



“I often have to explain to school staff what she needs”. School experiences of non-autistic siblings growing up with an autistic brother or sister

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ABSTRACT

Background: Recent autism research has evidenced a shift from psychological outcomes to contextualised approaches to understanding the varying needs of non autistic siblings of autistic children across different systems. Yet, there is limited research exploring the lived experiences of siblings in their school context.

Methods: First, a group of school aged sibling advisors worked with the first author to codesign research aims, methods and dissemination practices around the topic of the school experiences of siblings who grow up with an autistic brother or sister in the UK. Then, 28 school-aged siblings of autistic children completed adapted photo-elicitation interviews, to discuss their school experiences. A background questionnaire was also administered to their parents and carers.

Results: Thematic analysis was employed. The master themes included: (i) Impact of home experiences in schoolwork, including limited personal time and sleep disruptions (ii) Siblings' school interactions impact on overall school experience, including a wide range of both typical and difficult experiences such as school day disruptions, (iii) Varied perceived levels of support and understanding, including emotional and/or educational support by family members and a sense of connectedness with peers and teachers who are autistic themselves or connected to someone with a diagnosis of autism.

Implications: The results underline the ways home experiences can have an impact on school life of siblings, the positive contribution of the autistic school staff and/or staff who have an autistic family member and the need for an organisational culture of inclusivity and widespread acceptance and awareness around issues of neurodiversity. Our findings suggest several implications for school psychologists in core functions of the educational psychologists' role including training, consultation, assessment, and whole school support.

Data availability statement: The datasets generated for this study are not readily available because they include sensitive data (photos of siblings' houses, family members, personal objects, and school timetables). Requests to access the datasets should be directed to corresponding author.

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1. Introduction

According to recent statistics, almost 90% of the Western population has a sibling (Milevsky, 2011), which indicates that this is a common form of relationship in the life of students. Furthermore, around 1.1% of the United Kingdom (UK) population have an autism diagnosis (Brugha T et al., 2012). When family members are included, autism is a part of daily life for approx. 2.8 million people, according to the National Autistic society in the UK. Recently, there has been a considerable emphasis placed by health and educational providers on siblings as young carers (Cooper & Bruin, 2017). Schools that have adopted the highly praised by Ofsted 'Young Carers in Schools' programme have reported the identification of an average of 20 young carers per school (Carter et al., 2020). Up to half of the young carers are caring for a sibling, but it remains unclear to which extent these young carers with an autistic sibling or those who undertake caring responsibilities for their siblings at a young age self-identify as carers. Moreover, we still do not have enough data on siblings of autistic people who have declined a day-and-night caring role, but still want to have an active supporting role in the life of their siblings, as well as those who might need proactive support and access to information but don't get it because they do not fit in any of the above umbrella terms. Some organisations, such as Siblings Australia (2016), have expressed that policy related to Young Carers needs to be reconsidered with reference to siblings to ensure that siblings with no caring roles remain visible and supported. Meltzer (2021) drawing on evidence from national-level sibling support providers in the USA, UK, Canada, New Zealand and Australia provide evidence that siblings should have their own distinct policy and programmes within medical, health and social care practice.

1.1. The school experiences of non-autistic siblings of autistic children

Schools are responsible for safeguarding, promoting learning, and fostering the well-being of students to help them thrive (Public Health England, 2021). The National Institute for Health and Care Excellence (NICE) guidelines highlight that primary schools and secondary schools should embrace a 'whole school' approach to support young people's wellbeing that moves beyond schools' traditional focus on learning and teaching. Although schools are gradually recognizing the significant impact of the unprecedented pressures on young people's lives, the needs and well-being of siblings of autistic children remain unrecognized. While some siblings, just like every other student, are eligible to receive well-being support through general safeguarding and pupil support policies, these are rarely targeted specifically for the siblings of children with a disability (Hayden et al., 2019). Although siblings have been characterized as a risk group due to them not fitting under any diagnostic umbrella, they are eligible to access this support only once concerns have already been risen.

Considering that a large proportion of autistic children's siblings' days are spent at school, it is vital to understand their school experiences and identify whether (and to what degree) having an autistic sibling influences their school lives. There is a dearth of literature exploring exclusively the siblings' accounts focusing on their own school experiences. It remains unclear how having an autistic sibling may affect the roles and reputations held by non-autistic siblings within the school environment. However, limited findings into sibling relationships and experiences reveal that some siblings report less involvement in extracurricular activities (Barak-Levy et al., 2010), which may be explained by their increased responsibilities at home. Interrupted sleep and negative morning experiences appear verbatim from interviews with non-autistic siblings (Pavlopoulou & Dimitriou, 2017; Petalas et al., 2009). These areas all have logical follow-on consequences for siblings' experiences at school.

Studies have also identified several perceived difficulties in homework experiences for the non-autistic siblings with an autistic sibling (Herman, 2013; Pavlopoulou & Dimitriou, 2019). Furthermore, past research suggests that if both autistic and non-autistic siblings attend the same school, situations may arise which could have an additional impact on the non-autistic sibling's experience. For example, teasing (Petalas et al., 2009) or embarrassing behaviour towards teachers (Angell et al., 2012) may occur during school. There may also be differences in peer relationships and teacher expectations which could affect how the non-autistic sibling feels about themselves or school, as discussed in the study of Petalas et al. (2015). Various caregiving roles and responsibilities during school time were reported, including advocating for their brother with teachers and peers, liaising between the teachers and their parents, managing miscommunications, protecting their brother from bullies, and educating their brother about how to deal with other students (Cridland et al., 2015, p. 200), in addition to educating their local communities about autism (Pavlopoulou & Dimitriou, 2020). Non-autistic siblings can have mixed attitudes and feelings about undertaking these various roles, resulting in some ambiguity about the responsibilities, and underlining both the benefits and challenges associated with these roles (Cridland et al., 2015). In addition to the siblings' school experience, it is equally essential to consider their needs. Currently, there is limited research on the needs of children with an autistic sibling (Benderix & Sivberg, 2007; Gillberg & Wing, 1999), suggesting that siblings need further information about autism or desire more time for themselves during stressful periods (Angell et al., 2012).

We could find only two studies who look specifically at siblings in the school context, both focusing on psychological outcomes of siblings compared to control groups.

Chien et al. (2017) investigated school functioning among autistic and non-autistic siblings and identified the correlates for school maladjustment. Their study recruited autistic children and young people aged 8–19, their non-autistic siblings, and 132 controls. They found that non-autistic siblings had poorer attitude toward schoolwork and more severe behavioural problems at school than controls, suggesting that it is important to assess school function in non-autistic siblings of autistic brothers and sisters. Gregory et al. (2020) examined 65 siblings and a comparison group of 57 siblings of non-autistic children aged 11–16 years completed questionnaires measuring sense of school belonging, academic self-concept, and behaviour problems. Additionally, 73 parents in the autism sibling group and 67 parents in the comparison sibling group completed the behaviour problems measure. Siblings of autistic children reported significantly lower school belonging and academic self-concept and had significantly poorer self- and parent- reported behaviour problems. Importantly, when controlling for demographic variables and internalising and externalizing behaviour, robust sibling group differences on academic variables remained. The authors noted that siblings are at increased risk of experiencing a lower sense of perceived relatedness and competence in a school context.

To our knowledge, this is the first qualitative study looking explicitly into the school experiences of children with an autistic brother or sister through their personal accounts to contextualise the varying experiences and needs of siblings in the school context. Given their relative neglect, the overarching goal has been to stimulate the interest of educational psychology scholars in siblings by portraying their perspectives and needs through their accounts. Specifically, this study explored (i) the nature and impact of siblings' shared time at home during school term time, (ii) the nature and impact of siblings' shared time at school, and (iii) the levels of support that non-autistic siblings need/and or receive at school.

2. Methods

2.1. Research framework and community participation

Most studies on siblings exclude siblings in the research process of organizing and developing constructs and knowledge. A participatory approach is therefore needed to emancipate siblings in salient decisions that influence their lives (Raymaker & Nicolaidis, 2013). Participatory research methods allow siblings to provide their understanding by sharing their lived experiences, which increases the chances of the researchers studying topics that are relevant to their lives and findings being translated into practice (Pavlopoulou & Dimitriou, 2020). In our effort to create an inclusive research framework, the Siblings Research Advisory Group (SRAG) members ($N = 10$ siblings) worked together with researchers as advisors and contributors of research knowledge. The SRAG members and researchers co-developed the study aims and co-defined the term "school experiences" which includes the morning routines, peer relationships, schoolwork, support, and how this may be affected by having an autistic sibling. In collaboration with the first author, the SRAG members also discussed pre-study considerations, recruitment of participants, study visit considerations, and post-study considerations as per Gowen et al. (2019) guidelines to build equal partnerships with participant siblings during the advisory process. The SRAG team co-produced research materials (e.g., information sheets), and discussed appropriate methodologies and the implications of results during interactive and blended activities. Siblings who took part in SRAG were also trained in understanding key research terms, research ethics, and co-production in research and were reimbursed for their involvement. The study adopts an experience-based collaborative and flexible approach to understanding siblings' experiences in school rooted in the lifeworld theoretical model of Galvin and Todres (2013), modified by Pavlopoulou and Dimitriou (2019). The framework draws together eight dimensions of human experience, key to the siblings' wellbeing (insiderness, agency, uniqueness, sense making, personal journey, sense of place, embodiment and togetherness), placing a person at the centre of their own 'lifeworld' to acknowledge and validate them as the expert of their own experiences. This epistemological approach shifts our understanding of sibling wellbeing away from a deficit-focused, medical narrative and towards meaningful engagement with their troubles and joys in the school environment.

2.2. Background characteristics of participants

Participants were 28 siblings (boys = 8, girls = 20) without a diagnosis of autism aged 6–14 years old ($M = 11.2$, $SD = 2.4$) who were recruited through advertisements on school and autism social network sites in the UK. Most of the participants were attending a primary school ($N = 19$). A snowballing sampling technique was carried out to approach participants. Participants and their parents offered written consent before the study. All participants had an autistic sibling (3 girls and 25 boys) aged 4–13 years old ($M = 9.8$, $SD = 2.3$) with a formal diagnosis from the public health sector.

Most of the participating families were from a White British ethnic group, except for two families whose ethnicity was White Eastern European, two British Indian, two British Chinese, and two Black. Recruitment of participants was achieved via advertisement on social media pages of support groups and autism organizations, as well as word of mouth, after receiving Ethics approval from X. The 28 participants were from 24 different families living in London, South East, and Midlands. Additional diagnoses were reported for five of the autistic siblings, including Attention Deficit Hyperactivity Disorder (ADHD) and Down syndrome. None of the autistic siblings had a moderate or severe learning disability. Non-autistic siblings had no diagnosis of any neurodevelopmental or mental health condition. All households fell into the socioeconomic group (NS-SEC) categories 1–3 ($N = 18$ parents on high managerial jobs, $N = 6$ low managerial, and $N = 6$ parents on intermediate occupations) using the employment information provided by mothers (Office for National Statistics, 2020).

2.3. Personalized adapted photo-elicitation interviews and procedures

Photo-Elicitation Interviews (PEI, Banks, 2001) are a form of qualitative method using photos to prompt conversations around participants' experiences (Collier, 1967). Following the personalized adapted photo-elicitation interview procedures of Pavlopoulou (2020), each participant generated their photos, drawings, and/ or brought objects to reflect on their school experiences and determined their content by introducing subjects and ideas that are meaningful to them before a semi-structured interview. Each participant was given two weeks to take and select a maximum of 15 photos, drawings, or objects related to their lived school experiences, needs, and perspectives. The interview questions were generated from participants' photos and attributed meanings, promoting "deeper and more elaborated accounts of subjective experiences" (Hong & Goh, 2019, p. 431). This qualitative approach allows considering siblings as active participants in research, by recognizing their autonomy of thinking, as well as their perspectives and ideas (Pavlopoulou & Dimitriou, 2020). All participants were asked to choose a pseudonym or we gave them one to maintain confidentiality and anonymity.

The interviews took place at home and lasted between 60 and 90 min. Parents were only present on a few occasions upon request of the sibling. Participants were asked to elaborate on the reasons why each photo/object was chosen and what meaning this had for them based on the modified version of the ShoWed protocol (Pavlopoulou & Dimitriou, 2020). Table 1 shows the interview schedule.

Table 1
Interview schedule.

-
- Can you tell me about this photo?
 - Why did you choose to take this photo to show me?
 - What's important about this photo?
 - What has happened before or after this?
 - Is there anything that usually happens at the same time that we can't see in this photo?
 - How does [what we see in this photo] change what the rest of your day will be like?
 - Does this change how you feel/ how does this make you feel when you're at school/going to school?
 - If you think about what you see in this photo, is there anything that would make things easier for you/ is there anything you would change? (If relevant)
 - How do you think your family/brother/sister feels about this – is it important to them as well? (If relevant)
 - Do you think other people know how you feel about [what is in photo]?
 - Is there anything you'd want your teachers or friends to understand about growing up with XXX that they may not already know?
 - Is there anything you wish you could say to your friends or teachers?
 - Can you describe what a typical morning/day/evening is like for you?
 - When do you normally do your homework? OR What's it like doing homework at home?
 - How similar do you think your experience at school is to your friends'?
 - What usually means that you'll have a good or bad day at school?
 - What are usually the best things about your day and why?
-

2.4. Background data measures

A family, medical and educational history questionnaire was administered using hard copies provided by X (removed for blind review) to collect key background data of participant siblings and their families. The questionnaire items were divided into three parts: (1) background information on their family's demographics; (2) medical history, including official diagnoses and use of any medication or involvement in therapy practice; (3) siblings' educational status.

2.5. Data analysis

Interviews were audio-recorded and transcribed verbatim. Interviews were analysed from an inductive perspective using reflexive thematic analysis (Braun & Clarke, 2019), as this allows for an in-depth engagement with data, contrary to a more positivist approach. Participants' photos were used as a guide to stimulate the conversation, as they did not relate to the research topic on their own. Credibility of analysis process included prolonged engagement and examination of referential adequacy to check preliminary findings and interpretations against the raw data. To ensure reliability, additional intracoder reliability exercises took place to promote researchers' reflexivity (O'Connor & Joffe, 2020). The data interpretation was facilitated by group discussions within the research team, and a credibility check of themes was conducted by the second and third authors. Final consultation with the research team was followed to discuss specific theme descriptions and select the most relevant quotes.

3. Results

Table 2 shows the themes of the reflexive thematic analysis.





Table 2
Synopsis of the master themes and subthemes emerged by siblings' interviews.

Master Themes	Subthemes
Impact of home experiences in schoolwork	<ul style="list-style-type: none"> ■ Limited personal time ■ Sleep disruptions
Siblings' school interactions impact on overall school experience	<ul style="list-style-type: none"> ■ School day disruptions ■ Negative physical play ■ Extracurricular activities are key for siblings' social time ■ Typical positive and negative school experiences
Varied perceived levels of support and understanding	<ul style="list-style-type: none"> ■ Emotional and educational support by family members ■ Sense of connectedness with peers and teachers who are autistic themselves or connected to someone with a diagnosis of autism ■ The fear of stigma and negative reactions

A sample of photos that contributed to the themes can be found in Table 3.

Table 3

Sample photos that contributed to the theme generation.

Type of participant driven photos	Description	Sample of participant driven photos
Other people (N = 20)	Family members School members Siblings' moments	
Objects (N = 15)	Objects of hobbies that connect siblings with school members Objects that create conflict, joy or confusion Objects that represent a feeling or a situation that is experienced with a peer or teacher or parent	
Places (N = 15)	Classroom Playground Route to school Community settings related to school clubs	
Self only (N = 14)	Self at home during homework Self at school Self at outdoor activities Self in the car	

3.1. Theme 1: home experiences' impact on participating in school life

3.1.1. Limited personal time due to intensity of interactions

For some participants, interactions with their autistic siblings at home during term time affected their school experience. Siblings found it hard to constantly spend their free time with their autistic brother or sister or to try to complete homework when the autistic

sibling was around. While not all shared time is unwanted, sometimes it is ‘stressful’ to have to manage their sibling’s needs - ‘trying to get it all done on time and everything with everything else going on’. Some siblings found it difficult to explain to their siblings that they need time on their own to manage school homework or meet with peers.

Sometimes my brother was really stressing me out and I wasn’t able to complete my work... I had a really stressful morning, I might not be very on the ball, and they’ll go that’s ok... so if I am ever late to school then I’ll say Luke had a breakdown, I couldn’t leave, I couldn’t help him calm down. Mum wasn’t feeling well, it was all a lot more stressful because I have the responsibilities that I have at home.

Furthermore, some siblings struggled during a non-school period as the lack of structure and respite time put considerable pressure on them or they experienced extended periods of fighting or aggressive play.

I don’t like it when it’s the summer holidays. because I have to be with my brother. Last night he got on his back and kicked me in the face and head. and he made me dislodge a tooth.

This might have an impact on their mood during the transition back to school after a school holiday, as they come back to school “exhausted after being home” with a brother or sister. For most of the participant siblings, their sibling’s behaviour at home did not appear to affect having friends over. However, few siblings reflected on how their siblings’ past behaviour has created a ‘phobia in bringing friends over’.

The main reason why I haven’t had most people over is the fear of Alex kicking off. For example, I had one of my mates over and my little brother came in to walk into the room whilst we were playing with the PS4 and he just pulled down his trousers.

3.1.2. Sleep disruptions

Some participants noted difficulties with sleep or with trying to get to sleep. Of those, few discussed that there was an effect on their sleep quality too. Additionally, those who were not currently sharing a room with their sibling suggested that their sibling’s restlessness, reluctance to sleep, and sleepwalking either interrupted their sleep or created a fear of facing away from the door in case ‘he will come in and sleepwalk into my bed. And then I will wake up and freak because he’ll just be there staring at me’.

On the other hand, few participants discussed sharing a bedroom with their sibling which can keep them awake at night as it is ‘hard to go to sleep... She grinds her teeth’. Sharing a bedroom may also result in the sibling waking up in the middle of the night when their autistic sibling does. Several siblings reported that their autistic brother or sister may wake up very early and struggle to get back to sleep.

[My brother] wakes up, then he wakes mum up, and then we eat breakfast, but it’s very early, and then returns to bed to sleep a little longer like for 2 h.

While most siblings manage to meet school expectations, on some occasions a bad night of sleep at home might take a toll during the school day with siblings feeling “not very on the ball” and ‘tired because of a very busy night time’.

3.2. Theme 2: siblings’ school interactions’ impact on school experience

3.2.1. School day disruptions

Four out of fifteen siblings who attended school together reported rarely seeing each other during school. However, five of those who had regular interactions with their sibling during school hours identified disruptions to their class time. Experiences of bullying that siblings had from peers due to their autistic brother or sister were central and sometimes resulted in choosing to leave the classroom or being moved to a different table:

And it just gets you so annoyed, so I just ran outside... because we usually have the same tables, he [teacher] just let me move tables for the day until I’m feeling more comfortable to be on the same table with him [the peer who bullied the sibling].

Furthermore, eight siblings found themselves missing class on several occasions as they were trying to aid teachers in supporting their autistic brother or sister. School staff asked for help with siblings’ skills when dealing with behaviours of concern. Additionally, siblings felt that there was a need to ‘translate for him’ to school staff to improve the autistic brother’s/sister’s experience at school or to avoid an escalation.

In most cases, this involved attempting to resolve conflicts or issues between their sibling and peers during break time. This can be particularly stressful for siblings as they feel there is no appropriate proactive or reactive school support from school staff. Hence, siblings feel the need to intervene and protect their brother or sister who might struggle to communicate and interact in socially expected ways. Additionally, four siblings spoke about being frequently faced with the task of explaining autistic siblings’ behaviours to peers who show curiosity when their autistic brother or sister is upset:

Sometimes people in my class ask me ‘Can you see what Mike is angry about?’ (.), sometimes I think they just want to know why he is, what is it or if it is something they have done or anything.

Two siblings found themselves missing their class to aid school staff in supporting their autistic brother or sister:

If he did something naughty or they couldn’t understand him, I used to be the one that would translate for him. When Mike wouldn’t get up from the middle of the playground, the teacher helper who he is with asked me to come and help him.

In one case, when the autistic sibling got detention, the participant sibling also felt that the teacher wanted to send him home as well:

Before when my brother got excluded, they'd try to make me get excluded as well.

On other few occasions, siblings themselves needed to check with their autistic brother or sister to ensure that they were comfortable and happy. Siblings during the school day might spend time worrying in case there is a fight or a conflict:

I normally see her as much as I can cause she normally gets in fights and gets upset and things.

The latter also meant that in some cases, siblings would attempt to resolve issues but also interfere in a conflict:

I go and listen to the other side and see if it's the same but if it isn't then I have to leave her [the autistic sister] because it's her thing and I don't want to get into it. But, I overheard one of the girls she said that 'why is Amanda so special, everybody ignores me all the time'. She said that to one of the girls (.) Her friend said it. I went straight over to tell her.

This extra responsibility often resulted in interrupted playtimes in the playground:

In Primary School quite a lot of the time, Lottie's friends would come up to me and ask, for help, [ok], or something to try and help Lottie, or if Lottie was alone they'd come and tell me... also she could come up to me.

Whilst siblings occasionally perceived these interactions as frustrating with an impact on how they spent their free time, they also felt that it was important for them to be in the same school with their autistic sibling, as they were able to take care of the situations that could bring frustration and “things are ok”.

3.2.2. Negative physical play interactions

The mainstream school environment was reported to pose challenges to autistic siblings which, in turn, had a direct impact on the emotional experience of the siblings. For example, physical interactions at school negatively affected the school experiences of two participants. In one case, a sibling was not allowed to play with his sibling in school because they ‘are violent when we’re together’. Furthermore, this participant felt that it would be good for him to be in a different school from his sibling, so he does not have his brother ‘in the way’.

Moreover, a few siblings mentioned that it was emotionally painful to watch their autistic brothers showing aggression towards others and even more difficult to hear about their reputation from peers:

Well, Andy hurts people a lot and people know that he does that at school (.) It makes me feel bad when he does it at school cause everyone says, 'Andy just punched someone in the field'.

For some participants, their day at school depended purely on how their brothers’ behaviour was:

Well, it's kind of hard because some days Mike is fine at school, and he'll do all his lessons but other days like today he wasn't the best. And I was walking outside to break (.) I saw him in the gym, and he was curled up in a ball, I think, underneath a stand or something and it was just embarrassing. Cause sometimes it is really embarrassing cause another time he was curled up on the floor in the hallway and anybody that walked past noticed and everybody kind of knows that's my brother.

Such interactions create a strong sense of embarrassment. A deliberate lack of sibling interaction was also identified by two siblings who spoke about failed attempts to interact with their sibling during school before giving up:

Every time I tried to see her, I mostly tried to shout to her and though she could see me, she mostly kept on eating her lunch (.) I kept on saying it then she didn't even answer, then Olivia looked at me and she tried to say my name and I pretended I couldn't hear her so I did what I did.

Siblings who no longer or never attended school with their autistic sibling found their separation to positively impact their school experience. Few siblings discussed the shared benefits:

It's giving her a chance to make more friends at her school, and I can make more friends at my school.

I'm just like oh I'm not with him [Meaning the autistic brother], which is like really weird, but I mean it's really nice to know that I have my independence.

3.2.3. Extracurricular activities are key for siblings’ social time

Siblings reported that having hobbies or taking part in extracurricular activities is often an important aspect of school life that involves socializing with friends outside the classroom as well as taking part in sports which benefits their health or the development of other types of skills. Most participants relied on school offers to be involved in some form of a social or a sports club or an extracurricular activity.

We do after-school clubs, on Mondays we do ballet, then on Tuesday we do a sports club and on Thursday we do rainbows (.)

Involvement in extracurricular activities was viewed positively by many siblings. Several of them spent social time with friends or siblings and had opportunities that could positively impact their school experiences such as developing more confidence in class:

It's got me a lot more, you know confidence, so in drama lessons... now I really want to do stuff.

For others, their hobbies brought them enjoyment and pride:

We played on the walkway, and I could just see all of my classmates just dancing. And there were quite a lot of people watching, so I felt quite proud.

In general, time spent on hobbies and friends appeared unaffected by siblings' varying levels of responsibility at home. Half of the participants acknowledged that they have a lot of caretaking responsibilities that do not affect attendance of after school clubs:

I'm normally in charge of looking after my brother a lot (...) I do quite a lot of after-school activities.

There was only one participant who mentioned that her autistic sister might cause difficulty with after-school club attendance. Shared hobbies with their autistic brother or sister were also experienced positively as many of the siblings enjoyed shared time either at clubs or at home. Siblings often recognized that their autistic brother or sister might have fewer social experiences or opportunities and thus, they tended to invite them to be with their friends:

He really enjoyed the park, and it was just nice getting him out so that he could be with us.

Siblings spoke about the sense of connectedness and the joy that it brings to share time outdoors and indoors with their autistic brother or sister:

My favourite thing to do together is playing either football or basketball or sometimes it's just to be on our tablets cause we can play the same, we can be in the same game and things. It's fun to be in the same game and be able to do the same things.

3.2.4. Typical positive and negative school experiences

All the participants identified something positive about their school experience which was mostly related to teachers' behaviour or expressions of enjoyment for specific subjects. Most siblings were very academically driven and gave long descriptions of their strengths and difficulties around different subjects. For others, the best thing about school was the opportunity it gives them to play and socialize with friends.

Although it would be expected for most school-aged children to dislike some aspects of school, those aspects were, surprisingly, unrelated to having an autistic sibling:

I've made loads of friends at school; I like maths and I like science and I like ICT and I also like literacy which is quite a lot of lessons but sometimes I don't like them it depends on what we're doing in them (...) sometimes I don't like the way the lesson it's run.

Several of the siblings spoke about disliking school subjects, while others either made negative comments about homework and disliked teachers or described them as being "boring" and "tiring". Furthermore, six siblings spoke about issues that were not related to having an autistic sibling in school, but had to do with other peers:

My friends are quite nice but sometimes they fall out with us and we don't have anyone to play with (.) mostly because they don't like the game in the apple tree then they mostly go away then they come back.

3.3. Theme 3: varied perceived levels of support and understanding

3.3.1. Emotional and educational support by family members

Most siblings stated that their parents rarely helped them with homework, either because the parents had to focus on the caregiving responsibilities of the autistic child who was struggling with homework routines or due to their parents' assumptions that 'not having a disability means I can do independently with little or no help' which can be translated to 'it's not always easy to ask for extra attention and help'. Many siblings felt comfortable asking for help or clarifications from their peers and teachers when they needed help with schoolwork and, in many cases, they preferred to complete homework during school hours to access school support.

Siblings did not report any support available at school after witnessing their autistic brother's or sister's "scary", "unexpected meltdowns at school".

It is hard to see my sister struggling in the playground...people ask me why, I ask myself why.

I don't know what I feel. I just go and help cause I am the only one who might get it right for my brother.

Their parents' readiness to chat and name emotions played a pivotal role in offering reassurance by explaining autistic brothers/sisters' behaviour and reflecting on the ways both autistic and non-autistic siblings experience life at school. Many siblings felt that the autistic sibling, just like mum or dad, can help them self-regulate by listening to or explaining upsetting situations:

All it takes is my mum or dad or even occasionally my sister to re-go over it again... It doesn't take much to just get back into my senses again.

When he tells me what is going on (...) we can sort it out and have a laugh or play a game and I don't worry about it anymore.

Sometimes, it's best if I just see my brother and stay together, he knows how to calm me down with his smile and only few words.

3.3.2. Sense of connectedness with peers and teachers who are autistic themselves or connected to someone with a diagnosis of autism

Many siblings discussed their valued friendships at school and the positive feelings cultivated by being in contact with friends who 'understand' and 'listen to worries or events':

I think I can talk to a few different people, but I think it's mainly Kelsie because she understands more (.), because I'm with her most of the time (.). She's one person who understands how I feel if Mike does something so I think that's one way that we're quite close on how she can help me.

Those who appeared to provide the most powerful school support and understanding to the participating siblings were school staff who were neurodivergent or had a connection with an autistic family member:

Sometimes you just feel the need to get out to someone who's been in a similar situation as you, so I've got three people who are going through similar occasions with their parents and their families (...) we just talk to each other about it a bit and just make ourselves like reassure that everything's going to be ok with it.

I can talk to her about a lot of autistic things (...) she knows a lot about like how disabilities work and things... her brother's autistic as well... normally when I stay back on Thursdays I'll ask a few questions, about what's happened, if something different happened, then how do I deal with it.

He [referring to autistic support staff working in school] understands me and my brother, it's not a mystery to him a meltdown in a busy playground (...) he knows these things are stressful.

3.3.3. The fear of stigma and negative reactions

Many siblings feared being stigmatized and expected negative reactions when sharing the diagnosis of their sibling with people lacking a lived experience of the autistic condition. Peers' non-familiarity with the autistic sibling's focused interests and behavioural patterns made it difficult for them to talk comfortably to them about their brothers or sisters. It was reported that non-autistic friends could only understand their experiences once they had met their sibling:

Especially for people who haven't heard of autism before, it's really hard to explain, I'd have to like bring them home (...) to explain fully... for my friends (...) to meet her and see what I mean, they don't really know.

Therefore, they wanted to have control over who they shared with and how much they shared:

There are some things that Alex [the autistic brother] has done that I would never tell my friends because (.) I know what's going to happen with my friends and that's going to end up going around my class.

Limited understanding of autism in friends and classmates led to some siblings experiencing bullying at school which made them feel uncomfortable and sad, while others wished for their friends to be less judgmental of autistic behaviours that arise due to social differences:

He [the autistic brother] mainly goes around slapping people's butts most of the time (laughs). And then he comes round doing it to all my friends and it can be really annoying. But I think that if they [school peers] are a bit calmer they would all realize that it's actually just because he is a bit different to everybody else and he is not the same and he doesn't understand things.

Some participants outlined not wanting to speak with teachers about any home issues due to the misconceptions carried by some teachers about autism, or after siblings witnessed the lack of flexibility of teaching staff when working with their autistic peers or responding to their sibling. All siblings wished their teachers were aware of their siblings' circumstances too, as this would help them to better navigate the school system:

I wish that my teacher was more open and more aware about what was going on sometimes, if she didn't notice something. she could just be a bit more aware (...).

4. Discussion

The current study explores the school experiences of siblings growing up with an autistic sibling. To our knowledge, this is the first study focusing exclusively on siblings' school experiences and the impact of home life on school experiences using an adapted photo-elicitation interview methodology. The overarching theme of the findings was related to the practical aspects of providing support during and after school hours and the qualities of their relationships in their everyday micro-contexts of home and school. This study used an experience-sensitive methodological approach to provide insight into the school experiences and needs of siblings growing up with an autistic brother or sister. The lifeworld-led approach described in the Introduction consists of eight dimensions. Each dimension captures the human experience and reflects the strengths and vulnerabilities of the human experience. Each dimension is considered as a spectrum where a sibling is either given the opportunity by the systems around the person to have, for example, agency or not, which will make them vulnerable. The lifeworld model could help us understand qualitative data in a way that will enhance our research and professional capacity for a sensitive approach to the experiences, needs, and priorities of the siblings, thus avoiding premature dichotomies of positive/negative experiences. While not generalizable to all non-autistic siblings who grow up with an autistic sibling, the data sheds light on some important key findings.

4.1. Key findings and recommendations

4.1.1. Typical and positive school experiences

The preoccupation with the adjustment, behavioural or emotional outcomes of children with an autistic sibling has led to other pivotal aspects of their lives, specifically, their school experiences, being neglected in research. An important aspect that was identified in this study was that all the siblings reported typical school experiences. They reported that there were many enjoyable aspects of the school alongside some things they disliked. All siblings identified highs and lows of school experiences which, at times, were completely unrelated to their autistic sibling. Our results suggest that siblings do not automatically experience difficulties in adjusting at school, but may be at increased risk for experiencing some difficulties related to respite time, completing homework, day- and night-time caregiving, and stigma due to the lack of environmental support or lack of autistic awareness and acceptance (see sections below). This preliminary result moves beyond siblings' tolerance and suggests the important contributions of autistic siblings to the sibling dyad. Most importantly, it has significant practical implications for families and clinical/educational staff working with families, as it calls for professionals and parents to appreciate the autistic identity and shift their focus from behavioural interventions to practices of support at school and/or home that incorporate the perspectives of both autistic and non-autistic siblings.

4.1.2. The positive contribution of autistic siblings

This is the only study to provide some evidence for the important role autistic siblings can play in supporting their non-autistic siblings. Many siblings felt that their autistic sibling was helping them to self-regulate by being around, sharing time, or taking time to explain the situation from an autistic perspective. This is an important message for parents and teachers who are often worried about intervening during siblings' conflicts. This key message also challenges the typical assumptions made that the autistic siblings are a burden or a risk factor in the life of their non-autistic siblings and can be leveraged by parents and educators to support relationships between autistic and non-autistic siblings as well as boost, particularly, the self-esteem and emotional wellbeing of the autistic siblings.

4.1.3. The positive contribution of the autistic school staff and/or staff who have an autistic family member

Many siblings felt that they were supported by autistic friends. Despite the social context reinforcing views that autism negatively impacts relationships, our study indicates that autistic peers can be compassionate and trustworthy companions in the mainstream school and enrich the life of non-autistic siblings. A pre-occupation with autistic people being stigmatized as an economic burden (Lavelle et al., 2014), incapable of having moral selves, (Barnbaum, 2008), or inherently selfish/egocentric (Frith & Hill, 2004) has meant that the many strengths autistic professionals can bring in schools have been understudied. Importantly, our study indicates that autistic school staff or those who might have cared for an autistic person may contribute to schools by facilitating both autistic and non-autistic siblings to feel heard, supported, and understood. Subsequently, we echo Wood and Happé (2021) suggestions to do more to understand, and enable the recruitment, training, and professional development of autistic professionals in schools. An emphasis on empathetic and neurodiversity affirmative perspectives on school policies should be considered by policymakers and school leadership teams. There is a high need to consider the endless possibilities of autistic school staff to constitute role models for siblings and to facilitate the educational inclusion of both autistic and non-autistic siblings (Wood & Happé, 2021). Schools may benefit from bringing disability in the classroom and in the school as an issue of equality and awareness of the needs of children with disabilities, including employing disabled school staff.

4.1.4. Home experiences can have an impact on school life of siblings

For the past 20 years research has investigated sibling experiences at school and home separately (Benderix & Sivberg, 2007; Hodapp et al., 2005; Moyson & Roeyers, 2012). However, our research has indicated that we should consider these domains in conjunction with each other. A very common theme in past research is siblings' increased amount of household duties and taking responsibility for their sibling's care to allow their parents to take a break (Angell et al., 2012; Cridland et al., 2016;). In our study, we found that siblings' care may have an impact on their homework or feeling tired at school.

Similar to Pavlopoulou and Dimitriou (2017), only a small number of siblings were found to have disturbed sleeping patterns, mainly due to sharing a room with their autistic sibling. Sleep is important for health and well-being and lack of sleep could negatively impact a child's school day if they are feeling tired and unable to concentrate (Dewald et al., 2010).

Our study highlighted that school half-term/break time can be hard for some siblings as they may experience increased caretaking responsibilities and fewer opportunities to meet friends or have time for themselves. This finding suggests that access to homework clubs and short breaks/family support schemes is essential, as proposed by Kassa and Pavlopoulou (2021). It also stresses the need for parents and teachers to work closely to support the siblings' return to school, as this home-to-school transition may pose extra challenges to them considering that some siblings may have already experienced a difficult time at home due to their increased responsibilities.

4.1.5. Teachers and peers' attitudes may affect siblings' experiences and wellbeing

Many recent studies have reported that siblings may experience problems with their sibling's behaviours of concern or meltdowns (Angell et al., 2012; Costa & da Silva Pereira, 2019; Gorjy et al., 2017; Ward et al., 2016). Most of the siblings in our study were close in age, therefore, some of them had their playgrounds or classrooms near to each other. This maximizes the chances for siblings to experience behaviours of concern exhibited by their autistic siblings. While these behaviours can be exhausting, the siblings mentioned that can successfully adopt a mediating role, supporting both their autistic sibling and staff members. A sense of responsibility for their

autistic sibling has been identified in past research (Benderix & Sivberg, 2007; Petalas et al., 2009). Nevertheless, our study explains the emotional burden of anticipating negative comments or attitudes when peers and staff witness behaviours of concern. Unfortunately, some of the siblings also identified lack of teacher support. Peer reactions to autistic sibling behaviours during school time were an added stress for the siblings. Not only is there a need to improve peer understanding, but teachers also need to be more aware of the siblings' situations and offer adequate support. Therefore, school staff needs to be aware of the potential for siblings worrying about their siblings' behaviour or that comments from peers and teachers might/may have a negative emotional impact on the non-autistic sibling. A whole-school approach that enables school staff and students to practice empathetic perspectives around neurodiversity issues can be supportive for both autistic and non-autistic siblings. These values and attitudes towards disability need to be embedded in the school culture and this can be achieved by actively involving students and their families in co-designing the school ethos, vision, and programs employed.

4.1.6. Parents as an important source of sibling support

Siblings were grateful for their parents' emotional and educational support and wish they had more support at school, especially with homework. Parental warmth and contentment found in this study are in contrast with previous research suggesting that parents perhaps cannot understand siblings' needs as much as extended family members did (Cridland et al., 2016; Petalas et al., 2012) or focusing on parental differentiated practice (Chan & Goh, 2014; Costa & da Silva Pereira, 2019). Considering this, educational and clinical professionals should recognize and strengthen parental warmth and closeness in families raising an autistic child. Shared time between parents and non-autistic siblings could improve siblings' experiences.

4.1.7. Importance of school social time

The importance of extra curriculum activities was noted in siblings' accounts. We echo back Oberle et al. (2019) who suggested that increased opportunities to join extracurricular activities can have positive implications for students' mental health. For siblings, positive feelings may be cultivated through increased opportunities to share activities with their peers. Hence, practical implications for siblings' families and wider communities, such as removing potential barriers in involvement before they enter adolescence, need to be addressed further in both research and practice. Siblings with caring responsibilities can be supported by efforts to foster their connections with peers through team activities in school as well as encouragement to participate in extra-curriculum activities.

4.1.8. Siblings managing their brothers' or sisters' behaviours of concern

Past research has indicated that formal support services targeting autistic and non-autistic siblings are likely to be beneficial by providing information about autism and facilitating strategies to manage challenges (Bradford, 2010). In contrast, our study shows that non-autistic siblings actively support their autistic siblings and those working with them offering their insights as experts by experience. This often leads to them feeling tired or worried about missing out on time from lessons or meeting with friends and they wish school structures could offer more support, awareness, and acceptance. Peer reactions to autistic sibling behaviours were an added stress for the siblings. Siblings felt that these people could not offer them adequate support, since they were not aware of the siblings' situations and lacked insights. This is in line with the study of Brede et al. (2017) showing that parents and autistic young people typically report limited access to appropriate educational support. Siblings' support plans need to include explicit ways on how to support both autistic and non-autistic siblings to enjoy school life and contingency plans for behaviours of concern. Non-autistic siblings may contribute their expertise and decide how much or little they wish to help when their siblings struggle. School staff should also consider debriefing after similar incidents.

4.2. Strengths and limitations

This is the first study to interview siblings exclusively about their school experiences and needs. The use of semi-structured photo-elicitation interviews allowed for the young people's authentic voices to be heard, as they had the opportunity to talk about what mattered most to them. Nevertheless, this study comes with certain limitations. Some of the limitations include the small study sample and the lack of comparison controls. However, it allowed for comparison between those who attended the same school as their autistic sibling and those who did not. Furthermore, the sample of families that participated was recruited through online support groups and, thus, it may not capture the experiences of families who do not actively seek and access support. The sample was also not homogenous in birth order and the number of other siblings in the family. Consequently, it is difficult to conclude whether these were mediating factors in the siblings' experiences. Additionally, the lack of participation of black and Asian siblings limited the information about the perspectives of those groups. Much of the existing research on siblings' experiences has been conducted with predominately white, middle-class families who seek either in-person or online support. Thus, it is vital to extend this research and include families from a wider range of ethnic and socioeconomic backgrounds.

4.3. Implications for school psychologists

Mirroring suggestions made in recent reviews (Watson et al., 2021), and cited in the NICE (2013) guidelines, siblings of autistic children should have an assessment of their own needs and support should be given where necessary. Our findings suggest several implications for school psychologists in core functions of the educational psychologists' role including training, consultation, assessment, and whole school support. The following recommendations are cost-effective, rooted in an experience-sensitive approach and an ethos that celebrates neurodiversity in schools. Given that this is a single study, with noted limitations in terms of the diversity

of participants, recommendations are very tentative because of the need for further study in this area.

4.3.1. Training

Significant findings in this study stress the need for school psychologists to promote autism awareness and understanding amongst peers and teachers. Promoting peer acceptance may decrease any negative consequences for the non-autistic siblings and increase a sense of belonging and well-being at school. Intervention studies designed to reduce stigma and educate school-aged children about autism can increase knowledge and improve attitudes and behavioural intentions displayed towards autistic peers (Ranson & Byrne, 2014). Pavlopoulou and Dimitriou (2020) have noted the importance of involving siblings in educating their local communities where a more appropriate, responsive, and need-fulfilling strategy of proactive support systems can be initiated. Such an approach is cost-effective and could be adopted to educate teachers by increasing awareness of the difficulties and challenges faced by the siblings. Additionally, improving autism acceptance in schools could decrease the negative effects on siblings and enable teachers and peers to be compassionate and supportive. It is shown that disability awareness in school contributes to the educational efforts to help students become better active citizens (Lindsay & McPherson, 2012). Schools have a central role in embedding this awareness in the school ethos and culture and bringing it into the daily activities of the classroom.

4.3.2. Consultation

Educational psychologists could facilitate discussions about siblings' wellbeing, belonging with multi agency teams in order to coordinate or signpost to further support. Siblings may lead discussions on how they feel about homework, school relationships, respite time, and sleep/other home routines.

4.3.3. Assessment

Findings from this study identified that even those experiencing difficulties at school were still able to identify positive experiences. The negative effects of sharing school experiences may be overcome if siblings have appropriate sources of support at school. This has implications for children who experience significant difficulties but do not have the social support to protect them from the negative impact. The qualitative results, which are theoretically grounded in an experience-based approach of this study, provide an evidence base for addressing individual variations and siblings' perspectives to help the school staff understand their school experiences and consequences on their wellbeing. Educational psychologists might use adjustment questionnaires and experience-based conversations employing a Lifeworld framework to assess siblings' needs, or strengths and the position siblings hold in each other's lives at home and school. Understanding, for instance, the sense of belonging or the sense of place drawn upon siblings' accounts might equip professionals to make suggestions that could improve educational outcomes, identify wellbeing struggles, and co-develop solutions. An experience-based approach also benefits by drawing attention to the siblings' experience in their human relationships across the lifespan with an emphasis on the aspects of intimacy rather than the causal aspects of these relationships.

4.3.4. Intervention and support

A whole-school approach includes not only raising awareness of disability, but also developing specific policies, programs, and advocacy initiatives to promote a positive, empathic narrative about disability that moves away from the 'tragedy' narrative. The new narrative should focus on bringing disability into the classroom and in the school as an issue of equality and awareness of the needs of children with disabilities, including employing disabled school staff. It can be extremely empowering for all children and young people to understand disability and to take an active role in promoting kindness, empathy, and support for disabled children. These values and attitudes towards disability need to be embedded in the school culture and this can be achieved by engaging students and their families in designing the ethos, vision, and programs employed.

On the individual level, school staff, family members, and school psychologists should collaborate to ensure that they do not neglect the needs of siblings in their schools. Siblings can be supported to foster connections with peers through team activities in school and to participate in extra-curriculum activities. Siblings may also benefit from one-to-one interactions or sibling-led groups, in which they can normalize their experiences, share feelings, and ask for help. Professionals working with families need to ensure that there is accessible sleep management support for all families and respite options available to allow siblings to be healthy and enjoy personal time without having to offer family support day and night.

4.3.5. Research

Research on the experiences of children growing up with an autistic sibling is growing rapidly and there are many avenues for future research in schools considering the momentum created with the Green paper in 2014 where the UK government stated that schools should have a clear pathway to offer proactive and reactive support to all students by 2025. Participants interviewed in this study were relatively young and predominantly white. Future research would benefit from investigating more diverse samples. In this study, those who had shared school time with their autistic siblings identified experiences that resulted in disruptions in their day by undertaking roles to facilitate their autistic siblings' school experience. Furthermore, it would be meaningful to investigate the impact of shared school experiences on adolescents who already have extra stressors in the form of national exams. A qualitative approach combined with quantitative measurements of academic achievement and psychosocial well-being of young people would be beneficial. It is suggested that siblings should have options to use diverse tasks to express themselves including photo-elicitation and other relevant methods. Finally, more research looking at the ways siblings may improve inclusion for their disabled siblings and the ways we can maximize the positive impact of shared school experiences is needed.

CRedit authorship contribution statement

Clare Burns, Rosie Cleghorn, Theodora Skyrila: Data curation. Georgia Pavlopoulou: Formal analysis. Georgia Pavlopoulou: Methodology, Design, Supervision. Georgia Pavlopoulou, Clare Burns, Rosie Cleghorn: Writing – original draft. Clare Burns, Rosie Cleghorn, Theodora Skyrila, Julia Avnon: Writing – review & editing.

Data availability

The data that has been used is confidential.

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