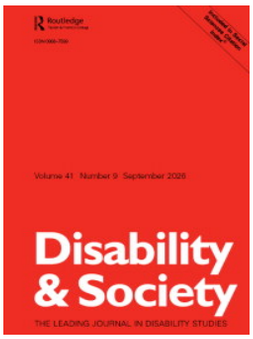

Disability & Society

ISSN: 0968-7599 (Print) 1360-0508 (Online) Journal homepage: www.tandfonline.com/journals/cdso20

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To cite this article: Karen E. Broomhead & Mia D. Smith (28 Aug 2026): Early adulthood with a disabled sibling: 'I'm more than just her sister, more now than I've ever been', Disability & Society, DOI: 10.1080/09687599.2026.2723732

To link to this article: https://doi.org/10.1080/09687599.2026.2723732

Published online: 28 Aug 2026.

DISABILITY & SOCIETY
https://doi.org/10.1080/09687599.2026.2723732

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Early adulthood with a disabled sibling: 'I'm more than just her sister, more now than I've ever been'

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ABSTRACT

Siblings of disabled individuals play a central role within the family system, often taking on responsibilities and providing support amounting to parentification. Despite holding valuable insights, the perspectives of young adults are scant in literature. This qualitative study examines the lived experiences of five *emerging adults* in England, who have a disabled sibling. It explores the emotions and experiences characterising this specific conceptual life stage. Participants described positive outcomes associated with having a disabled sibling, including empathy and strengthened family relationships. Alongside these positive outcomes, two interconnecting themes were identified: (i) participants held caregiving roles that expand the dynamics of the sibling relationship, highlighting parentification, and (ii) the complex emotions regarding their future. The experience of parentification may therefore shape the transition into emerging adulthood for individuals with disabled siblings, with caregiving responsibilities emerging through the interaction of family relationships, limited external support, and broader social expectations surrounding care.

ARTICLE HISTORY
Received 4 February 2026
Accepted 6 August 2026

KEYWORDS
Parentification; sibling-carers; emotions; emerging adulthood; caregiving

Points of interest

- Young adults with a disabled brother or sister often take on caring roles, which can change the usual sibling relationship.
- Young adults report positive experiences such as strong family bonds, but also describe worries and uncertainty about their sibling's future care.
- The findings show that siblings' wellbeing and support needs should be recognised, as providing appropriate support can benefit both siblings and disabled family members.
- The study highlights the need to include sibling views in research with disabled people and their families.

Introduction

The sibling relationship is one that often expands other familial and key relationships in a person's life. The positive outcomes of sibling relationships are

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widely acknowledged, including their contribution to social and cognitive development (Brody 2004), as well as fostering nurturing traits and behaviours (Naylor and Prescott 2004). In recent years, research has turned its attention to sibling relationships in the context of disability. This literature suggests that having a disabled sibling can have both positive and challenging implications for non-disabled siblings. Positive outcomes include increased empathy and maturity, whilst challenges may include elevated caregiving responsibilities, emotional stress and concerns about future caregiving roles (Buyco, Reimer-Kirkham, and Astle 2026; Hanvey, Malovic, and Ntontis 2022; Heller and Kramer 2009; Hodapp and Urbano 2007; Petalas et al. 2012). Consequently, research has increasingly sought to understand the diverse ways in which disability shapes sibling experiences and relationships across the life course.

Family Systems Theory (Minuchin 1974) provides a useful framework for understanding how familial roles, relationships and family member's self-perception can shift in response to disability. When an individual is disabled, the impact is felt by each member of the family system including siblings, with Gant (2018) indicating that the particularity of the disability takes a central role in shaping sibling experience.

Whilst Family Systems Theory provides an important lens for understanding how disability may shape family roles and relationships, it primarily focuses on processes occurring within the family unit. A social relational approach to disability (Thomas 1999, 2007) extends this understanding by recognising that experiences of care and responsibility are also shaped by wider social, cultural and structural contexts. From this perspective, sibling caregiving roles are not solely produced through family dynamics but are influenced by factors such as access to support services, societal expectations surrounding care, and the availability of formal and informal support networks. This perspective resonates with ethics of care perspectives, which conceptualises care as a relational and socially organised practice rather than a responsibility located exclusively within families (Tronto 1993). Together, these perspectives provide a useful framework for understanding how caregiving roles emerge and are experienced by siblings during the transition to emerging adulthood.

Research examining the direct impact on non-disabled siblings has presented mixed findings. Several studies report negative outcomes, including internalising difficulties such as stress, anxiety, depression, and social withdrawal (Banks et al. 2001; O'Neill and Murray 2016; Rossetti and Hall 2015) with the non-disabled sibling often reported to be overlooked by family and wider social networks. This is referred to by Hanvey, Malovic, and Ntontis (2022, 941) as 'invisibility' or recognising the 'glass child' metaphor (Hanvey, Malovic, and Ntontis 2022, 945). Other studies have highlighted positive outcomes, suggesting that growing up with a disabled sibling may foster greater

empathy, stronger psychosocial skills (Edery and Harvey 2025; Petalas et al. 2012; Scavarda 2024), alongside deep relational bonds and a sense of pride in their sibling (Buyco, Reimer-Kirkham, and Astle 2026; Moran-Morbey et al. 2024).

The sibling relationship can be characterised by caregiving and support (Burke et al. 2012; Corsano et al. 2017) which can in some cases extend to parentification (Hooper 2008; Jurkovic 1997; Levante et al. 2022). Parentification is the term used to describe siblings permanently assuming parent-like roles and responsibilities, crossing the boundaries to the parental subsystem (Chase 1999; Minuchin 1974) in an attempt to 'fill the vacuum of care within the family' (Byng-Hall 2008, 147). Caregiving and parent-like roles may overlap but are not synonymous; care within sibling relationships exists on a continuum, whereas parentification involves a more specific shift in role boundaries and assumption of parental functions (Hooper 2008; Jurkovic 1997). Parenting roles can indeed become part of children's identities within their family system and, if fulfilled for an extended period, can become harmful (Byng-Hall 2008; Jurkovic 1997). Literature (e.g. Hooper et al. 2011a; Levante et al. 2022; Nuttall, Coberly, and Diesel 2018) refers to two forms of parentification; the more salient form in this context is sibling-focused parentification. This form of parentification refers to non-disabled siblings assuming caregiving or parental responsibilities for their disabled siblings, shifting their role from sibling to quasi-parent. Alternatively, parent-focused parentification describes how the non-disabled child takes on caregiving and/or emotional support for their parents. There are also various levels of parentification such as instrumental and emotional (Byng-Hall 2008). Instrumental tasks relate to practical tasks or duties such as assisting disabled siblings with feeding, dressing, bathing and mobility; whereas emotional tasks refer to the psychological and relational responsibilities the non-disabled child undertakes to support the emotional wellbeing of others in the family system. Interestingly, sibling-focused parentification has been associated with the development of positive sibling relationships. On the other hand, parent-focused parentification is more commonly linked to adverse effects on the non-disabled child (Hooper et al. 2011b), including heightened levels of anxiety and stress (Nuttall, Coberly, and Diesel 2018).

As parents age or become unable to care for their disabled child, caregiving responsibilities may intensify and consequently transfer to non-disabled siblings (Lee and Burke 2018). Sciscione (2022, 6) referred to these siblings as 'parental surrogates'. The shift to becoming the main carer for a disabled sibling is often an anticipated role (Heller and Arnold 2010, Petalas et al. 2012; Leane 2020), which can be embedded by parental expectation (Davys, Mitchell, and Haigh 2014). Rossetti and Hall (2015) indicated that many siblings feel underprepared for the transition into the primary caregiving role and would benefit from information and support. Despite potential under preparedness, some research has indicated a motivation to care for disabled

siblings (Leane 2019; Rawson 2010) and has outlined positive outcomes such as developing a deeper understanding of disabled siblings' lives and strengthening the sibling relationship (Sciscione 2022; Tedeschi and Calhoun 2004). However, the prospect of taking on the main carer role is often a concern for adult non-disabled siblings, particularly due to the anticipated impact on their own lives and their previous negative experiences with support services (Davys, Mitchell, and Haigh 2010; Gant 2018). This is further complicated by the tendency of some parents to avoid making plans or involving siblings in such planning (Heller and Kramer 2009; Sciscione 2022). Leane's research (2020) highlighted how parents can defer and avoid discussions about future planning. This may be due to concerns around the pressure that comes with the intergenerational transfer of caregiving responsibilities, and/or a desire to avoid making their non-disabled adult children feel pressured or obligated. Ultimately a lack of open dialogue can place stressors on siblings, with Leane (2020) highlighting that greater attention must be paid to the emotional impact associated with caregiving responsibilities.

Gant (2018) highlighted the complex and often conflicting emotions that non-disabled siblings may hold toward their disabled siblings, ranging across a spectrum from ambivalence to enrichment to antagonism (Gant 2018). In the context of intellectual disabilities, Leane's (2019) research offered valuable insight into the emotional complexities embedded in sibling dynamics, which can present in a range of emotions such as anticipatory guilt, empathy, self-love, and righteous anger. Participants who shared a strong emotional and physical attachment with their disabled sibling during childhood showed heightened emotional sensitivity, underpinned by a moral duty to 'care out of love' (Leane 2019, 269). This can be counter balanced with themes across the literature of resentment and guilt for pursuing their own lives (Davys, Mitchell, and Haigh 2010; 2014; Leane 2019). Leane (2019) identified the need for siblings to be provided with opportunities to consider their own voice and emotions in relation to the moral dilemmas they can experience.

The need for siblings to feel seen, heard, and validated reinforces the importance of research that explores sibling's lived experiences, paying close attention to the emotional impact of perceived roles and responsibilities held. Whilst there is a significant body of literature considering the experiences of non-disabled siblings (e.g. Davys, Mitchell, and Haigh 2014; Hanvey, Malovic, and Ntontis 2022; Leane 2020; Moran-Morbey et al. 2024), there seems to be scant empirical studies that focus specifically on the transition, or as Arnett (2000, 2006) suggests the *emerging* into adulthood stage. Emerging adulthood is a notion theorised by Arnett (2000, 2006) as a distinct developmental stage in which young adults (aged between eighteen to twenty-nine) are positioned 'in between' adolescence and adulthood – a stage in which the emerging adult is establishing independence whilst simultaneously remaining closely connected to their parents. Considering the perspectives of non-disabled siblings within this age category,

therefore, allows for an exploration into their emotions and experiences during this specific conceptual emergence stage into adulthood which is rarely captured within the literature.

In addition to this, it is important to acknowledge that non-disabled siblings live complex lives, shaped by a wide range of influences. It is therefore not always possible, or appropriate, to directly link specific outcomes solely to having a disabled sibling. Furthermore, adopting a strengths-based approach (Saleebey 2009; Tedeschi and Calhoun 2004) to understanding the lives of non-disabled siblings is critical, recognising their adaptability and the meaningful relationships that they have built within their family, characterised by love and commitment. Nevertheless, such positive experiences are commonly situated within broader contexts of complexity and challenge. In recent years, research has increasingly shifted away from focusing on the stress and challenges faced by families of disabled individuals, towards a more positive, strengths-based perspective that emphasises factors such as resilience and adaptability (Buyco, Reimer-Kirkham, and Astle 2026; Edery and Harvey 2025; Heyman 2018; Scavarda 2024). While this reframing may contribute more empowering narratives, researchers such as Muir and Strnadová (2014) and Knight (2013) caution that this may result in losing sight of the wider political and social context in which caregiving occurs, and so acknowledging both dimensions is important. This study therefore seeks to understand sibling experiences not only within family relationships, but also in relation to the wider social conditions that shape opportunities for care, support and future planning.

Research process

This paper is drawn from a broader study exploring the experiences of non-disabled siblings, with particular focus on the factors influencing their choice of a university degree programme in Special Educational Needs and Disability, and their considerations around future career planning. Our primary aim was to gain rich, in-depth insights into participants' lived experiences across distinct developmental stages – namely, childhood, adolescence, and adulthood, without imposing predefined categories or expectations. Rather than framing the study around specific constructs from the outset, we sought to allow participants' narratives to guide the discovery of salient themes, thus following an inductive nature of design.

The research was granted full ethical approval from Liverpool John Moores University.

Design

Semi-structured interviews were used to explore the lived experiences and emotions of non-disabled siblings allowing for the retrieval of rich data

(Fraenkel and Wallen 1995), using a life history approach. This enabled sensitivity to context, allowing participants to speak openly about having a disabled sibling within the context of key life stages. It also allowed for participant-led insights (Flick 2002; O'Leary 2004), thereby ensuring the authenticity of the participants' contributions. Each interview was conducted in a familiar university building and lasted approximately one hour. All interviews were audio-recorded and transcribed verbatim.

To safeguard the integrity of the research process, we developed the interview schedule collaboratively, using key life stages as a guiding framework (i.e. childhood, adolescence, adulthood). Whilst some questions were asked relating to various life stages such as, 'can you recall your earliest memory with your sibling?' and 'when you were of primary school age, what was family life like?', these were purposely kept general to enable participants to talk openly about what was meaningful to them. This approach aided the development of themes inductively from participants' narratives, rather than being imposed by the researchers. We also maintained reflective journals following each interview, which served as a tool to draw attention to our underlying perspectives and assumptions (Olmos-Vega et al. 2022; Ortlipp 2008). This ongoing reflexive practice supported a deeper understanding of our own preconceptions and positionalities, allowing us to critically examine how they shape our interpretation of the data.

Sample

This paper draws specifically upon the lived experiences of five female participants who have a sibling with a range of multiple and complex needs. Each participant was enrolled on the BA (Hons) Education and Special Educational Needs delivered at [university] and, at the time of interview, aged between eighteen and twenty-one, positioning them within Arnett's (2000, 2006) conceptual category of emerging adulthood. Participants were selected through purposive sampling. A short overview of the study was presented to the entire student cohort; this was followed by an email outlining the research sent to all students. Those who met the inclusion criteria and expressed interest were invited to contact the research team and subsequently provided with a participant information sheet. The researchers made the decision not to follow up with those who had expressed initial interest, instead waiting for students to initiate further contact if they wished to take part. The gender composition of the sample closely mirrors the demographic profile of the degree programme. We acknowledge that females often anticipate higher levels of long-term caregiving responsibilities (Burke et al. 2012; Richardson and Stoneman 2019), making their voices especially important in understanding such sibling dynamics.

Participants' siblings had a range of diagnoses, including Autism, Attention Deficit Hyperactivity Disorder (ADHD), Global Developmental Delay (GDD),

Down's Syndrome and Cerebral Palsy. Two participants had siblings diagnosed with both Autism and ADHD, one of whom was also pre-verbal, while another participant's sibling had Autism alongside GDD. This diversity of diagnoses provided insight into sibling experiences across a range of disability contexts. Whilst participants' siblings had a range of neurodevelopmental, developmental and physical disabilities, the small sample size did not allow for meaningful comparison. The study sought to explore shared experiences of sibling caregiving and family life across differing disability contexts rather than draw conclusions relating to any specific diagnosis.

Positionality

It is important to acknowledge that both researchers are the current joint programme leaders for the degree from which we recruited our participants, and as such, we felt the weight of the ethical complexities that double agency presented (Ferguson, Yonge, and Myrick 2004; Liebel and Chakraborty 2021), particularly relating to power. In this context we refer mainly to two forms of power: (a) positional power and (b) expert power. Positional power carried the potential to make students feel subtly coerced into participating in the study and influence behaviour, through the perceived ability for us to grant benefits or impose sanctions, ultimately leading our students to feel a *captive* participant (Ferguson, Yonge, and Myrick 2004). Expert power (French and Raven 1959; Gibson et al. 2014) had the potential to alter how our participants responded to our interview questions; we recognised how they may have felt inclined to provide responses they believed were *expected* of them, particularly in light of a strengths-based approach to disability.

We took several steps to minimise potential coercion arising from researcher-student power dynamics. For example, in relation to positional power, although we had prior knowledge of some students who fitted the participant criteria (i.e. had a disabled sibling), the research was advertised to the entire cohort (over 120 students) to avoid applying undue influence over individual participation. Additionally, we made it explicitly clear to all students that showing their interest, choosing to participate, or even withdrawing from the research at a later stage, would have no impact on their academic outcome. In relation to expert power, we ensured that all participants were aware that we were looking for *their* personal experiences, and there were no right or wrong answers, regardless of how they perceived it would be interpreted by us. Participants were aware that this was an opportunity for *their* voice to be heard and to, importantly, be respected. However, we recognise that such measures cannot eliminate the relational power inherent in the researcher-student relationship.

Additionally, to reduce the potential for bias, both researchers reflected on their pre-existing assumptions about the topic. This was particularly important

as one researcher brought dual perspectives as both a lecturer in the field of SEND and a mother of children with multiple and complex needs. While this personal experience provided valuable contextual understanding of disability, family life and caring relationships, the researcher did not occupy the same social position as participants. Rather, she approached the research as a parental ally situated on the periphery of the cohort being researched, acknowledging that her experiences as a parent differ from those of siblings who undertake caregiving roles. Throughout the research process, reflexive practice was used to critically examine how personal experiences, assumptions and emotional investments might shape data collection, interpretation, and analysis. Regular discussions between the researchers took place, in order to challenge interpretations, consider alternative explanations and ensure that participants' accounts remained central to the analysis. This reflexive approach sought to balance the benefits of 'insider' knowledge with an awareness of the limits of that perspective, thereby reducing the risk that parental experiences would be conflated with the distinct experiences of sibling caregivers.

Data analysis

We conducted our analysis using Reflexive Thematic Analysis, as developed by Braun and Clarke (2006, 2013, 2019). While we followed the foundational six-phase process outlined in their 2006 framework, we adopted a reflexive, interpretative approach to theme development. It is important to recognise the active role researchers play in generating knowledge. In this form of analysis, it would prove naive to assume a single 'correct' interpretation (Braun and Clarke 2013), themes do not 'emerge'; instead, they are generated by the researcher/s resulting in multiple meanings being drawn from the same dataset. As such, Braun and Clarke (2019) argue that thematic analysis is a reflexive process and reflects not only the data itself but also the researcher's theoretical assumptions, analytical skills, and available resources. Recognising the reflexive nature of the analysis and given that this project involved more than one researcher, we worked collaboratively on the analysis stage regularly discussing emerging themes to challenge assumptions and promote a balanced interpretation. This process allowed for active and reflexive interpretation by both researchers, multiple perspectives to be considered and for discrepancies to be resolved through critical dialogue (Byrne 2022). This process served to support the rich development of themes and co-construction of meaning.

Limitations

This study has several limitations that should be considered when interpreting the findings. First, the sample comprised only five participants, all of whom were female university students. Whilst the small sample size is

consistent with the study's qualitative design and enabled an in-depth exploration of participants' lived experiences, it inevitably limits the transferability of the findings. Furthermore, recruiting exclusively from a university population may have excluded siblings whose caring responsibilities influenced their educational pathways or prevented them from accessing higher education altogether. Although the gender composition of the sample reflected voluntary participation and the demographic profile of the degree programme from which participants were recruited, future research would benefit from a broader and more diverse sample in order to capture a wider range of sibling caregiving experiences.

The study also focused on participants whose siblings had a range of diagnoses, including autism, ADHD, Down's syndrome, cerebral palsy and global developmental delay. Whilst this diversity enabled exploration of experiences across different disability contexts, the small sample size does not allow conclusions to be drawn regarding the experiences associated with any particular diagnosis. Future research involving larger or more diagnostically focused samples could usefully explore how sibling experiences may vary across differing support needs and family circumstances.

In addition, this study focused solely on the perspectives of non-disabled siblings and did not include the voices of disabled siblings themselves. In keeping with disability studies principles and the importance of centring disabled people's own experiences, future research should seek to incorporate the perspectives of disabled siblings in order to develop a more holistic understanding of sibling relationships, caregiving dynamics and family life (Richardson and Jordan 2017).

Finally, the researchers' dual role as investigators and programme leaders may have influenced participants' accounts through power dynamics and social desirability bias, particularly given the strengths-based framing of the study. Although extensive reflexive practices were employed throughout the research process, the influence of the interview context and existing researcher-participant relationships cannot be fully discounted.

Results

Whilst positioned within the conceptual 'emerging adulthood' stage, participants described significant caring responsibilities for their disabled siblings, often amounting to parentification, intensifying with age and affecting education or work. Participants in this study experienced profound and conflicting emotions about their current and future lives with their disabled sibling. They described a strong sense of duty, despite experiencing significant fears and uncertainty about their future.

Analysis generated two overarching themes: *Caregiving and Parentification* and *Conflicting Emotions and 'the Future'*. The first theme explored

participants' experiences of instrumental and emotional parentification, the ways in which caregiving responsibilities were directed towards both siblings and parents, the intensification of caring roles over time, and the importance of opportunities for external respite. The second theme captured participants' complex emotional responses to their sibling relationships, including a dual awareness characterised by acceptance alongside sadness, the centrality of their sibling within family dynamics, anticipation of future caregiving responsibilities, and feelings of anxiety and uncertainty regarding the future.

Before turning to the findings in detail, it is important to emphasise that participants' lives were multifaceted, and influenced by a wide range of intersecting factors; not solely their disabled sibling. Instead, we can only offer a glimpse into their everyday realities, which are shaped by the broader context of family life, where, as Gant (2018) notes, disability takes a central role. Whilst aligned with a strengths-based perspective, participants' positive experiences with their disabled sibling were intertwined with complex and challenging realities. Acknowledging both dimensions is essential in order to authentically capture their lived realities and conflicting emotions regarding their future.

Theme 1: caregiving and parentification

This theme explores the extensive caring roles undertaken by participants, many of which were experienced as consistent with sibling-focused parentification, with some accounts also reflecting dynamics associated with parent-focused parentification. These dynamics often shaped their sense of identity and relational position within the family. Caring roles frequently expanded with age, impacting education, work and influencing future planning. This was compounded by limited access to external support, particularly respite, reinforcing family unity as essential for managing the demands of care. These ideas are explored below.

Participants described experiences consistent with both instrumental and emotional parentification. For example, firstly, although Jess and Megan described themselves as 'just a sister', their accounts also included extensive instrumental caregiving;

> *He still needs help like with everything, we need to wash him, we need to wipe his bum, I don't mind at all, he needs help, so I help him* ***(Megan)***

> *I wash her hair, I shower her, you know I take her out in the car with me, me mum and dad they're like [shouts] 'hurry up and get down, quick, throw the nappies, throw the wipes'… it's always full on in ours* ***(Rebecca)***

For some, there was explicit self-recognition of roles consistent with sibling-focused parentification as they got older, with participants actively identifying themselves as their sibling's 'parent' or 'second mum';

I feel like his parent, but it's fine, my mum would say definitely I'm taking on that role ***(Jess)***

I am practically the second mum, which is like my main thing, my main responsibility ***(Sophie)***

Libby openly reflected on the internal conflict she experienced as a consequence of sibling-focused parentification, recognising the disparity between the caregiving role she occupied and the 'typical' sibling relationship she desired;

I'm his sister and his mum apparently, he's got two mothers you know [laughs] I have this parent role, and no it shouldn't be like that should it, it does bother me because I don't want my brother to grow up and see me as another parental figure, I want him to trust me like a sibling and argue with me like a sibling, and to not have to walk the straight and narrow with me because I'm not his mum ***(Libby)***

Libby's discomfort highlights how parentification not only influences the caregiving sibling emotionally, but may also alter the sibling relationship in ways that can lead to identity conflict.

Dynamics consistent with emotional parentification were also evident in participant descriptions of their lived experiences. Here we observed parent-focused parentification, which was particularly apparent in the lives of Libby and Sophie, who demonstrated a conscious awareness of their role in providing emotional support to their mothers, in some cases reflecting dynamics consistent with parent-focused parentification;

I'm the person that Mum turns to if she needs some advice, I let her get all of her crying out ***(Libby)***

Amber has loads of appointments and stuff so I go, because my mum needs the emotional support, and I am <u>the</u> *emotional support* ***(Sophie)***

Sophie revealed that this dynamic affected her relationship with her mother;

Because mum had me, I feel like we've not really took on a daughter and mother role, we've been more sisterly if that makes sense ***(Sophie)***

Participants also described how caregiving responsibilities intensified over time. Sophie described this as beginning early in childhood, which progressively evolved into a substantial and sustained caregiving role for her disabled sister. The following narrative captures how this transition emerged through a gradual internalisation of a caregiving identity, with discussion of moving towards being 'more';

I'm more than just her sister, more now than I've ever been, when I was younger Amber was just a play friend that I had, she was just my little sister, and then as I got older, it was like 'oh she's my sister but she's disabled, she's now somebody I care for and look after' ***(Sophie)***

As Sophie noted above, caregiving became her norm, despite recognising that others her age were not expected to adopt such responsibilities.

Finally, participants highlighted the scarcity of external respite for their siblings, which meant that the entire family had to collaborate closely in providing care. Jess benefited from support within an extensive family network including siblings, grandparents, aunts, uncles and cousins, who all played an active role in supporting her disabled sibling alongside her parents and herself. However, others, particularly Megan, Sophie and Rebecca, were often the only family members supporting their sibling besides their parents. This increased the intensity of their responsibilities but also strengthened their sense of unity and commitment to 'sticking together' and working as a team.

> *We have to stick together, because if we don't that's when it'll all just crumble* ***(Megan)***

> *It takes a village to raise a child because it's such a hard thing, but what happens if you don't have a village? The support side of things is so lacking**…**my mum doesn't have any friends and family that live close, so I'm the only person that my mum can go to for anything* ***(Sophie)***

These reflections reveal the profound impact of the availability (or lack of) external respite and extended family support. Viewed through a social relational lens, participants' caregiving experiences appeared to be shaped not only by family commitment, but also by the availability of wider sources of support. Jess's experiences reflect a distributed caregiving model, where the presence of multiple caregivers can mitigate the intensity of responsibilities for any one individual. On the contrary, the experiences of Megan, Sophie, and Rebecca highlight the challenges faced by primary caregivers in families with limited external support. Sophie's narrative reinforces the emotional toll of limited support; when '*the village*' is absent, the caregiving load and obligation becomes concentrated, often without adequate systemic or informal relief.

Theme 2: conflicting emotions and 'the future'

This theme highlights how participants navigating the transition and emergence into adulthood alongside a disabled sibling experienced complex, often conflicting emotions. They acknowledged the significant, lasting impact that their sibling's needs had on family life, including challenges, sadness, and empathy, especially towards their parents. Despite struggles to express these feelings, many showed acceptance and a strong protective love for their sibling, viewing them as an integral part of their identity. Looking ahead, several anticipated assuming future caregiving roles, often feeling a deep sense of duty mixed with worry. This theme identifies the emotional complexity and evolving responsibilities that siblings face during this transitional life stage.

Firstly, all participants acknowledged that their sibling had profoundly and undoubtedly impacted their lives, presenting numerous challenges along the way;

> *It's so challenging, it really is, it's up and down constantly, the way they act, the way they feel, he has changed our lives, and it's hard* ***(Megan)***

> *It is so difficult, and I don't think many people would understand the difficulty of actually living it* ***(Sophie)***

An underlying sense of sadness also permeated participants' reflections of their experiences. At times, this sadness rose to the surface more explicitly; for example, Sophie expressed how upsetting it was to watch her sister experience such complex mobility and medical needs. However, for others such as Megan, this sadness seemed rooted in a longing for a different reality, wishing that their siblings did not face the difficulties that they did;

> *It's a bit like, I don't know [long pause] you just want the brother that you haven't got really, I suppose my mum and dad might think that they want the kid that they haven't got, but I wouldn't change him for the world now, but it's just like, I don't know, do you get what I mean?* ***(Megan)***

Megan seemed to struggle expressing this, as evidenced by the long pause and hesitation before offering the almost automatic reassurance, '*but I wouldn't change him for the world*' revealing her internal conflict. Despite these feelings, participants did not express any blame toward their siblings; instead, they simply wished that the circumstances were different;

> *I understand that it's not his fault, he didn't ask to have the needs that he has, but I just wish it was different* ***(Libby)***

> *She didn't ask to be born the way she is, it's not her fault* ***(Sophie)***

Opportunities to express these emotions were not always evident. For example, Sophie reported feelings of being frequently overlooked, as she perceived herself to be sidelined in a family dynamic where her sister remained the central focus;

> *It feels like you are not the main focus within the family, she is the sun and you're the moon… I know it's like a weird analogy to say it, but like she's the centre, she's at the centre of the universe, she's the sun, within the solar system, she's everything, she's the main person within the family and everybody has to revolve around her, and because you revolve around her so much, you get tired and you start slowing down, but you can't slow down you've got to speed up, and it's very hard to continue it and at one point you are just going to explode* ***(Sophie)***

Conversely, alongside these complex emotions, participants expressed acceptance of their sibling and their caregiving roles, considering their circumstances as an ordinary part of life and embracing the mindset of '*it is what it is*' (Libby);

> *You just have to accept them for who they are, it is what it is literally [laughs]* ***(Jess)***

> *It's just, that's the way it is, so it's a nightmare, but [sighs] it's fine***,** *you get through it, we'll find a way through it* ***(Megan)***

> *It's just normal to me, this is my life isn't it, this is my experience of being a sister, it might seem crazy to everybody else but this is my life* ***(Libby)***

Yet, alongside the challenges, there was also a deep, protective bond with their sibling. Participants spoke with warmth about their siblings, who were often described as their best friends. Many participants affirmed that they '*wouldn't change their sibling for the world*', highlighting the connection that transcended difficulties and defined their lives;

> *It's made me into the person I am now, I wouldn't have changed anything, he's made me the person I am today, I can't picture my life without him* ***(Jess)***

> *It makes me so happy as well like…she's the most loving little girl, she's a good little egg, there are positives and negatives to it all but I wouldn't change it for the world, she is like me best mate, she is perfect as she is. And we love her for who she is and that's all that matters* ***(Rebecca)***

These narratives capture dual awareness; a simultaneous recognition of hardship for their circumstances, alongside affection for their disabled sibling. Viewed through a strengths-based lens, these reflections highlight participants' emotional resilience, empathy, and relational maturity. Whilst they acknowledge sadness and loss, they also demonstrate capacity for acceptance and perspective-taking.

Finally, thoughts turned to the future. Although still young adults with their own lives ahead of them, all participants anticipated taking on the responsibility of caring for their sibling once their parents could no longer do so. Megan framed this as parental expectation;

> *It's what I have to do, it's an expectation, it's an expectation from my mum too so she's said 'never put him in a care home' and I'm like 'no he won't ever be going into a care home', it's definitely my responsibility to look after him when my mum and dad pass away it's my role, so I've always said that he can live with me, it's always been what's going to happen (Megan)*

The finality of '*it's always been what's going to happen*' makes it explicit that becoming her brother's 'parental surrogate' (Sciscione 2022, 6) is a role that Megan is willing to undertake. In contrast, Libby articulated that the expectation to assume a caregiving role is one she imposes upon herself, rather than one explicitly communicated by her parents. She described this role as a commitment rooted in both love and a sense of obligation, regardless of whether it was a responsibility she had actively chosen to assume;

> *I think there'd be expectation, but not like from my parents saying you need to have him, but rather my own inside voice saying 'you need to look after him, that's your brother'… it's the duty that I have as a sister to be there for him and to look after him, whether I want to or not* ***(Libby)***

It is unsurprising that this sense of responsibility was frequently accompanied by feelings of anxiety and uncertainty about the future, as Rebecca highlights;

> *I just worry … this is all I think of, if anything happens to my mum or dad… I will be her main carer like, it's gonna be me. So sometimes I worry about that and if anything goes wrong or like me nerves just go* ***(Rebecca)***

Discussion

With regards to Arnett's (2000, 2006) conceptual 'emerging adulthood' stage, the transition from adolescence to adulthood is often characterised by identity exploration, instability and the pursuit of future possibilities, establishing independence whilst maintaining family connections. However, according to our findings, this transitional stage may be altered or constrained significantly for non-disabled siblings due to their experiences of parentification, and the conflicting emotions that may ensue.

Caregiving and parentification

In relation to our first theme, findings revealed how both instrumental and emotional parentification were pervasive in participants' lives, aligning with prior conceptualisations by Byng-Hall (2008). Many participants undertook tasks far beyond age-appropriate responsibilities, echoing literature that describes a blurring of familial roles between being a sibling, emotional anchor and surrogate parent (Hooper et al. 2011a). One participant's discomfort around her dual role as sibling and parent highlighted that of 'role distortion' described by Hooper (2008, 34), where identity confusion can result from potentially mismatched developmental expectations and familial duties. Literature highlights how this may result in a loss of normative sibling experiences, such as rivalry, and emotional reciprocity (Naylor and Prescott 2004). The findings also identified an intensification of care, as participants transitioned from childhood to emerging adulthood. This gradual process and its potential impact on identity is highlighted within previous literature, where caregiving roles slowly become central to the individual's self-concept, with a potentially unnoticed shift from age-appropriate behaviours to adult-like caregiving roles (Hooper, Marotta, and Lanthier 2008; Lee and Burke 2018).

The impact of both types (sibling-focused or parent-focused) and levels (instrumental or emotional) of parentification on participants were evidently far-reaching. Whilst instrumental parentification may build competence and responsibility, excessive or developmentally inappropriate demands are reported to potentially limit social opportunities and increase overwhelm for the non-disabled sibling as they age (Chase 1999; Jurkovic 1997). Additionally,

whilst emotional parentification can foster resilience, it could also result in suppression of the non-disabled sibling's own needs, premature maturity, and challenges with identity formation. These outcomes illustrate a reversal of the 'expected' parent-child dynamic (Chase 1999; Hooper 2007; Hooper et al. 2011b). This may be particularly challenging during the emerging adulthood stage, which is typically characterised by increased autonomy and open dialogue with parents about future aspirations.

Finally, participants' experiences with external support varied. Viewed through a social relational understanding of disability, these findings suggest that caregiving responsibilities were shaped not only by family relationships but also by the availability of wider support networks and respite provision. This highlights how experiences of parentification may be influenced by broader social contexts, rather than occurring solely within the family unit. Such findings reinforce previous research suggesting that when broader familial networks are involved, caregiving can become a distributed experience, fostering greater resilience and cohesion within the family unit (Buyco, Reimer-Kirkham, and Astle 2026; Heyman 2018; Kyzar et al. 2012). These benefits are particularly evident when caregiving roles are perceived as meaningful and mutually supportive (Seltzer et al. 2001; Richardson and Stoneman 2019). However, when caregiving responsibilities fall primarily on nuclear family members, often just parents and siblings, it can intensify the emotional and practical load (Aldridge and Becker 1999), exacerbating the complexities of parentification. Without respite the caregiving role often became entrenched, especially in under-resourced families, yet participants demonstrated both resilience and adaptability. This shaped their transition into adulthood, which became less about exploration and more about responsibility.

Conflicting emotions and 'the future'

Alongside these role-based shifts, participants reported a wide range of conflicting emotions, which complicated identity formation. These emotions included deep affection for their disabled sibling, coexisting with frustration and guilt (supporting Heller and Arnold 2010; Hanvey, Malovic, and Ntontis 2022). These tensions are particularly salient when considering Arnett's (2000, 2006) emerging adulthood stage; for many participants, this stage was not characterised by freedom or possibility but by anticipatory caregiving. Future care was often framed as a certainty, not a choice, reinforced by family expectations or internalised beliefs (Davys, Mitchell, and Haigh 2014; Edery and Harvey 2025; Heller and Arnold 2010, Petalas et al. 2012; Leane 2020; Richardson and Stoneman 2019), and for some participants, a perceived lack of viable alternatives within formal systems of support.

Consequently, participants' futures were often envisioned through the lens of a lifelong obligation of non-negotiable caregiving, restricting the very

autonomy and exploration that defines emerging adulthood (reinforcing Tong, Nissim, and Goldstein 2024). This commitment was grounded in both love and a sense of obligation, mirroring Leane's (2019, 269) concept of 'care out of love', irrespective of whether it was a responsibility they actively desired to undertake. However, it often coincided with guilt experienced by participants, when prioritising their own needs, social lives or aspirations. This internalised pressure to 'always be available' for their disabled sibling reportedly increases the risk of burnout, anxiety, and long-term difficulty in boundary-setting (Hooper 2007). Nevertheless, whilst this emphasis on care and emotional support appeared to influence the way participants made decisions about their future, with caregiving obligations often taking precedence over individual aspirations, it also highlighted participants' abilities to prioritise family and navigate complex dynamics.

These experiences identify an underexplored area; whilst sibling-focused and/or parent-focused parentification involves taking on *some* parental roles during childhood and adolescence (emotionally or instrumentally), these responsibilities are still typically performed under the shadow of a living parent. But when a parent dies, there is a marked shift, from being a caregiver to *becoming* the primary parent. This concept of 'becoming' is particularly interesting, especially when considered alongside Arnett's (2000, 2006) emerging adulthood stage, with participants already aware of the role that they intend to play in the future, and the impact that it may have on their own lives. It is well-documented within the literature how caregiving roles intensify with age (Heller and Arnold 2010; Leane 2020; Petalas et al. 2012), and is supported by the current study's findings, but little consideration of how the transition to *becoming* the parent evolves and escalates.

Additionally, participants often hesitated to voice sadness or frustration, neutralising concerns with statements such as 'I wouldn't change them'. This could be tentatively interpreted as suppression of difficult emotions, which aligns with previous research regarding sibling management of challenging emotions (Hanvey, Malovic, and Ntontis 2022; Nygård, Clancy, and Kitzmüller 2024). Such suppression is closely linked with anxiety and eventual burnout (Greene et al. 2017). Additionally, Sophie's 'solar system' metaphor, describing herself as orbiting the needs of her sibling, captured the sense of invisibility and marginalisation recognised in previous literature (Hanvey, Malovic, and Ntontis 2022) with non-disabled siblings reportedly living in the shadows of their disabled sibling.

Implications

Our findings indicate that parentification may reframe emerging adulthood from a time of self-discovery into one of premature maturity. Importantly, the findings suggest that parentification is not solely a family-level phenomenon

but rather how it is also shaped by broader social and structural factors. Participants revealed a nuanced picture of love, duty, and identity shaped under the weight of responsibility. To address this, services must recognise and validate the caregiving roles of non-disabled siblings through early identification, access to respite care, and sibling-specific support mechanisms such as therapy and peer groups. Structured, non-judgmental conversations around future care responsibilities may reduce anxiety and empower sibling-carers to make informed life choices (Fleitas Alfonzo et al. 2022). Additionally, educational, health, and social care frameworks must actively recognise siblings as integral members of the caregiving unit, addressing invisibility and potentially distributing care more sustainably. Policy reform, particularly within statutory frameworks such as the Care Act (2014), should include formal recognition of sibling-carers and commitment to supporting them; not only in the act of care, but in navigating its lifelong implications.

Conclusion

This study highlights how caring responsibilities may shape emerging adulthood experiences of those who have disabled siblings. Rather than a time of identity exploration and autonomy, participants described balancing their own developmental transitions alongside family responsibilities and concerns about their sibling's future. The emotional complexity of these experiences, characterised by love, guilt and anticipated responsibility, was often associated with reduced opportunities, anxiety and uncertainty about the future. These findings highlight the importance of recognising and supporting the experiences of non-disabled siblings during emerging adulthood, while also ensuring that the perspectives and preferences of disabled people remain central to discussions about family support and future care. Support should include recognising siblings' contributions, providing appropriate emotional and practical support, and creating opportunities for inclusive family conversations about future planning throughout this important life stage.

Disclosure statement

The authors report that there are no competing interests to declare.

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