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RESEARCH

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The experiences of children with Williams syndrome and their nondisabled siblings of their relationship

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Abstract

Objective: This study explored sibling relationships from the perspective of children with Williams syndrome (WS) and their nondisabled (ND) siblings.

Background: WS, a genetic condition with a profile that can include intellectual disabilities, hypersociability and anxiety, might be predicted to impact sibling relationships, but this has not been qualitatively explored from the children's perspective.

Methods: Thirty-nine children (6–17 years; 20 male, 19 female) participated: 20 sibling dyads in which one child had WS and the other was ND (one child with WS did not participate). Children were interviewed about experiences of their relationship. Data were analyzed with reflexive thematic analysis.

Results: Siblings described multifaceted relationships, in which love and positivity were overtly evident and embedded in the reciprocity of sibling expertise and support. Children skillfully navigated the spaces and boundaries of their relationship across home, school, and friendship contexts, with parent support. ND siblings' knowledge of WS supported interactions, relationships, and advocacy, but some children with WS felt their sibling lacked knowledge of the challenges of WS.

Conclusions: The WS profile was woven through multidimensional relationships.

Implications: Findings have implications for how parents are supported to help siblings navigate relationships and learn about WS, and how schools support WS sibling relationships.

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KEYWORDS
developmental disability, qualitative, sibling relationship, thematic analysis, Williams syndrome

Sibling relationships hold a unique and important role in children's lives, and they are shaped by a multitude of child, family, societal, and cultural factors (White & Hughes, 2018). In particular, they may be influenced by the presence of a developmental disability in one child (Gray et al., 2024). Nondisabled (ND) children report a range of experiences and outcomes associated with having a sibling with developmental disabilities, including taking on additional caretaking responsibilities, negative school experiences, poorer mental health, and positive personal growth (Gregory et al., 2020; Pavlopoulou & Dimitriou, 2019; Petalas et al., 2009; Wolff et al., 2022). Findings to date are relatively equivocal on the role of demographic characteristics in ND children's outcomes, although sibling relationship experiences do change as children age (Wolff et al., 2022). There are some commonalities in sibling relationships across different developmental disabilities, but they do differ depending on the specific diagnosis of the child (Shivers et al., 2019; Wolff et al., 2022) and research findings relating to one developmental disability cannot be generalized to all. Although sibling relationships in some developmental disabilities, such as autism, have been extensively explored (e.g., Leedham et al., 2020), the nature of these relationships when one child has Williams syndrome (WS) is far less well understood.

WS, which arises randomly through the hemizygous deletion of approximately 28 genes on one copy of chromosome 7q11.23, occurs in up to 1:7,500 individuals (Kozel et al., 2021). It is associated with mild–moderate intellectual disability and an uneven cognitive profile, although this profile varies across individuals and across the lifespan (Farran et al., 2024). Sibling relationships might be impacted by aspects of the WS phenotype, including sociability, anxiety, and health difficulties. Children with WS can have a strong interest in interacting with others ("hypersociability"), high levels of affective expression, and higher levels of empathic concern than developmentally matched controls (Doyle et al., 2004; Plesa Skwerer & Tager-Flusberg, 2016). However, sociocognitive difficulties are also reported, as are challenges with friendships (Gillooly et al., 2024). Some individuals with WS also experience heightened anxiety (Royston et al., 2017) and a range of physical health difficulties, including cardiovascular disease and slow physical growth (Kozel et al., 2021).

Although WS shares some characteristics, such as intellectual disability, with other developmental disabilities that have been studied in relation to sibling relationships (e.g., Hayden, Hastings, et al., 2019), its distinctive developmental profile may give rise to sibling relationship experiences and sibling support needs that differ from those found in other developmental disabilities. However, although researchers have explored the perspectives of parents of children with WS in relation to their own well-being or family functioning (Ashworth et al., 2019; Pereira et al., 2023), there has been minimal research into sibling relationships, and no qualitative research exploring the relationship from the perspective of the children themselves. The ways in which aspects of the WS profile influence sibling relationships are therefore not well established.

In terms of existing research, Scallan et al. (2011) explored WS sibling relationships from the parents' perspective, finding that many reported positive impact on ND siblings, such as them becoming more caring and more aware of disability. Cebula et al. (2019) explored adjustment quantitatively in ND siblings of children with WS. They found varied, but largely positive sibling relationships overall, with ND sibling adjustment similar to population norms. However, siblings themselves reported slightly more behavioral, emotional, and relationship difficulties than parents perceived them to have, emphasizing the importance of understanding the children's own perspective.

Relating specifically to the WS phenotype, Cebula et al. (2019) found significant positive associations between the prosocial behavior of the child with WS and warmth in the sibling relationship. Anxiety of children with WS has been found not to be significantly associated with anxiety or adjustment in their ND sibling, or with relationship quality (Cebula et al., 2019; Leyfer et al., 2009). Some specific medical conditions in WS, such as congenital heart disease, have been shown to be associated with parent-reported family quality of life (Pereira et al., 2023), although previous research has found that the total number of medical conditions of the child with WS is not associated with ND sibling adjustment or with sibling relationship quality (Cebula et al., 2019). Although these studies suggest largely positive sibling relationships and potential associations with sociability in WS, qualitative research may allow for a richer, more holistic understanding of the sibling relationship and of the impact of the WS phenotype on siblings' daily lives.

Other aspects of sibling experiences in WS have not been explored at all to date, despite their relevance for understanding sibling support needs. For example, having an autistic sibling has been shown to impact on ND children's school experiences, including lower feelings of school belonging and a role in supporting the autistic child at school (Gregory et al., 2020; Pavlopoulou et al., 2022), but this has not yet been explored in relation to WS. Siblings of children with WS may have unique school experiences (for example, relating to the hypersociability and anxiety of the child with WS) that would benefit from teachers' understanding and support, but schools are often not well informed about such rare disabilities (Fidler et al., 2002). Similarly, siblings of individuals with developmental disabilities report that their friends can be supportive, but do not always fully understand developmental disabilities or their experiences (Niedbalski, 2024). Again, the developmental profile of WS may lead to unique friendship experiences for ND siblings, but this has not yet been explored.

A sibling relationship, by definition, includes two or more individuals. Yet sibling research in developmental disabilities has often explored the relationship exclusively from the perspective of the ND sibling, with the views of the disabled sibling themselves excluded (Richardson & Jordan, 2017). This has marginalized disabled siblings and limited the breadth and depth of knowledge gained (Meltzer & Kramer, 2016; Meltzer & Muir, 2022). Despite calls for studies to include the perspectives of disabled siblings (Kovshoff et al., 2017; Meltzer & Kramer, 2016), few have included children with developmental disabilities and there are no published studies of the sibling relationship from the perspective of the child with WS. Yet interviewing children with WS about their relationships has been shown to be feasible. For example, Gillooly et al. (2024) used this method to explore friendship experiences in children with WS.

Current study

Given the dearth of qualitative research published about the sibling relationship from the perspective of either the child with WS or the ND sibling, and the potential for such research leading to a better understanding of children's support needs, we therefore undertook an interview study to explore this.

The research was framed by the Siblings Embedded Systems Framework (Kovshoff et al., 2017). This framework integrates elements of several theoretical models often used in developmental disability family research, including family systems theory (Minuchin, 1974), bioecological systems model (Bronfenbrenner, 1979), and the double ABCX model (McCubbin & Patterson, 1983), with these adapted and applied within the framework specifically to the study of sibling relationships. Although originally conceived in relation to siblings of autistic individuals, the framework is not specific to autism (Kovshoff et al., 2017) and has been recommended for use in other developmental disabilities (Hayden & Hastings, 2022). As this is a first study into sibling experiences in WS, we explored these experiences broadly and from the children's own perspective. This aligned well with the Siblings Embedded Systems Framework, which conceptualizes sibling relationships as actively shaped by children, and situated in dynamic integrated family, community, and societal systems. As outlined above, this study built on previous research findings of positive experiences of ND siblings of children with WS (Cebula et al., 2019; Scallan et al., 2011), fitting well with this framework, in which disabled children are not positioned a priori as a cause of negative outcomes for ND siblings. Further, the framework facilitates the incorporation of the perspective of disabled children, providing an ideal basis for this study, which explored sibling relationships from the perspective of children with WS and their ND siblings.

The study explored the question "What are the perceptions and experiences of children with WS and their ND siblings of the sibling relationship?"

METHOD

Participants

Thirty-nine children (6–17 years) participated in this study: 20 sibling dyads in which one child had WS and the other was ND. In one dyad the research design was not sufficiently accessible for the child with WS, even with parent support; in all other dyads, both siblings participated. The inclusion of both children within the dyad enabled a "rich sample," by ensuring a closeness of fit between the sample and the topic of interest: the relationship between the two children (Roy et al., 2015).

Table 1 provides parent-reported demographic information. Given the low prevalence of WS, participants are described at group rather than individual level to ensure confidentiality. The mean age was 10.89 and 11.30 years for the children with WS and ND siblings, respectively. Parent report indicated the diagnosis of the children with WS had been confirmed with fluorescent in situ hybridization testing ($n = 15$) or chromosomal microarray ($n = 3$), and one method was unknown. All the children with WS had at least one associated medical or health condition, the most common being sensory sensitivities ($n = 16$), sleep difficulties ($n = 12$), cardiac problems ($n = 11$), and mobility difficulties ($n = 10$). One child with WS also had co-occurring neurodevelopmental conditions (autism and ADHD). Although "nondisabled" best characterizes the ND sibling group, it should be noted that two had special educational needs (1 = dyslexia, 1 = unspecified). The interview data from these children were not noticeably different in content from the other children with ND and were therefore retained. All children were of White ethnicity and lived in the United Kingdom. Nineteen dyads were full siblings and one was half siblings. Siblings spent a lot of time together on average—more than 12 hours across a typical weekend—though there were differences across dyads.

Procedure

Ethical approval was obtained from the first author's institution. Families were included if they had a child with WS and another ND child, both 6–18 years old, who were both living at home together most of the time. For consistency, in families with more than one ND child, the one whose age was closest to that of the child with WS was asked to participate. Families were recruited via social media, with the assistance of family support charities, and via a mailing list of families who had participated in previous studies. Families were sent parent information sheets and two versions of a child information sheet: written and illustrated "easy-read." Consent was obtained from the parent. Verbal assent was given by all children, with additional written assent

TABLE 1 Sample parent-report demographic and developmental characteristics.

Characteristic	Mean (*SD*) or *N*
Child with WS ($n = 19$ [a])	
Age (years)	10.89 (3.68) (range: 6.17–16.31)
Gender (male/female)	13/6
Age of diagnosis (years)	1.89 (1.57) (range: 0.19–7.00)
Time since diagnosis (years)	9.05 (4.01) (range: 3.20–14.98)
Intellectual disability: mild–moderate/severe-profound	14/5
School attended: mainstream with support/specialist provision	9/10
ND sibling ($n = 20$)	
Age (years)	11.30 (3.15) (range: 6.17–17.84)
Age compared to child with WS: older/younger/same	12/7/1
Gender (male/female)	6/14
Gender match with child with WS	6
Family	
Two-parent/blended two-parent household	19
Annual household income greater than £45 k ($n = 18$)	12
Managing financially [b]	1.90 (0.91) (range: 1–4)
Total no. children in family [c]	3.00 (1.17) (range 2–6)
Sibling weekend time [d] (hours) ($n = 18$)	12.11 (7.37) (range 1–24)

Note. ND = nondisabled; WS = Williams syndrome. [a] The age of the nonparticipating child (male) with WS was 7.09 years. [b] 1 = Living comfortably; 2 = Doing alright; 3 = Just about getting by; 4 = Finding it quite difficult; 5 = Finding it very difficult. [c] Includes all sibling relationships (e.g., full, step, and half). [d] Parent report of the number of hours that the siblings spend together (e.g., playing, eating) over a typical weekend.

given by many. At the end of a home visit lasting around 2 hours (which included data collection for another research study as well as breaks), the researcher (A.G.) reaffirmed child assent, and then interviewed the children individually.

A single semistructured interview schedule was used with all children (regardless of age or WS/ND status) to enable an analysis that integrated data from all participants. This schedule (see supplemental materials) was developed by the research team, drawing on topics covered in qualitative sibling research in other developmental disabilities (e.g., Petalas et al., 2009, 2015; Tsai et al., 2018). The questions explored the children's views on aspects of their sibling relationships, including what it was like to be the other's sibling; whether they spent time together and if so, what kinds of activities they did; whether they spent time together at school; whether they spent time with their sibling's friends; and the extent to which they felt that their sibling was a source of support. Topic areas were broad in order to surface the issues that were important to the children themselves, rather than imposing the researchers' ideas of specific concepts drawn from previous developmental disabilities sibling research (such as differential parenting: Tsai et al., 2018). Focusing the interview questions on concrete aspects of the sibling relationship also ensured accessibility (Kramer et al., 2013). Following the approach of Kramer et al. (2013), the primary focus was on the relationship itself, rather than the disability: None of the initial questions mentioned WS, and the topic was not raised unless the child themselves did so (although participants were aware that this was a WS sibling study). The interview questions were designed to ensure that the siblings did not feel obliged to provide what they felt were socially desirable answers, mindful of the power dynamic of an adult from outside the family asking questions of children (Hayden & Hastings, 2022; Scott-Barrett et al., 2023). Additional prompts then enabled greater depth and detail (e.g., on what the siblings did together, or why they did not spend much time together). The interview questions were piloted with ND children and a child with another developmental disability; no changes were felt necessary following this.

The researcher allowed ample response time and modified the complexity of the questions as required depending on the child's age and understanding. The other child was not present in the room during interviews. Depending on the child's preference, a parent was either present in the room (but did not contribute) during their interview or in a nearby room. Mean interview length was 9 minutes (range: 4–15 minutes) and 11 minutes (range: 5–23 minutes) for children with WS and ND siblings, respectively (full transcripts for all children were available for analysis but the data on interview length were lost for five children with WS and four ND siblings). All interviews were audio recorded using a Dictaphone recording device and were later transcribed verbatim. Each child was given a £10 gift voucher to thank them for their participation.

Analysis

A reflexive thematic analysis was undertaken, led by the first author, following the six broad phases outlined by Braun and Clarke (2022). The first and second authors read the transcripts several times to familiarize themselves with the content, noting and discussing aspects of interest. Coding and generating of initial themes were then undertaken by the first author. Several "sweeps" of the transcripts were undertaken to develop initial codes. Drawing on previous sibling dyad analysis methods (e.g., Kramer et al., 2013), in some sweeps the transcripts were considered dyad by dyad, and in other sweeps all transcripts of children with WS were considered and then all transcripts of ND siblings. This process allowed for foregrounding of aspects of interest within and across the dyads and the neurotypes. As there was variation in the length and complexity of children's answers, a conscious effort was made to ensure that the views of participants who spoke more briefly were still centered in the analysis. Sample demographic characteristics were considered during analysis, though this was done with caution, mindful of the relatively small sample size. The first author reviewed the initial themes in relation to the transcript data. All authors then refined and named the final themes and interpreted them in the context of the wider literature.

The analysis process was more inductive than deductive, though it was informed by previous theory (particularly the Siblings Embedded Systems Framework, Kovshoff et al., 2017) and by research literature in this field. The authors' own identities, experiences, and theoretical positionality were crucial elements of the analysis (Braun & Clarke, 2022). The authorship team comprised academic researchers with experience of both Williams syndrome and sibling research. The team had personal experience of sibling relationships, including those with a neurodivergent child. This experience will inevitably have contributed to the framing of the interview questions, analysis, and interpretation.

RESULTS

Four themes were developed from the data (Figure 1). Some subthemes related predominantly to only the children with WS or only the ND siblings, whereas others related to both children, sometimes in similar and sometimes in different ways. Quotes are provided with CWS (child with Williams syndrome) or NDS (nondisabled sibling) and participant dyad number (1–20).

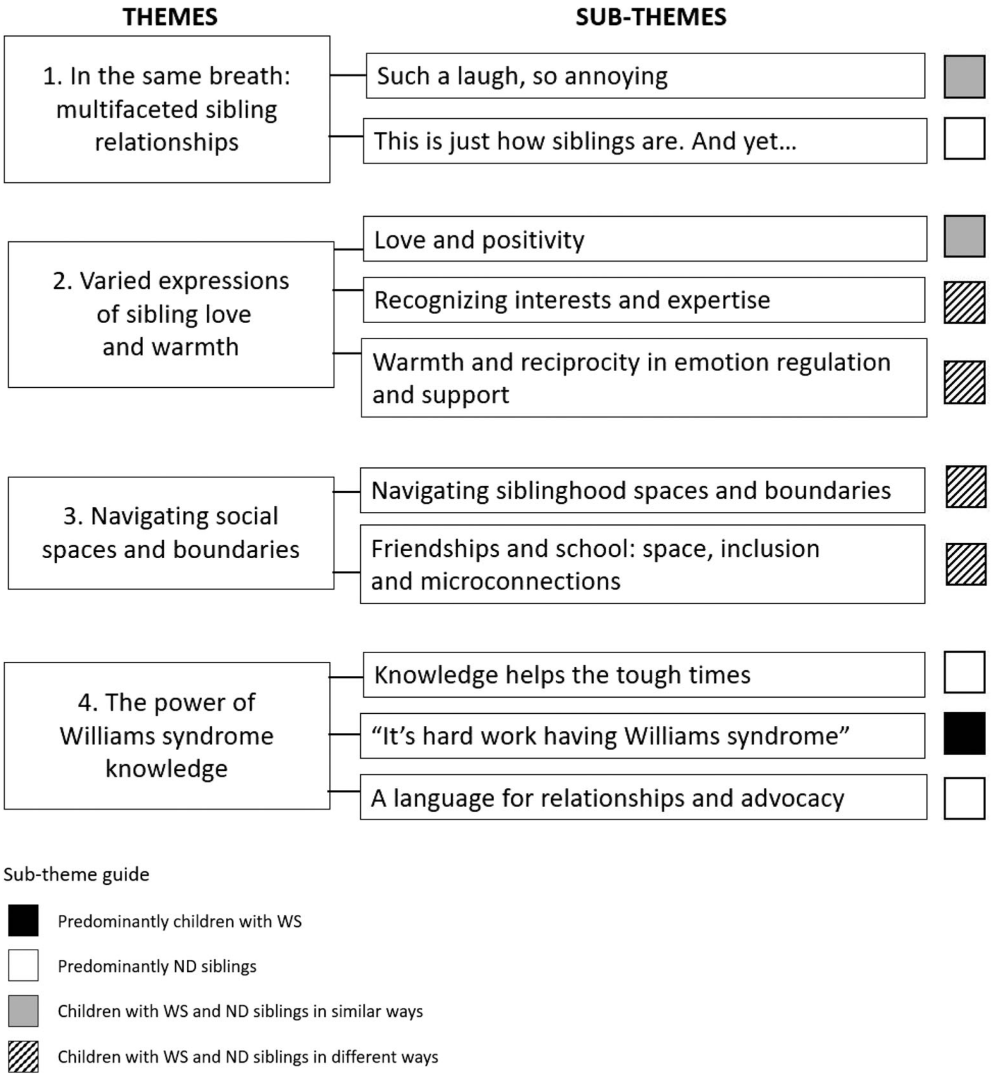

FIGURE 1 Themes and subthemes *Note*. ND = nondisabled; WS = Williams syndrome.

Theme 1: In the same breath: Multifaceted sibling relationships

Contrasting with the stark dichotomy of "benefits" and (often) "challenges" that characterizes much disability sibling research, the relationships described by the children with WS and their ND siblings were technicolored: simultaneously joyful, annoying, typical, and unusual.

Such a laugh, so annoying

Although some relationships were described in wholly positive terms, and a few were clearly predominantly challenging, for most of the pairs there was not a dichotomy—their siblings were both fun and annoying, often expressed in the same sentence: "She is funny, she is a bit annoying" (CWS-14); "Sometimes she annoys me then sometimes she is just a great laugh to be around and it's amazing" (NDS-20). This resonates with sibling relationship studies in other disabilities (Connors & Stalker, 2003; Pavlopoulou & Dimitriou, 2019) and with quantitative research findings of sibling relationship warmth alongside a degree of conflict reported by ND siblings of children with WS (Cebula et al., 2019).

The participants' relationships were at times playful and at others routine and everyday. There was variation across pairs in their specific activities but almost all talked about fun activities they shared: playing with toys for some, hanging out playing video games for others. For some siblings there was a sense of routine to this play, with activities chosen according to the time of day, weather, or season, emphasizing the longevity of the relationship. Arguing and annoyance featured in many pairs but was often balanced with joy and silliness. Song, dressing up, and performance was a focus for some: "yesterday we were watching *Strictly Come Dancing* and me and [NDS-2] performed a dance" (CWS-2); "Yeah pretending to be popstars with microphones and stuff, that kind of thing" (NDS-20). Although this is, perhaps, reflective of the social disinhibition and affinity for music often reported in WS (Thakur et al., 2018), there was clear enjoyment of these activities for some of the ND siblings too.

This is just how siblings are. And yet…

ND siblings often explicitly emphasized the typicality of their relationships and that it was just their norm: "We can either get along really well or really don't get along like most brothers and sisters" (NDS-14); "I just find that [WS is] part of my life so that's really just normal for me" (NDS-15). At the same time, some also reflected that they did not really think that they would want a "typical" sibling relationship, and some mentioned the joy they experienced from the aspects of the child's behavior they found a bit different from the norm: "He is just nice to play with and like most other brothers are mean" (NDS-11); "but you know it's good, and he is always giving random facts about fire engines and stuff" (NDS-9). The ability to "hold" both typical and different aspects of the sibling relationship has previously been reported in developmental disability sibling research (Petalas et al., 2015).

Although typicality was emphasized by ND siblings, they were also aware of aspects of WS that affected their play. Most commonly this was the child with WS's behavior (Theme 4), difficulty with understanding, or in a few cases, sensory sensitivities: "it's sometimes just a bit hard as she doesn't understand the concept of the game and she keeps going off" (NDS-15). Children sometimes chose their activities to accommodate this, with ND siblings working to the child with WS's strengths: "We normally play like things that he is good at. So, he likes to play the Wii as he knows how to work all the controllers and stuff, so that's like normally what we do" (NDS-11).

Theme 2: Varied expressions of sibling love and warmth

This theme described the love and reciprocity that was evident in many of the sibling relationships, expressed in a variety of ways: sometimes overt, sometimes subtle or unconventional.

Love and positivity

Despite the annoyances expressed in Theme 1, there was a strong impression of positive emotions about the sibling relationships in most, though not all, of the dyads. Many children—those with WS and their ND siblings—expressed affection for the other: "She's my friend and I really love her" (CWS-4); "He's awesome … He's happy, he's funny, he's cute and I love him a lot" (NDS-7). This warmth was also evident in many of the children's descriptions of the emotions they felt in being together: "Every time I talk to her it makes me just feel happy" (CWS-6); "He just always hugs people, makes you feel, like it's hard to explain, he is just really nice" (NDS-13). For other siblings, warmth was evident but more understated, with relationships described as "All good" (CWS-4) and "Like, alright" (NDS-12).

Recognizing interests and expertise

As well as these overt positive expressions, warmth was also expressed in a more embedded manner. For many, it was evident in the level of knowledge that the children had about the interests and preferences of the other child, and descriptions of their "togetherness" (Pavlopoulou & Dimitriou, 2019, p. 7) as a pair with shared interests: "[NDS-12] likes football and I like horse-riding" (CWS-12); "We like playing outside … We like bouncing on the ball on the grass" (CWS-15).

The warmth was also evident in the appreciation that the children had for the expertise of the other. For the children with WS, this was often the independent skills of their ND sibling: "She does the right thing, like she can keep an eye on [little brother], keep her phone on, text mum and do all of that" (CWS-14). For some of the ND siblings, it was sometimes recognition of play skills of the child with WS: "She always makes up the best games too, I'm not that good at making up games" (NDS-15).

For some of the ND siblings, one of the areas of expertise they recognized in the child with WS was their sociability, apparent confidence in interacting with others, and empathy: "Well I would describe him as kind as when like little babies are crying in the street he goes over to them like 'what's wrong?' He doesn't like people crying" (NDS-4). One ND sibling shared that this sociability had "completely helped boost my confidence in talking to people" (NDS-16). Although hypersociability of children with WS brings concern, for example, around "stranger danger" (Riby et al., 2014), in these discussions, sociability and empathy were more commonly framed as kindness and care for others.

Warmth and reciprocity in emotion regulation and support

Another way in which warmth manifested in some pairs was care and support for each other. "Role asymmetry" is reported in the sibling relationships of children with developmental disabilities, with ND siblings sometimes assuming a directive role and additional caring tasks (Abramovitch et al., 1987; Pavlopoulou & Dimitriou, 2019). Certainly, in some dyads the ND sibling supported the child with WS, for example to regulate emotions:

> She [sibling] calms me down sometimes when I'm in a bad mood … She talks to me, I like people who talk, that makes me feel calmer.
>
> (CWS-9)

> He really doesn't like little children and he gets quite anxious when they are there so we went a little walk outside as there was some children in and we had a talk about what we are doing that day.
>
> (NDS-16)

This aligns with findings of heightened anxiety in some children with WS (Royston et al., 2017) and shows ND siblings responding to this supportively.

There were also examples of the ND sibling, particularly the girls, caring for the child with WS at home, at school, and in the community. This included preparing meals, assistance with fine motor skills, and help with homework, and often drew on the ND siblings' greater independence:

> She's my sister, she helps me.
>
> (CWS-16)

> [NDS-3] can go to Spar [a neighborhood store] and get me some chocolate Bounties and she's going to get me a big Nutella.
>
> (CWS-3)

> …sometimes we have problems because he is so friendly, it happened once…he made friends with a little boy who was very rude to him… so when he called [CWS-19] an idiot I literally went up and told him to shut up and took [CWS-19] away.
>
> (NDS-19)

However, support was not unidirectional. Although it was the case that some ND siblings felt that the child with WS was limited in their ability to provide support due to their intellectual disabilities, a number did discuss the emotion regulation and support provided to them by the child with WS: "Like if I'm upset then I'll tell [CWS-16] that I'm upset and he usually like gives me a cuddle and things like that, makes me laugh" (NDS-16). The ND siblings also found the child with WS to be a source of support for some types of situations, even if this might not be for all circumstances and was shown in less conventional ways:

> Well all of the times I fall off my bike, he comes up to me and gives me a giant hug and says "are you okay?" and he gets me lots of plasters, I don't need many plasters it's just a bruise.
>
> (NDS-17)

Some described how the child's social disinhibition and even their anxiety enabled and evidenced these expressions of empathy and care:

> He worries a lot, like worries a lot about the family and stuff and it kind of shows he does care, even though sometimes he might not show it as it can be quite difficult, but you know he does so that's like good.
>
> (NDS-14)

Theme 3: Navigating social spaces and boundaries

This theme captured how the siblings navigated the physical and social spaces they occupied and the boundaries to these spaces, at home, at school and with friends.

Navigating siblinghood spaces and boundaries

As shown in Table 1, some siblings spent significant time together as consistent playmates, whereas others came together just at mealtimes. Limited time together was not necessarily associated with poor quality relationships. Siblings were also aware of boundaries, and infringements were a challenge for a few ND siblings: "He comes into my room and he does opera singing … it's just really, really annoying" (NDS-2). Children were aware that parents helped them to navigate these spaces and boundaries, supporting them to have time apart and facilitating time together. Time apart was sometimes applied as a coping strategy by ND siblings—taking themselves out of spaces where the child with WS was, particularly if the child was experiencing anger, aggression or, in a few instances, where the ND sibling felt embarrassed by the child with WS's socially uninhibited behavior:

> I find it kinda difficult as if she's in a bad mood, she will start doing silly things like screaming, shouting, I guess. Then if it's in public I'll walk on the other side of the road or something and don't want to be seen with the person who is screaming or shouting.
>
> (NDS-5)

The lack of social boundaries of the children with WS and the embarrassment experienced by ND siblings has also been reported by parents of children with WS (Lough et al., 2016) and is similar to that reported by ND siblings of children with other developmental disabilities (Gray et al., 2024). Although "time apart" coping was predominantly mentioned by ND siblings, a small number of children with WS also mentioned it: "he is a bit annoying but that's okay. Like 'go away now you are annoying me' [laughs]" (CWS-10).

Sibling spaces were navigated within the context of family. Some children also discussed "subsystems" within the family. For example, where the child with WS was younger or had more severe intellectual disability, the ND sibling (both girls and boys) sometimes formed a "caring subsystem" with the parents: "Then me and my mum and dad play this game with him called 'ball,' where we get a ball and we roll it to each other" (NDS-8). Here, from a family systems perspective (Minuchin, 1974), the ND sibling aligns with both the sibling subsystem and, at times, with the parent subsystem, through the adoption of a caring role.

Friendships and school: Space, inclusion and microconnections

Siblings who were at school together also navigated their relationship there. Although a few siblings were obvious school playmates, others saw very little of each other. Again here, for some there were boundaries to be navigated: "Sometimes we would just say hello and give a hug but other times she would want me to play with her the whole break" (NDS-3). For some ND siblings, being at the same school meant that they could keep an eye on the child with WS, reducing their concerns: "Yeah. I kind of like spy on [CWS-20] often as I'm always looking out for her but we don't usually play together, we are usually with our different friends but yeah I definitely look out for [CWS-20]" (NDS-20).

Both children with WS and their siblings also talked about friendships. A few children with WS describing having many friends and spending "a lot of time with my friends" (CWS-11). However, more commonly, friendships for children with WS happened at school and did not often spill over into home life—"Just play with them in school" (CWS-19)—sometimes because friends from special schools did not live nearby. This fits with Gillooly et al.'s (2024) findings that although some children with WS have strong friendships, there are generally greater friendship difficulties than for ND children. Indeed here, despite the sociability of many children with WS, the ND siblings sometimes had a wider social world, with increasing independence with age: "I'll be down in the park and she'll be at home" (NDS-5). For these children with WS, social connections with and via family members were perhaps particularly important. In some cases, children with WS's time with the ND sibling's friends was substantial, but sometimes it was just "microconnections"—brief moments of interactions, with which both children seemed very comfortable, but which also allowed ND siblings to have independent time with their friends: “Yeah he likes having a chat with them. Yeah he will have a chat or sometimes he will pop his head in and say turn the music down or that’s a good song, that type of thing” (NDS-9). Again, parents were sometimes described by ND siblings as helping with the boundaries between siblings and friends: “My dad is quite good he will usually go ‘[CWS-19] come over here and play with your Lego’ so [having friends round] it’s not that bad” (NDS-19).

Theme 4: The power of Williams syndrome knowledge

This theme captures the way in which knowledge of WS and associated behavior seemed to bring a range of benefits to both children, to relationships, and to the community.

Knowledge helps the tough times

Some of the ND siblings, even some of the youngest, had knowledge about WS, and described genetic, medical and physical characteristics, and intellectual disabilities. ND siblings explained both “textbook” aspects of WS and aspects that were contextualized within their relationship: “[Children with WS] have difficulty with fine motor skills so [CWS-9] needs help brushing his teeth and with buttons and zips but he’s a nice guy” (NDS-9).

Some of the ND siblings discussed moments when the child with WS experienced anger or aggression, something they found upsetting or annoying. Yet knowledge of WS and of associated behavior seemed to help them deal with such challenging issues, with some ND siblings able to explain why the behavior was occurring: “He likes his routine so if some of his routine can’t happen or doesn’t happen then he gets really angry” (NDS-16). ND siblings had a range of practical ways of dealing with this behavior and of finding ways to prevent the situation from escalating, and some could reflect on why particular approaches were effective:

> I usually find it best to just walk away and leave him for 5 minutes to calm down as if you try and get annoyed back he will just punch you. That’s it, he has got boney fingers and it hurts.
>
> (NDS-9)

Parents also played a key role in easing interactions. It is notable too that whereas some ND siblings discussed the aggressive behavior of the child with WS, only one child with WS themselves did so, though a few referred to their bad moods.

“It’s hard work having Williams syndrome”

A few children with WS also discussed their emotional labor: “It’s hard work having Williams syndrome and a sore back when you’re just a little boy like me” (CWS-6); “I think he [ND sibling] just doesn’t understand why life is so hard for me because he is younger than me and also he doesn’t have Williams syndrome like me so that can make things really difficult” (CWS-12). For some, there was a feeling that their ND siblings did not fully understand these inherent challenges of WS.

A language for relationships and advocacy

In some dyads, knowledge of WS gave the ND siblings language that helped with their relationships or advocacy activities. It meant that the ND sibling had a way of explaining WS to their friends, which in turn helped their friends to be more supportive of them, or eased the interactions when the friends came to visit: "I'll tell you the question that they [friends] ask me 'why is your sister disabled?' my answer is she has got something called Williams syndrome that means there is part of her genes missing" (NDS-10); "[If friends understand what WS is] they don't treat [CWS-8] like a normal kid, they treat him gently because he has Williams syndrome" (NDS-8). WS knowledge may be important: ND siblings of children with developmental disabilities often report that their friends can be supportive, but that they do not always fully understand developmental disabilities or their experiences (Tsai et al., 2018). Yet knowledge alone may not be enough: it was recognized that some friends are more prepared than others to listen and take WS knowledge on board.

For some ND siblings, the benefits of their experiences and knowledge of WS were more broadly felt: improving their own understanding of disability and helping them to educate others. Among some ND siblings there was a clear sense of advocacy: "I've got my book [about WS] … and I presented it to the whole class. Ours was the only one [presentation] that left the whole class speechless. We had statistics, the facts and also the emotive language in it" (NDS-19).

DISCUSSION

This study was the first to explore experiences of the sibling relationships from the perspectives of the children with WS and the ND siblings themselves. As with ND sibling relationships (White & Hughes, 2018), there were individual differences: Although many expressed very positive experiences, a few found their relationship more distant or challenging. Some findings, such as the reciprocity of emotion regulation and support, have previously been reported in other developmental disabilities, but are reported here for the first time in relation to WS. Other findings relate specifically to the WS phenotype. Four themes were developed from the data. These highlighted the multifaceted nature of the sibling relationships; the varied expressions of sibling love and warmth; the ways in which the siblings navigated a range of social spaces and boundaries, across home, school, and friendship contexts, with parent support; and the benefits that knowledge of WS brought to the relationship.

Overall, the influence of the WS phenotype on the sibling relationship was neither unidimensional, nor experienced as only negative. Rather, it was woven through the relationship (and the interview themes) in a multitude of ways and across a range of contexts. For example, hypersociability was recognized by ND siblings at times as part of the expertise of the child with WS, and at others as a source of embarrassment. It was, perhaps, also evident in the exuberant expressions of affection within many relationships. Anxiety, common in WS (Royston et al., 2017), was also evident in the relationship in a variety of ways, sometimes quite subtly and not always explicitly labeled. For example, ND siblings discussed understanding the child with WS's need for routine and supporting them with emotion regulation. Some children also discussed the moods of the child with WS—these were perhaps anxiety related. Anxiety was also referred to as evidence of the child with WS's care for the family. Although anxiety of the child with WS has previously been shown not to be significantly associated with sibling relationship quality (Cebula et al., 2019), this was therefore perhaps because it does not influence the relationship in a unidirectional manner. Whereas some aspects of the phenotype, such as hypersociability and intellectual disabilities, were quite evident, other aspects, such as health difficulties, were highlighted more subtly or less frequently. This may be because parents seek to mitigate the impact of these aspects on the sibling relationship or because some aspects of the phenotype were not a significant influence on the sibling relationship at the time of the study. Although both children with WS and ND siblings referred to the WS diagnosis, it was far more common for the ND siblings to do so. This may be because the verbal skills of ND siblings more readily allowed them to discuss this topic, or more simply because here children were primarily being asked about their sibling rather than about themselves.

The findings revealed multifaceted relationships in which a myriad of feelings often coexisted in a relatively comfortable manner and children "held" both typical and different aspects of the sibling relationship. Such findings should not be surprising: Sibling relationships are complex and multidimensional (White & Hughes, 2018). Yet the findings contrast with the more negative findings from many quantitative disability sibling studies, which have often focused on the adjustment of ND siblings and have been less likely to measure positive experiences (Wolff et al., 2022).

The findings also showed the love and positivity evident in many of the relationships, both overtly and embedded in the reciprocity of sibling expertise and support. Although many qualitative studies report warm connections between children with developmental disabilities and their siblings (Leedham et al., 2020), it is possible that the hypersociability, positive affect, and empathy of children with WS (Doyle et al., 2004; Plesa Skwerer & Tager-Flusberg, 2016) was reflected in how strongly these emotions were felt in many of the dyads. The reciprocity described by the participants aligns with research showing greater reciprocity in the sibling relationships of individuals with disabilities than might have been assumed (Kramer et al., 2013). Meltzer (2018) noted that research that includes the perspective of the individual with disability "challenges the idea that there is only one normative way that reciprocity can be expressed between siblings," which was certainly the case here (p. 1215).

The findings also showed how sibling spaces and boundaries were skillfully navigated by the children at home, at school, and with friends. Parents played a key role in supporting boundaries, aligning with the family systems theory (Minuchin, 1974) incorporated within the Siblings Embedded Systems Framework (Kovshoff et al., 2017), which framed this analysis. At school, boundaries were again an issue for some ND siblings, with others playing a role in checking on the child with WS. School experiences are rarely considered for siblings' relationships in developmental disabilities (Gregory et al., 2020), yet ND siblings of children with WS might be particularly involved at school because schools are often not well informed about rare disabilities (Fidler et al., 2002). The findings from this study and others (e.g., Pavlopoulou et al., 2022) emphasize the value in schools recognizing the expertise that some ND siblings have of disability: nurturing their advocacy skills and their ability to educate their peers in this area. However, this is part of a bigger picture, which also includes the need for school-focused supportive interventions for some ND siblings (Hayden, McCaffrey, et al., 2019); whole school inclusive approaches (e.g., Alcorn et al., 2024) to improve experiences of disabled children at school, thereby reducing the worries that ND children have about them; and school staff having the time and resources to develop disability expertise, so that ND children can care for their disabled sibling on their own terms, rather than because there is a support gap that needs filled at school.

In relation to friendship, the time that children with WS spent with the ND sibling's friends was varied, but interestingly it sometimes took the form of positive microconnections. This echoes research into adults' minimal social interactions with strangers, which finds a range of positive outcomes, such as positive affect and a sense of belonging (Sandstrom & Dunn, 2014). Encouraging such microconnections, where appropriate, may fit with Meltzer and Muir's (2022) concept of "pulling a lever" within the bioecological system (Bronfenbrenner, 1979) to create positive change in the lives of children with WS and in their sibling relationships.

Although misconceptions have been reported among ND siblings of children with rare conditions (Vatne et al., 2015), the findings showed that was not evident here, with many ND siblings showing accurate knowledge of WS that was put to good use supporting interactions, relationships, and advocacy. ND children's knowledge of their sibling's diagnosed condition tends to be associated with easier sibling and family relationships (Lobato & Kao, 2002; Wolff et al., 2022). That appeared to be the case here, with knowledge of WS and associated behavior helping ND siblings to navigate challenging interactions. However, knowledge of why anger or aggression is occurring may not in itself be sufficient to make the experience manageable for ND siblings—behavior frequency or severity may also play a role (Connors & Stalker, 2003), as might the siblings' interactions outside these moments. Within the dyads in our study, knowledge of WS and associated behavior was clearly not the only factor to ease children's relationships, but it did appear to play a valuable role. Some ND siblings also used their knowledge of WS to support their friendships and advocacy activities. ND siblings of children with developmental disabilities may be aware, even in childhood, of the powerful potential of their advocacy work (Pavlopoulou & Dimitriou, 2020). Effective sibling advocacy requires a range of skills and knowledge (Burke et al., 2015), and little is known about how this develops across childhood: further exploration of this would be helpful.

Despite the knowledge that ND siblings held of WS, from the perspective of a few children with WS, the inherent challenges of having a disability may be a powerful piece of knowledge that some ND siblings are missing. This perhaps occurs because although many parents share information about their child's genetic condition with the child and their siblings, understandably, they often take a positive approach, not dwelling on negative consequences of the condition (Gallo et al., 2005).

Much research into the sibling relationships of children with developmental disabilities focuses only on ND siblings (Kovshoff et al., 2017). Here, the inclusion of both the child with WS as well as the ND sibling, recognized the children with WS's expertise of their own experiences, foregrounding aspects that would not have surfaced without their inclusion. It also resulted in a more holistic understanding of the relationship, drawing on both perspectives. Some subthemes related to both children, sometimes in similar and sometimes in different ways. Other subthemes related primarily just to one group. Notably, the subthemes relating to the emotional aspects of the sibling relationship (love, joy, annoyance) were similar, but those relating to experiences of other aspects (e.g., disability, knowledge) or to other contexts (e.g., school, friendships) differed somewhat. Although these differences in the perspectives of the children with WS and the ND children may relate to their differing disability status, they may also relate to the social and political forces that shape the experience of children with disabilities, and their sibling relationships, within society (Meltzer & Kramer, 2016): For example, whereas ND children experienced a range of friendships, for children with WS such friendships were often inaccessible because friends from their specialist school provision did not live nearby.

The findings aligned with the Siblings Embedded Systems Framework (Kovshoff et al., 2017). For example, the siblings' experiences of reciprocity and of navigating the spaces and boundaries of family subsystems fits with the aspects of family systems theory (Minuchin, 1974) incorporated in this framework. The multiple broader influences on the sibling relationship, such as the role of school and friends, aligns with the bioecological systems theory (Bronfenbrenner, 1979) elements of the framework. The Siblings Embedded Systems Framework is likely to continue to be useful in future WS sibling research seeking to understand the broader systems influences, such as socioeconomic status, on WS sibling outcomes. It should also be of utility in the development of testable predictions about detailed aspects of WS sibling experiences raised in the present study, such as how knowledge about WS from parents mediates outcomes for ND siblings. For example, research drawing on the double ABCX (McCubbin & Patterson, 1983) elements of the framework could explore the extent to which knowledge about WS positively impacts ND siblings' "internal resources" (i.e., their understanding of WS) and their interpretation of events (e.g., understanding why their sibling with WS behaves in a challenging manner sometimes), resulting in more positive sibling relationship outcomes.

Limitations and future research

There were limitations. First, although there was participant diversity in some respects (e.g., severity of intellectual disability in the child with WS), all participants were of White ethnicity and the majority of families were financially "comfortable" or "alright." Given how culture and socioeconomic status can influence sibling relationships (Hayden, Hastings, et al., 2019; Tsai et al., 2018) there is a clear need to explore more diverse sibling relationships in WS. As with many sibling studies, families experiencing high levels of stress or less positive relationships may have been less likely to participate, and there is also a need for future research to include all siblings in larger families. As is common in much WS research, the low prevalence meant that a wide age range of children were included to ensure an appropriately sized sample; interview questions may have been interpreted somewhat differently by the younger compared to the older children. Furthermore, although the inclusion of children with intellectual disabilities did facilitate a more holistic perspective on the sibling relationships, and the interview and analysis were designed to be accessible and inclusive, the interview was not sufficiently accessible for one potential participant with WS, and for a few children there were challenges in discussing some topics, with short or no answers given to a small number of questions. Some of the interviews were also relatively short in length. This was similar to previous interview research with children with WS (e.g., Gillooly et al., 2024) and may also have reflected the young age of some participants. Although rich data were still generated, enabling full analysis, the use of a longer interview schedule (with more detailed questions for older or ND participants) may nevertheless have enabled additional insights into specific aspects of the sibling relationships, such as their experiences of differential parenting or anxieties about the future. More accessible and participatory research methods, for example, using stimuli such as photos or working with children as coresearchers will also be important in future research to further explore sibling relationships with children with WS.

Implications for practice

The research has potential implications for supporting the sibling relationships of children with WS, foremost of which is the obvious need to listen to the views of the children themselves about their relationships. Although many children recounted positive experiences, for others, support to help with the more challenging aspects of their sibling relationships and to enable them to recognize and develop reciprocity within the relationship may be beneficial. Supporting children to understand the similarities and differences in the ways that they and their sibling experience their relationship may also foster empathy and understanding for each other. Drawing on the recommendations of Marquis et al. (2023) for sibling support program design will be helpful here. Parents had clear expertise, from the siblings' perspective, in helping children to navigate sibling spaces and boundaries, and future research should explore the techniques that they use to do this, in order to develop ways to help parents who require support with this role. Parents and practitioners may also need to be supported, for example, through intervention (Lobato & Kao, 2002), in effectively sharing knowledge about WS with children, both the medical and educational elements and perhaps the emotional labor of it. This knowledge may have powerful positive effects that ripples beyond the immediate family, benefitting the ND sibling's friendships and allowing children, who wish, to grow as disability advocates. Research with individuals with WS to better understand which aspects of WS knowledge they think are particularly important for ND siblings to understand would be helpful. School staff should be supported in understanding sibling relationships, and research should also examine the siblings' school experiences in more detail from school staff and the children's perspectives. Although many WS sibling relationships are warm and positive, they and those around them may at times require support to ensure that these relationships thrive across the lifespan.

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Additional supporting information can be found online in the Supporting Information section at the end of this article.

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