' I wouldn't have said that [something's wrong] – you don't know how

> to verbalize it; you can't tell what you are missing. There's nothing [else to which] you can compare.

Elisa positions herself as a child with ***limited awareness and language*** to evaluate or articulate her experiences. She constructs a past self who would not have identified herself as needing help due to the absence of a comparative reference point. Through their retrospective reflections, several interviewees contrasted their childhood perception with their present understanding and highlighted how the realization of unmet needs and negative emotions – described by Anna as 'unfairness' and 'bitterness about not being seen as a child' – had emerged later in life as an adult. This narrative trajectory aligns with research findings (see MacDonald & McLaughlin 2024) on how young carers' sense of injustice and (mis)recognition often develops retrospectively, rather than during the time of caregiving itself. Helena reflected that she had only realized the experienced burden of her childhood years once she had moved out of her family home, and had acquired a reference point by which to compare her childhood experiences: 'As a child, there were just so many things I had to manage – things that were overwhelming – and then when those started to ease up, and there just weren't as much [things to manage] anymore, life actually became so much easier after I moved out on my own.' Her continued narration illustrates how interviewees actively challenged their childhood roles and voiced critique of their accumulated burden:

> I shouldn't have had to be responsible for whether my dad was doing okay or not. […] But then, I also shouldn't have had to be responsible for supporting and comforting my mom. And maybe I also shouldn't have had to take such a big responsibility for myself, for taking care of myself, or for taking care of my little sister.

Conclusions

In this article, we have analyzed the accounts of Finnish former young carers with a parent with MHD/SA. Our findings illustrate how former young carers had navigated their caring roles as a means of maintaining stability, aligning with Tronto's (1993) notion of care as an effort to 'maintain, continue, and repair one's world'. Our findings elaborate on former young carers' experiences from the framework of emotion work (Hochschild, 1979) and highlight the multifaceted nature of emotional care; responsibilities related not only to caring for the ailing parent, but also to oneself, support for other family members, and engagement with the broader social environment. In our analysis, former young carers described aligning their needs and expectations with their realities, often by regulating their own emotions and the display of those emotions, avoiding burdening others, and concealing their need for help from 'outsiders'. Based on this understanding we argue that when studying the experiences of current and former young carers, it is essential not only to pay attention to the relationship between the young carer and the person who needs care, but also to the nuanced and various ways in which care expands beyond this dyadic relationship.

Emotion work done in relation to care is often difficult to measure, for example, in hours spent on caring, which in care research is a relatively common way to understand and assess the intensity and burdensomeness of caring. We argue that such an understanding of temporality can oversimplify how we understand caring and does not adequately recognize the possible emotional burden and the long-term consequences of caring. We emphasize the importance of focusing on and developing means to evaluate the hidden, difficult-to-measure emotional aspects of care when assessing the burden of children. We argue that this understanding of emotion work as part of care should be better incorporated into the assessment of young carer's situations and support needs in order to develop a more holistic understanding of children's caring and its consequences. This is especially important within the context of MHD/SA, as the fluctuating and often unpredictable nature of these conditions can create exceptionally burdening environment for children.

As highlighted in our analysis, former young carers' experiences are shaped by complex emotional and moral dynamics, constrained by structural vulnerabilities and societal norms (see also e.g. Schweiger 2025). Our interviewees described various ways in which they aimed at making sense of their experiences of being carers for their ailing parent(s) during childhood and adolescence. They reframed their experiences through the epistemic dimension (characterized by limited knowledge, understanding, awareness, and language to make sense of and articulate their experiences as they were unfolding), the moral-affective dimension (including moral obligation, family loyalty, and fear), and the structural-practical dimension (marked by a care void within the family).

We interpret the epistemic challenges the former young carers had faced stemming, in part, from not having the words or terminology to make sense of one's experiences as they were unfolding. As noted, in Finland questions regarding young carers are still highly invisible. Therefore, it would be crucial to raise public awareness, and establish terminology in public discussion, among children and young people themselves, and among the professionals working with them (e.g. teachers, social and healthcare workers). Furthermore, we argue that addressing the moral-affective dimension would require a multifaceted approach covering societal and institutional levels that includes recognizing young carers' roles, providing whole-family support, and challenging the stigma and silences that perpetuate their hidden struggles.

The structural-practical drivers shaping the interviewees' experiences were varied, but there were also many similarities. The interviewees had often fallen through society's safety networks, regardless of age, gender, or the parent's illness. This is striking as Finland is often considered as a Nordic welfare state where the state aims for universal and equal access to social and healthcare services for all. The right to adequate social and healthcare services is written in the constitution (The Constitution of Finland, §19 1999), and legislation that aims to guarantee children's wellbeing in cases of parent incapacitation is relatively comprehensive (Goodger & Kennedy 2024). Even though these legal rights are strong, they are not necessarily adequately implemented in the everyday practices of the service system (see The Central Union of Child Welfare 2024).

For several of our interviewees, regardless of their age, their experience had been that the support and services offered to their parent(s) had not been adequate. Such experiences can reflect the long-term development and the unequal provision of both mental health and substance abuse services in Finland. The dehospitalisation trend in mental health services has been prominent since the mid-1970s, accompanied by the focus of mental health care shifting from those with more serious mental health issues to those with ‘milder’ problems. This has left room for further excluding those with the most serious problems. (Alanko 2017). In substance abuse services, the service structure is scattered and regionally unequal (Kuussaari et al. 2021). In addition to the lack of availability of services, the experiences of the interviewees might also reflect the stigma associated with both mental health care and substance abuse services.

To conclude, our findings highlight the need for developing more refined ways to analyze and assess the emotional care of young carers and the ongoing need for support in adulthood. Our findings also highlight the need for developing a holistic, multi-systemic support system that addresses practical service gaps, acknowledges children’s moral and emotional realities, and provides them with the understanding and vocabulary to make sense of their experiences.

This study also has limitations that should be considered when assessing the results. Only three of the interviewees were male, even though in Finland, the gender differences when it comes to young caring are surprisingly small (Helenius et al. 2024). Also, retrospective interview accounts have both strengths and limitations. In the case of this study, retrospective accounts represent how adults remember and interpret their past as the children of an ailing parent, which inevitably differs from how an adolescent would narrate their experiences with an ailing parent as the situation unfolds. Also, it is likely that especially those who experience that they have been able, at least to some extent, to turn the challenges they have faced as children of an ailing parent into strengths, constitute those who participated in the interviews. Consequently, more research, especially among the most vulnerable groups of current and former young carers, is needed.

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