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Glass children: The lived experiences of siblings of people with a disability or chronic illness

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Abstract

Siblings of disabled or chronically ill children are often hidden family members and their needs for support might not be met. Current research however is limited in its understanding of siblings' lived experiences. This study uses semi-structured interviews to explore the lived experiences of 16 individuals (referred to as siblings) who grew up with a disabled or chronically ill brother or sister. Participants reflected on their childhood and adolescent experiences as siblings, focusing on their social interactions and relationships, social support, and wellbeing. Using thematic analysis, we identified four distinct but theoretically related themes; participants experienced (a) feelings of invisibility during social interactions, (b) psychological difficulties due to the internalisation of family roles or life conditions, and (c) feelings of guilt and self-blame. Finally, (d) social support was central as siblings were sometimes unable to understand their own needs, and support from family and peer groups helped them have their negative experiences validated. Our findings suggest greater support for siblings is required with a focus on addressing negative feelings and the availability of social support from people with similar experiences.

KEYWORDS

chronic illness, disability, lived experience, siblings, social support

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1 | INTRODUCTION

There are over half a million children and over one and a half million adults in the UK (referred to in this paper as siblings) who have a brother or a sister with a chronic illness or disability (Sibs, 2020). McKenzie Smith, Pinto Pereira, Chan, Rose, and Shafran (2018) estimate that between 7 and 17% of children are siblings of children with a chronic illness, which includes both mental health and physical disorders. Unlike those with a disabled parent, who are more readily identified as young carers in need of support (Clay, Connors, Day, Gkiza, & Aldridge, 2016), children and young people with a disabled or chronically ill brother or sister are less likely to be perceived as a population with significant and specific vulnerabilities and needs (Rainbow Trust, 2018) with the impact of their complex experiences often being overlooked. Thus, findings on siblings' lived experiences of growing up with a brother or sister with disabilities or chronic illnesses are rather limited and scarce in terms of the daily stressors or feelings that siblings might face, their psychological responses to them, and the importance of social support. Our aim in this study is to address that gap in the literature through an in-depth qualitative interview study that examines the lived experiences of siblings of people with a disability or chronic illness as well as processes of social support.

1.1 | Sources of distress, mental ill health, and the centrality of social support

Traditionally a renegotiation of family rules and roles will take place during the transitional period of a child moving into adolescence. However, in cases where there might be a build-up of family stress due to the presence of a person with a disability or chronic illness, it is not uncommon to observe an increase of psychological difficulties during such periods. Empirical focus in the past has been on a range of stressors involving family-related factors (Kvisti, Nielsen, & Simonsen, 2013; Mailick Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001), educational impact (Hastings, 2014; Kovshoff, Cebula, Tsai, & Hastings, 2017) and social challenges in terms of peer relationships (Bluebond-Langer, 1996) that might emerge. Experiences of isolation and sadness have been reported as a result of feeling misunderstood (Condon, 2010), especially where the sibling is unable to spend time with peers who share similar experiences.

Studies have explored the extent and variety of stressors for those providing informal care for family members (Pearlin, 1989; Pearlin, Mullan, Semple, & Skaff, 1990). However, despite being less likely to experience the same volume of caring responsibilities as their parents, these young people are still open to stressors identified in families with a disabled or chronically ill member. These include primary stressors such as the cognitive status and potential associated challenging behaviour of the family member, or secondary stressors such as the financial hardship that the family might be facing, or loss of self, role captivity, and role strain due to the constriction of social life (Pearlin, 1989; Pearlin et al., 1990). Role strain – that is, the stress of trying to fulfil multiple role obligations (Goode, 1960) – may be observed in young siblings attempting to balance caring responsibilities with schoolwork, being a “good son/daughter” for their parents, and any additional identities or obligations they hold or are endeavouring to develop. If the demands of their role as a sibling become too onerous, perhaps exacerbated by the additional stress of caring responsibilities, the associated role strain can lead to increased anxiety, depression, or even yielding of the specific role and the caring responsibilities associated with it (Pearlin, 1989; Pearlin et al., 1990; Stoneman, 2005).

Children aged nine and ten have been found to recognise and understand the responsibility to be relational, taking account of others' feelings and happiness when making decisions, especially within their families (Such & Walker, 2004). Siblings' awareness of their caregivers' distress or worries, as well as the demands on their time through their brother or sister's additional needs, may lead them to make self-censoring choices about their own behaviours to protect those adults from further concern (Tritt & Esses, 1988). Indeed, one study found that 58% of adolescent siblings had unexpressed emotions regarding their disabled sister or brother (Opperman & Alant, 2009).

The implications of comparable negative life events within the household, parental stress, and relational and social isolation or loss are predictors of the four most common childhood internalising disorders: depression, anxiety, somatic complaints, and teenage suicide (Liu, Chen, & Lewis, 2011). However, the presence of meaningful and supportive relationships and the social support they render available have been found to have the potential to mitigate against deleterious outcomes such as social isolation, stress, and mental and physical health difficulties (Simich, Beiser, & Mawani, 2003). The importance of social support as a protective factor of wellbeing and mental health has been observed in a variety of situations, and so its theoretical application to siblings as a group with shared, challenging experiences is not incongruous. Usually, where secure peer relationships exist, they allow for authentic expression of thoughts, feelings, and behaviours all of which have been linked with lower scores for depression, anxiety, and stress (Foubister, 2017). Specifically, young siblings who have been able to spend time with others in similar situations, such as through support groups, reported multiple benefits, including a reduction in feelings of isolation (Naylor & Prescott, 2004). Similarly, the experience of common fate (i.e., facing a common distressing factor) can often lead to an emergence of shared social identity (Turner, Oakes, Haslam, & McGarty, 1994) and the latter in turn can facilitate the provision and expectation of social support from fellow group members, which can be beneficial for wellbeing (Haslam, Jetten, Cruwys, Dingle, & Haslam, 2018). Moreover, people are more likely to seek and accept support that comes from fellow group members (Jetten et al., 2017). However, despite the potentially powerful protective role of social relationships (Bellin & Kovacs, 2006), evidence on the positive or negative effects of social interactions and social groups during the sibling's development and the course of everyday life are limited and further exploration is necessary. Where it has been trialled, school-based support for siblings and young carers has been found to be varied and "tokenistic" (Clay et al., 2016, p.77), with many siblings not viewing school as a place where they expected to receive sibling-specific support, often due to a lack of understanding and awareness from teachers. To improve such negative experiences, the charity "Sibs" piloted a school-based intervention, in recent years, for siblings which yielded some positive changes for participants, demonstrating the efficacy of targeted interventions (Hayden, McCaffrey, Fraser-Lim, & Hastings, 2019).

Overall, as we highlighted above, siblings face a variety of personal and social stressors and there is a need for social support to mitigate potential negative outcomes. Our aim in this paper is to address the literature gaps in relation to (a) siblings' lived experiences of growing up with a brother or a sister with a disability or chronic illness, (b) how this specific life condition might be transferred outside of the household and shape their social interactions and subsequent psychological responses, as well as (c) the dynamics of social support.

2 | METHOD

2.1 | Participants

We interviewed 16 individuals that identified as siblings of a brother or sister with a disability or chronic illness. Fourteen participants were female and two were male. The participants were between 20 and 68 years of age ($M = 33.25$, $SD = 14.31$). All but one were from the UK and Northern Ireland, with one participant being from Germany. Two participants reported having two disabled brothers or sisters, with another two siblings discussing someone who was no longer alive.¹ Family members' diagnoses and conditions were recorded as provided by our participants, and their ages ranged between 16 and 52 ($M = 28.25$, $SD = 8.96$) (see Table 1 for further details). No further personal or demographic information, such as occupation or ethnicity, was collected. Recruitment entailed tweeting details of participant inclusion criteria (having a disabled or chronically ill brother or sister; being over the age of 18; not having been home-schooled) from the first author's personal Twitter account and sharing the details of the study with several organisations related to disabilities or chronic illnesses and researchers within the UK. Five participants responded to tweets, with the remaining 11 recruited through a conference run by the sibling charity "Sibs"; whilst attending the event in a personal capacity, the first author was able to share the details of this study

TABLE 1 Participant information and characteristics of brothers or sisters^a

Participant	Participant age	Family member with disability	Family members' conditions
P1	21	Brother	Autism
P2	23	Brother	Crohn's disease, epilepsy
P3	56	Sister	Moderate/severe learning disabilities, epilepsy, hypertrophic cardiomyopathy
P4	27	Sister	Complex learning disability
P5	20	Brother	Autism
P6	34	Brother	Moderate intellectual disability, autism, ADHD
P7	23	Brother	Autism, catatonia
P8	54	Sister ^b	Williams syndrome
P9	32	Sister	Family quadriplegic cerebral palsy, epilepsy, additional brain injury, learning difficulties
		Brother	Grand mal epilepsy, bipolar disorder
P10	22	Brother	Acquired brain injury, learning difficulties, epilepsy
P11	26	Sister	Quadriplegic cerebral palsy, epilepsy
P12	24	Brother	Autism
		Brother	Asperger's
P13	27	Brother	Autism
P14	38	Brother	Cerebral palsy, periventricular leukomalacia
P15	68	Brother ^c	Severe learning difficulties, epilepsy, autism
P16	37	Brother	Cri du chat

^aWe intentionally do not refer to individual participants' gender or their family members' ages to reduce the risk of participants being identified.

^bDied in 2004.

^cDied an unspecified number of years ago.

with other attendees, several of whom agreed to be interviewed. All participant information was anonymised at the transcription stage. Participants' names have been removed and replaced with "P" followed by a number (e.g., P2 indicates Participant 2). We also removed participants' gender from both the analysis and from Table 1. Where mentioned, the names of participants' brothers and sisters have also been removed and replaced with [brothers' name] or [sister's name].

2.2 | Interviews

All interviews took place over the phone or on Skype between March – April 2020 and lasted from 27.37 to 66.39 min ($M = 43.53$ min, $SD = 11.27$, $total\ duration = 702.1$ min). Interviews followed a semi-structured format and focused on topics regarding childhood experiences as a sibling, support received, friendships, school, and general mental health and wellbeing. Due to the potentially sensitive nature of the topic, participants were reminded at the start of the interview that they could pause, skip questions, or stop at any time. Flexibility regarding interview structure and question content was particularly required on a couple of occasions when siblings felt emotional due to the memories discussed. In these instances, participants were asked if they would like to terminate the interview, but all chose to complete the interviews. Written consent was obtained from all participants before the interviews for them

to be audio-recorded and transcribed in full. Ethical approval for the study was granted by Canterbury Christ Church University and no form of remuneration was offered or given to participants.

The 11 participants recruited through the conference were aware that the first author was also a sibling herself, as the conference was only open to those with a brother or sister with a disability or chronic illness. This knowledge may have influenced their responses in some way, but there was no significant difference in content or tone between these and the five interviews conducted with individuals recruited through Twitter. On those occasions, the first author disclosed her status as a sibling towards the end of the interview in a moment that felt appropriate. The interview questions were designed by all three authors. Once the first author conducted the first interviews, all three authors discussed the appropriateness and usefulness of the interview questions and participants' responses to them to ensure that data of high quality would be collected.

2.3 | Analytic approach

Once the interviews were transcribed verbatim by the first author, the data were examined using thematic analysis (Clarke, Braun, & Hayfield, 2015). Considering the lack of theoretical background through which to drive our reading of the data, we selected an inductive approach whereby our themes were constructed in a bottom-up manner. During the first reading of the transcripts, we took initial notes of parts of the interviews that were related to our research question, namely participants' experiences of living with a brother or sister with a disability or chronic illness. In subsequent readings of the data, we created codes (analytic units; Braun & Clarke, 2020) that helped us capture various aspects of our initial observations. We then started merging codes of similar content. These clusters of codes were then re-worked until they formed distinct and theoretically important themes that elucidated different aspects of the data and by the extent of participants' experiences. Reading of the data, coding, and early theme development were primarily carried out by the first and third authors, followed by discussions between all three authors regarding the appropriateness of the themes and their accurate representation of the data. The extracts used to substantiate our results below were selected for their richness and ability to represent participants' emotions or experiences, with any omitted text indicated by square brackets and ellipses: [...].

3 | RESULTS

Through our analysis, we constructed four independent but theoretically related themes that capture participants' experiences of growing up with a brother or sister with a disability or chronic illness. The themes reported below comprise participants' (a) feelings of invisibility during social interactions, (b) psychological difficulties due to the internalisation of family roles or life conditions, (c) experiencing guilt and self-blame for not being able to offer constant support to their brothers or sisters or due to leading independent lives, and (d) issues related to social support such as siblings' inability to understand their own needs and the importance of support from family and peer groups in helping them to have their experiences validated.

3.1 | Feeling invisible to others during social interactions

As the healthy, able-bodied siblings of people with additional or complex needs, many participants reported a disparity of attention received between themselves and their brother or sister. As we can see below, this often came from immediate or extended family, or other adults known to them, even during demanding times such as during the death of a family member:

P3: Nobody really asked me anything. Like when my mum actually died, everyone just kept asking me how my sister was coping with my mum dying, nobody actually asked me how I was, they asked me how my dad was or how my sister was, but nobody actually asked me how I was.

P13 below further discusses the issue of invisibility and the feelings it generated. For some participants, being a sibling extended beyond a family role or a demographic characteristic and became an identity (“sibling with a capital S”). In turn, this identity affected participants' interpersonal relationships and communication in that others would primarily refer to their brothers or sisters rather than themselves, generating feelings of invisibility and neglect:

P13: If I wasn't a sibling with a capital S, if he was just a regular sibling, if I saw his teacher or something, and she knew me, she wouldn't default to asking how he was. The commonsense thing is you ask the person in front of you how they are, and then go “how's the family?” But it's like you're just invisible, you're just a gateway to see how your brother is. And it's like “I'm here too”. Ask me! I'm the one that stood here!

Some participants also referred to interactions that generated positive feelings, precisely due to a sense of acknowledgement and recognition of one's presence and individuality beyond their status as a sibling. For example, P5 below discusses the need for questions from others that address one's personal feelings and perspective, explaining that when a person close to them eventually addressed P5's state and feelings, the latter experienced a sense of validation:

P5: it would be nice for somebody to say “and how's that to live with?” or “how does that make you feel?” Because nobody ever asks that. I mean, I have a running joke with one of his old teachers, I used to see her because she would come into the shop where I worked every so often, and her first thing would always be to ask how my brother was before she asked how I was. It took her a few times, and I think the fifth or sixth time she came into the shop she was like “[...] I realise I've been really ignorant, so how are you?” And I was like “oh, I'm really well, thank you! How are you?” And we got about five minutes in before she said and “how is he?” I could tell she was waiting to ask, but she was making a conscious effort. And that really touched me, [...] so I felt actually quite validated by that.

3.2 | Psychological difficulties due to the internalisation of family roles or life conditions

Apart from a sense of invisibility due to their status as a sibling, participants also reported experiencing psychological difficulties described as stemming from the internalisation of their family roles and wider life conditions. For example, P12 refers to their anxiety which, with the help of a school counsellor, was traced as originating to their experiences of living with an autistic brother and the difficulties of managing his diagnosis and difficulties in life:

P12: I remember a school counsellor [...] she took me aside, especially when my anxiety was getting really bad at school, and she said “shall we just have a chat?” And she was the first person that suggested to me that some of the things I might be finding difficult at school might be down to the fact that I am a sibling of someone who is autistic. And I had never reflected before on there being an issue with my brothers' autism in me, if you see what I mean. I always thought of it as “I just feel awful for my brother, he's the one having to go through that”, and I never really reflected on the fact of how the diagnosis might have affected me, because I was like “I'm fine, I'm neurotypical, it's not a

thing to affect me". So that was probably the first time I really reflected on it, was actually a teacher addressing it to me [...] it's kind of a relief when you say "ah, that's probably what's been the source of this anxiety for however long". But it's also kind of difficult because it makes it very real [...] when I realised it was affecting me as well, it just made me very angry at the world.

Similarly, P11 talks about negative feelings and anxiety generated due to worries about their sister across a range of contexts including school, other people's behaviours, and about their own relationship. Participants often mentioned that they repressed such feelings due to perceiving them as inappropriate ("you shouldn't be having those feelings"). Expressing any feelings or concerns (such as in the case of P11 below) was often treated as potentially invalidating parental struggles or raising further concerns to people already perceived as feeling troubled. Thus, on some occasions, internalisation was strategically performed by participants due to a lack of alternative sources of support, but also at the expense of their own wellbeing:

P11: I think I had a lot of those anxieties that I kept inside because I felt bad probably for feeling worried about [sister's name] being at school, and being worried about her being my sister, and being worried about what people might say about her, and worried. I think all of those anxieties that I had, I probably felt like I shouldn't have been feeling like that [...] I think that because my mum is so inclusive, and fought so hard at giving [sister's name] an amazing life, I think I would have worried if I had said to my mum or anyone else that I'm worried about [sister's name] coming to school, I would have thought that it would be badly received. So I probably kept those feelings quite deep, and thought "you shouldn't be having those feelings". Whereas if I had somebody who wasn't a family member, and wasn't a friend, who was independent and was there to support... A safe space where I could have said how I was feeling, and they could advise me

Many participants also reported a subsequent recognition of how they repressed their feelings. Negative externalising reactions to psychological distress ("inconsolable", "couldn't stop crying"), were eventually attributed by participants to emotional repression that became even harder to address without appropriate support and communication:

P7: I was just inconsolable, I just couldn't stop crying [...] I just recovered from those situations and brushed it off and started walking, but I think what that shows me when I look back is that all the pain was there, it definitely was lurking under the surface, but there was no one asking the questions or talking about that stuff to open the lid and let it out.

3.3 | Experiencing guilt and self-blame for not being able to offer constant support to siblings or due to leading independent lives

The third theme in our dataset concerns feelings of guilt that various participants reported experiencing due to their status as a sibling. One reason for feelings of guilt was participants' reported inability to provide their brothers and sisters with constant support:

P4: I kind of feel guilty about not ever, trying to, you know, be there for them, well not be there for them because I didn't need to be there for her because she had a friend at the time, but be more involved and know her a bit better because then you could try to steer her in a bit better directions when she got a bit older.

For other participants, guilt did not stem from their perceived inability to be supportive at all times, but rather due to achieving more in life compared to their sisters or brothers. Thus, guilt was manifested not at the interpersonal level but was closer to some form of self-blame in relation to their sisters' or brothers' life stages and progress. For example, P9 refers to guilt arising from finishing university and not facing mental health difficulties, whereas P6 reports guilt and discomfort due to attending medical school. Thus, it was common for participants to feel uncomfortable for making choices that placed them on an independent path that their brothers or sisters could possibly not follow:

P9: I feel a bit guilty maybe that I still managed to achieve more than my brother, who didn't finish uni and has had all these mental health problems since, that makes me feel a bit... guilty... that I did okay.

and

P6: I've always felt a lot of guilt about going away to medical school, and the impact that had on [brother's name]. That never completely went, even now. So I've never felt completely comfortable with that.

3.4 | The centrality of social support: Siblings' inability to understand own needs, and the importance of peer and family support in validating negative experiences

In the previous themes, we discussed how participants reported feeling invisible to others, as well as guilt and the internalisation of their life conditions that led to psychological discomfort. A final central theme that we constructed from participants' accounts was related to issues regarding social support. Participants referred to a lack of social support as both themselves and others did not recognise or address important needs both in earlier and later life. For instance, it was common for participants to report that they did not identify a need for support during their early years and would have potentially rejected any offers, which stood in contrast to how they would approach the issue retrospectively by accepting any support made available to them. As P11 states, one reason for not acknowledging the need for support concerned participants' inability to recognise and express their feelings as well as the need for assistance:

P11: I didn't think of me needing that support. But looking back on it, I think I did need that support. [...] when you're a bit older and you can look back and think "yeah actually, I probably was struggling at that time". I think if somebody had said to me "are you okay, are you struggling?" I probably would have said, "yeah, I'm fine". Actually, I probably wouldn't have realised unless somebody had really come up to me. Having said that, I think as I got a bit older, and there had been a support group there and it had been offered to me, I think I would have taken it. [...] I probably didn't have the words or the skills at that time to express how I was feeling.

Apart from a lack of recognition of one's feelings and the inability to seek support, some participants retrospectively expressed their need for greater guidance and support. For example, P7 below refers to the need to be explained as a child about the needs arising from having a brother with a disability so as to create specific expectations regarding the challenges that one will potentially face from these specific family circumstances:

P7: I would have liked anyone, my family included, to have been talking to me about the future with [brother's name], because that's been a bit of a bulldozer that's hit me in the face in the past few years [...]. I wish that there had been services like going to "Sibs" now, that would have been amazing to

know siblings back then, and I think that would have started me on the journey of realising how different my life was from other people's.

On other occasions, support was mentioned not only in terms of its provision from other family members but to how it can stem from peers. Participants retrospectively mentioned that regular communication with peers would have been beneficial in terms of facilitating the open expression of feelings or negative experiences while not being monitored by others (e.g., family members), venting and feeling heard, validated, and having one's own needs recognised:

P13: I think it probably would have been either another sib that I could have spoken to, whether it was a phone call or a meet up every couple of months or whatever, without your parents listening in if you say the right thing, but where you can honestly and openly say, well not that you would say as a 6-year old, but "I've had a crap couple of months, he's really been getting on my nerves, he's been getting away with blue murder, I'm fed up, I can't do the things I want to do, please tell me that you understand what I'm going through?" And I think that would probably be enough.

Apart from regular contact with peers, participants also mentioned the need for participating in a wider social network that comprises people with similar life experiences and facilitates expectations and the provision of social support. For example, P14 below mentioned that sharing a group with other siblings can make one feel understood and heard, normalising one's own experiences and difficulties:

P14: I think having people that understand. And because I haven't really had anyone that understood, that's been tricky. Finding "Sibs" [UK] and being able to talk to another sibling and being like "wow, there's somebody else in the world who's been through something similar!" is really helpful, and to know that some of those feelings you have and those family dynamics are stemming from what happened to you. It doesn't necessarily mean that you can move past it, but it just makes you understand it a bit more, and go "it's OK, this is normal for someone in my situation".

4 | DISCUSSION

This study complements the growing body of sibling research and provides new knowledge and insights into the experiences of growing up with a brother or a sister with a disability or chronic illness. Although holistic and interwoven, the results of this study fell into four main themes: participants' feelings of guilt, the internalisation of feelings stemming from adverse life experiences, a sense of invisibility during social interactions, and a reported lack but also need of social support from family, peers, and wider networks comprising people with similar needs and experiences. Some themes were in line with the findings of existing literature, such as the presence of internalising behaviours (Sharpe & Rossiter, 2002), the importance of social support (Haslam et al., 2018), and a frequent disparity in attention received from adults when compared to the disabled brother or sister (McHale & Pawletko, 1992). However, the topic of guilt was not anticipated by previous research but was mentioned by multiple participants. Social support and access to a peer group with shared experiences from an early age was of great importance to the participants and was strongly associated with more positive outcomes for mental health and wellbeing; for participants who had not experienced this, most expressed that its presence would have been beneficial to them when they were younger.

Existing literature suggests that an absence of social support from others with shared experiences can contribute to feelings of social isolation, stress, and other negative mental health outcomes (Bellin & Kovacs, 2006; Simich et al., 2003). This was observed in this study with those participants who chose not to discuss their experiences with friends due to concerns about their response or a lack of understanding, as they were more likely to report regret, sadness, or frustration, and that they had not been able to fully express those emotions. The idea of unexpressed

emotions was closely associated with the delayed recognition of particular challenging experiences, and the impact these had on the participants' lives. As previously stated, participants often exhibited an elevated awareness of the needs and feelings of those around them from a young age (Tritt & Esses, 1988). This was balanced by the significant realisation later in life that there were aspects of their own lives as siblings which they had not understood or processed (Sharpe & Rossiter, 2002). There was relatively little mention of externalising behaviours, but almost all participants reported the presence of internalising behaviours in childhood, adolescence, and even adulthood, increased rates of which have been observed in past studies (Fisman, Wolf, Ellison, & Freeman, 2000; Lamorey, 1999). The qualitative nature of this self-reflective study allowed these adult siblings to provide their own descriptions and understandings of the processes underlying this in a way that they often could not verbalise as children. One of the most frequent explanations was a desire to make what they observed to be an incredibly challenging situation for their parents a little easier by self-censoring the expression of their own needs. Furthermore, an expectation that others, adults and children alike, would and could not understand their situation and feelings as a sibling was felt to be a driving factor in not speaking up and therefore internalising negative emotions. This reflects existing studies which show that feeling misunderstood by others can lead to increased isolation and sadness (Condon, 2010).

These internalising behaviours are often linked with the disparity of attention reportedly received by siblings from many of the adults in their lives (McHale & Pawletko, 1992). Although clearly related to interactions with others, this theme was explored under psychological impacts as participants tended to focus on the personal, emotional outcomes of these situations, rather than the events themselves. Many siblings in this study felt that the nature and additional time demands of their brother or sister's condition often resulted in the inability of others to see their needs too, hence this study's usage of the "glass child" metaphor (TEDx Talks, 2010). This created a sense of invisibility both inside and outside of the household during interaction with others, which carried significant levels of frustration and sadness for the siblings, resulting in powerful and memorable reactions when those needs were eventually recognised by others. "Invisibility" in this context is a noteworthy finding which has not previously been observed in these terms in sibling literature and has strong implications for sibling support. To meet siblings' needs and provide appropriate support for their particular challenges, those issues must first be recognised: if siblings themselves felt that this vital step was rarely accomplished by the adults in their lives, it is unsurprising that they also reported a higher level of unmet emotional needs, impacting on their wellbeing.

One particularly complex area of discussion unanticipated by previous research was that of self-reported guilt. Although previous researchers have tended to comment on the presence of guilt feelings, reviews of the work have failed to find explicit evidence (Buchanan & Rotkirch, 2021). In the current study several participants reflected on the apparent ease of their own life when compared to their brother or sister with a disability or chronic illness, such as in daily tasks, reaching milestones, and independent living, and this often spontaneously segued into expressions of guilt or self-reproach for their own health and abilities. There was also concern about how their actions would impact their sister or brother and their family, as well as internal conflict about both the legitimacy and outward expression of negative emotions regarding their brother or sister. As many siblings themselves reflected, it is almost impossible to know to what extent the various elements of their personalities and coping mechanisms were the direct result of their experiences as siblings. Whilst a hugely significant aspect of their childhood and adolescence, it is important not to fall into the trap of presuming that any challenges siblings face are necessarily due to the presence of their sister or brother and their disability or chronic illness. Young siblings' lives are every bit as rich and complex as their non-sibling peers, with a full complement of events and relationships outside of experiences with their disabled brother or sister.

4.1 | Limitations and future research

One of the limitations of this study was the disparity of gender representation: 14 of the 16 participants were female. A more even division could have allowed for a greater understanding of how traditional gender roles within

families, if present, may impact sibling experiences, particularly regarding caring responsibilities and levels of internalising and externalising behavioural responses to stressors. Similarly, data on the number of other siblings in the family and the participant's position within that were not collected. A child with a disability or chronic illness can have an impact on both individual family members and the family unit as a whole, and so this additional demographic information may have provided further insight into any underlying factors and processes at play in sibling outcomes.

Like much research carried out this year, this study was impacted by the effects of COVID-19. Although ethical approval was originally granted for face-to-face or phone interviews, the national lockdown meant that permission for face-to-face interviews was rescinded, rightly, for safety reasons. Fortunately, this did not disrupt the schedule or quantity of data collection, but any potential differences in interview tone or content that may have occurred in face-to-face interactions cannot be known. Some participants whose brothers or sisters lived in supported accommodation or who were particularly vulnerable to the virus due to their condition mentioned additional concerns they were facing given the current situation, and so this heightened sibling-specific anxiety may have had some bearing on their overall emotional state during the interviews. However, as the primary focus of the questions was that of childhood and adolescent reflections, the memories recalled were all from a pre-COVID-19 time and thus unaffected. The methodology of the study itself was somewhat unusual: although speaking to adult siblings about childhood allowed for levels of self-expression and reflection which would be unlikely from younger participants, this style of data collection could run the risk of misremembering events or projecting adult experiences and emotions onto the younger self. However, many participants were quick to differentiate between their recent and childhood feelings, and often explicitly distinguished the two to avoid conflating them.

This study provides both rich findings on the lived experiences of siblings and much scope for future research. As discussed previously, a particularly noteworthy finding of this study was the prevalence of feelings of guilt amongst siblings. An interesting direction for future research would be to explore this phenomenon further: it would be worth considering potential connections or parallels with survivor's guilt or even grief, as young siblings attempt to navigate and process their significant differences from their sisters or brothers who have a disability or chronic illness, and the subsequent implications for both of their futures. The efficacy of peer support has been well-documented in psychology and there are indications through the recent pilot of the Sibs Talk intervention (Hayden et al., 2019) that increased understanding and knowledge from teachers can contribute towards positive outcomes for siblings. This study demonstrates that many siblings feel strongly that they would have benefited from both contact with other siblings and greater awareness of their situations from teachers: research into the underlying processes of this may prove beneficial in devising future interventions and more formal support structures for young siblings.

5 | CONCLUSION

An understanding of the particular and often extremely challenging events and emotions that young siblings experience is frequently limited, even from those closest to them. This study demonstrates that many of the negative outcomes reported by siblings are not, in fact, the direct result of their brothers' or sisters' conditions, but rather the consequences of this insufficient understanding and support. Even for those with the advantage of a supportive social network, and the full recognition and meeting of their needs by others, it is undeniable that being a sibling is a hugely impactful identity and experience. In her discussion of the "glass child" analogy, Alicia Arenas describes how many of the more hurtful or negative potential outcomes associated with growing up as a sibling could be transformed by even the smallest of acts from others (TEDx Talks, 2010), an observation also echoed by the participants of this study.

CONFLICT OF INTERESTS

The authors declare that there are no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

ETHICS STATEMENT

This research has been approved by the institutional review board at Canterbury Christ Church University, UK.

ENDNOTE

¹ As the study primarily focussed on childhood experiences with a disabled or chronically ill sibling, individuals whose brothers or sisters died in adulthood were not excluded from participating.

DATA AVAILABILITY STATEMENT

The raw dataset is not available due to privacy concerns and ethical restrictions.

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