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# A Comparison of Attitudes and Knowledge Towards Autism Based on Adult Sibling Experiences

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## Abstract

Studies examining relationships between neurotypical and autistic siblings have reported inconsistent findings when focussing on children and adolescents, with little research investigating adult autistic sibling relationships. This is of particular interest as siblings can often take over the guardianship or care of a sibling when their parents are no longer able to. The current study examined knowledge and attitudes of adult siblings towards autism. 50 mixed sibling types (autistic sibling + neurotypical sibling) & 59 matched sibling types (neurotypical sibling + neurotypical sibling) completed knowledge and attitude questionnaires. In addition, a thematic analysis of responses provided by neurotypical siblings from the mixed sibling types was used to explore experiences with autism based on sibling relationships. Results showed a non-significant difference of attitudes towards autism and a significant difference in knowledge of autism. From the thematic analyses four themes were identified: Robbed Childhood, Sibling over Self, Concerns for the Future, and Autism Awareness. The study found that having a sibling diagnosed with autism can predict knowledge of autism, however, knowledge of autism does not drive attitudes, therefore further research is needed to understand which factors drive neurotypical sibling attitudes since attitudes predict behaviour. The qualitative research showed mixed experiences within childhood and adulthood, with implications on care in the future. The adult perspectives of the autistic sibling relationships are discussed.

**Keywords** Autism · Adulthood · Sibling relationships · Attitudes · Knowledge

## Introduction

Autism is a neurodevelopmental disorder, characterised by deficits in social interaction and communication, alongside the presence of restricted and repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). Russell et al. (2022) estimate that there are roughly 700,000 people diagnosed in the UK, affecting 3:1 males to females with a 3–6% risk of a sibling also being diagnosed (Frith, 2003). As autistic characteristics are presented as social communication, restricted, repetitive behaviour domains and hypo- or hyper-reactivity to sensory

stimuli, the diagnosis is likely to impact individuals differently (Charman, 2015). Those who are diagnosed as having autism may face challenges such as difficulties with self-expression and information processing (Kendell & Jablensky, 2003). Due to this, those who have an autism diagnosis can have poorer outcomes in several domains such as independent living, education, and employment, compared to other disabled groups (Sosnowy et al., 2017). This is likely a result of autistic individuals being required to fit into neurotypical environments that are not adapted for each autistic individual's needs (Hsiao et al., 2013).

## Sibling Relationships

Family dynamics, composition, and relationship quality are important factors for child development and mental health (McHale et al., 2012). Immediate familial relationships including sibling relationships can have a direct effect on development since siblings serve as role models and social partners, and will influence parent and child interactions (McHale et al., 2016). Both positive and

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negative findings have been identified in the type of relationships experienced by those who have autistic siblings (Petalas et al., 2009; Walton, 2016). Those with an autistic sibling are at higher risk of displaying both internal and external problem behaviours (Fisman et al., 2000), potentially through jealousy of their autistic sibling requiring more support and attention from parents (Howlin, 1988). Neurotypical siblings (hereafter known as siblings) that choose to be involved in their autistic siblings' support network are at risk of becoming "parentified" through a duty of care felt towards their autistic sibling (Seligman & Darling, 2017), which can lead to both negative (e.g. resentment towards the autistic sibling) and positive outcomes (i.e. better social skills and increased responsibility).

### Sibling Relationships in Adolescence

The experience of growing up with an autistic sibling differs for everyone (Hastings, 2003; Lovell & Wetherell, 2015). Petalas et al. (2009) showed that children were able to identify the disruption and impact their autistic sibling made in their daily life, while Gorjy et al., (2017) found that adolescent siblings additionally deal with negative attitudes and lack of understanding from their peers regarding their home circumstances, such as planning social activities far in advance to account for resistance to change. Younger siblings were also able to recall the beginning of their caretaking duties, expressing that they never felt like the younger sibling despite chronologically being younger (Petalas et al., 2009). Sibling relationships began to be portrayed more positively through the progression of childhood via the increased acceptance of autistic siblings' conditions and becoming proud of siblings' achievements (Ferraioli & Harris, 2009). In contrast to their neurotypical peers, siblings found they had learned how to respond to others with a disability through their experience of having grown up with an autistic sibling and appreciated the happiness their sibling brought to their life (Pavlopoulou & Dimitriou, 2019).

Further work by Petalas et al. (2012) showed that throughout adolescence, some individuals found themselves in an emotional conflict through feeling frustrated at the increase of their autistic sibling's aggression and erratic behaviours, but also empathised and had understanding for the reasons behind these behaviours (Petalas et al., 2012). Similarly, Corsano et al. (2016) found evidence that siblings began to worry about their autistic sibling's future but did not necessarily feel pressure to become a potential future caregiver in the later stages of adolescence. However, siblings still felt guilty at the idea of their autistic sibling remaining dependent on their parents.

### Sibling Relationships in Adulthood

There is substantially less research on the outcomes of autistic sibling relationships in adulthood. This is important as invariably the neurotypical sibling will have to assume caretaking responsibilities when parents are no longer able to (Heller & Arnold, 2010). Research shows that the autistic sibling tends to be held in positive regard by their neurotypical brother or sister (Orsmond & Seltzer, 2007) but that they may experience less emotional closeness than other sibling pairs when one has a developmental disability (Tozer et al., 2013). Adult siblings who report having taken on more caregiving responsibilities for their brother or sister as children also report more positive relationships with their sibling in adulthood (Tomeny et al., 2017). Additionally, Wright et al. (2022) reported autistic siblings influenced the career choices of their neurotypical brother or sister, with positive attitudes often mitigating some of the challenges of having an autistic sibling. However, siblings also report challenges of having an autistic sibling which are related to problem behaviour and caregiving responsibilities (Moss et al., 2019).

### Autism Awareness

Knowledge of autism can have a beneficial influence on a sibling's relationship with their autistic brother or sister. A study exploring sibling relationship satisfaction found that the higher degree of autism knowledge that the neurotypical sibling had, the less embarrassed they were regarding their autistic sibling's behaviour and the better they were able to accept the challenges of autism (Macedo Costa & Pereira, 2019).

Indeed, the general public often make inaccurate assumptions about autism (Huws & Jones, 2010). For example, evidence suggests that neurotypical individuals have more negative social first impressions of autistic individuals than any other disability (Sasson & Morrison, 2017). Further to this, Woods (2017) concluded that children hold more negative attitudes towards their autistic peers than neurotypical peers. This is despite a plethora of campaigns in recent years to promote autism awareness through strategic action plans (e.g. Department of Health, 2015) and health promotion campaigns such as the United Nations-led World Autism Awareness Month. Utilising this experience provides the public with the opportunity to correct misconceptions (Cage et al., 2018), and establishes acceptance through portraying positive attitudes, as opposed to reflecting prejudice (Morin et al., 2012). Worryingly, however, a recent study investigating attitudes showed that while neurotypical adults exhibited positive explicit attitudes towards autistic adults, implicit attitudes were negative (Dickter et al., 2020).

Finally, societal attitudes towards autism have been highlighted as impactful when considering autistic siblings. In a cross-cultural study of Taiwanese and UK sibling experiences of autism, a more negative tone towards autism was reflected in the Taiwanese families' experiences, due to societal judgement and culture-specific expectations such as more responsibility on the non-autistic sibling, which resulted in a poorer coping style for the sibling and less information shared between the parents and siblings about autism (Tsai et al., 2018). Therefore, it is important to further examine if attitudes towards autism influence the sibling relationship.

## The Current Study

There is currently limited research examining neurotypical and autistic sibling experiences within adulthood. Siblings have been presumed to accept their situation of becoming the main carer for their autistic sibling (Yacoub et al., 2018). A recent study suggested that 97% of siblings reported having negative experiences because they lacked both family and social life, but that despite this, 55% still stated that their autistic sibling brought positivity into their life, suggesting that the sibling experience is mixed throughout the lifespan (Moss et al., 2019). Due to the lack of research in adult sibling relationships between those who are autistic and neurotypical, the current study aimed to examine the adult sibling relationship between such siblings, including factors that may influence this such as knowledge of autism and attitudes towards autism.

The current study was therefore focussed on what it means to have an autistic sibling in adulthood and how autism knowledge and attitudes are different between sibling types. The study involved two phases. Phase 1 assessed the quantitative aspect of the study and hypothesised that there would be a significant difference between those who have neurotypical and autistic sibling types (i.e. mixed = autistic sibling + neurotypical sibling or matched = neurotypical sibling + neurotypical sibling) and their attitude towards autism. It was also proposed that there would be a significant difference between sibling types (mixed or matched) and their knowledge of autism, and that knowledge of autism would predict overall positive and negative attitudes of autism. The experiences of autism were also recorded, as previously stated, awareness campaigns may educate the general

public and participants may have other personal or professional experience of autism, outside having an autistic sibling. Phase 2 addressed the qualitative aspect of the study, to explore the lived experience of having an autistic sibling and whether this impacted on attitudes to, and knowledge of, autism, through answering the research question: 'what are the lived experiences of having an autistic sibling?'.

## Materials and Methods

### Participants

Participants in the study were the non-autistic adults who had either autistic or neurotypical siblings and the term 'sibling' referred to the siblings of the non-autistic participants, both mixed (neurotypical sibling + autistic sibling) and matched (neurotypical sibling + neurotypical sibling). Participants with autistic siblings were recruited first then participants with neurotypical siblings recruited after to guarantee an even split of participants.

Participants were recruited through two social media platforms: Facebook and Twitter. Recruitment on both social media platforms was done via posts shared with contacts. Participants were also resourced on Facebook through autistic support groups. All social media posts consisted of the weblink to the survey and a description of the study with appropriate hashtags to engage participants. It was then the interested participants' choice to respond. Online recruitment is an effective data collection strategy which is time and resource efficient (Baltar & Brunet, 2012; Kosinski et al., 2015; McRobert et al., 2018).

Table 1 displays demographics of all participants for both sibling types. The age ranges of the participants are shown, however, the participants in both matched and mixed sibling pairs are relatively young (68% under the age of 32 for matched and 86% under the age of 32 for mixed sibling pairs). Also, whereas only ages of the autistic sibling were recorded, this sample was also relatively young with an age range between 3 and 40 years of age, and 92% of the participants' siblings being under the age of 30. Table 2 shows the percentage of participants who have had experience with autism, either personally or professionally. A chi-square test of independence was performed to examine the frequency of occurrence between sibling types

**Table 1** Demographic of sibling type, gender, ages, & the ages of their siblings

Sibling type	Male	Female	Participant age ( <i>M SD</i> )	Participant age range	Sibling age ( <i>M SD</i> )
Matched	4	55	31.6 (13.3)	18–64	N/A
Mixed	2	48	25.3 (8.0)	18–51	22.3 (7.4)
Total	6	103	28.7 (11.6)		22.3 (7.4)

**Table 2** Percentage of participants' experiences of autism interactions

Sibling type	Little to no contact		Friend		Family member other than sibling		Volunteering		Primary caregiver		Through employment		Other	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Matched	7	11.9	3	5.1	23	39	2	3.4	4	6.8	12	20.3	8	13.6
Mixed	0	0	1	2	40	80	1	2	2	4	1	2	5	10

and having a family member diagnosed with autism. The relationship between these variables was significant  $\chi^2(6, n=109)=23.0, p<0.001$ . Although the matched group did not have an autistic sibling, 39% reported having another autistic family member.

## Procedure

Ethical approval was obtained from the home institution and no part of the project commenced until this was granted. Participants were offered the opportunity to join a study investigating adult experiences of living with an autistic sibling and how this had influenced their attitude and knowledge towards autism. Participants were advised the findings would be compared with the perspective of adults that do not have an autistic sibling and how their experiences affected their attitude and knowledge towards autism. The online survey was distributed on social media platforms containing an information sheet, a consent form, the questionnaire and a debrief sheet. Completion of the questionnaires took approximately 30 min and data were collected between 7th November and 20th December, 2019.

## Measures

### Autism Knowledge

The Knowledge about Childhood Autism among Health Workers (KCAHW; Bakare et al., 2008) was used to assess autism knowledge. The questionnaire had been used extensively across different groups to assess knowledge of autism (i.e. Ballantyne et al., 2021; Igwe et al., 2011) and with a good test–retest reliability and internal consistency. The coefficient alpha reliability coefficient was 0.748. Although the questionnaire was originally intended for health care professionals, there are no specific questions that are unsuitable for this group and therefore deemed reliable to administer to the current population. A minimum score of zero and a maximum score of nineteen could be obtained. One of the three choices in each question was correct. The scores for the questionnaire were calculated by giving the correct option in each question a score of one and the two incorrect options

received a score of zero. A minimum total score of zero and a maximum total of nineteen could be obtained.

- Domain 1 (max score 8, min score 0): Assesses individual's knowledge about impairments in social interaction.
- Domain 2 (max score 1, min score 0): Assesses individual's awareness of impairment in communication and language development.
- Domain 3 (max score 4, min score 0): Assesses knowledge of impairments in behavioural development found in autistic children.
- Domain 4 (max score 6, min score 0): Assesses individual's understanding on basic information about autism such as the possible co-morbid conditions and onset of autism.

### Autism Attitudes

The Societal Attitudes Towards Autism (16 item version; SATA; Flood et al., 2013; current coefficient alpha reliability coefficient of 0.76) was used to assess participants' attitudes towards autism. It included items such as 'People with autism should not have children' and 'A person with autism is a financial burden to his/her family'. Total scores below 30 identified a negative attitude towards autism; with scores of 15 or less indicating a strong negative attitude. Total scores of 31 and above identified a positive attitude towards autism, with total scores between 46 and 60 identifying a strong positive attitude.

### Qualitative Measure

In order to further explore the experience of having an autistic sibling, participants with an autistic sibling only were further asked a series of free-text questions based on their sibling experience, exploring the likes of how their sibling had impacted their life, what their relationship was like, and what the positives and negatives of having an autistic sibling were (see Appendix for full list of questions). The research question guiding Phase 2 of the study, therefore, was, *what are the lived experiences of having an autistic sibling?* All mixed siblings in the study answered these questions.

## Data Analysis

### Phase 1

Differences in attitude scores on the SATA between the two groups (mixed + matched) were examined using independent *T* tests. Further, a Pearson's correlation were computed to examine if there was a relationship between attitude scores and total knowledge scores for mixed and matched sibling types. Finally, a simple linear regression was carried out to investigate if any of the domains on the KCAHW could predict attitude scores for both sibling types.

Overall knowledge of autism was examined by independent *T* tests between the mixed (neurotypical + autistic sibling) and matched (neurotypical + neurotypical) groups. A repeated measures ANOVA with a between subject factor of Group (mixed × matched) and a within subject factor of Domain (Domain 1, Domain 2, Domain 3, Domain 4) was used to examine differences between the four domains on the KCAHW, with planned comparisons to look at differences between domains.

### Phase 2

Braun and Clarke's (2006) inductive approach to thematic analysis was applied to the data set, consisting of the following six stepwise stages: 1. Becoming familiar with the data; 2. Generating initial codes; 3. Searching for themes; 4. Reviewing themes; 5. Defining and naming themes; 6. Producing the report (Braun & Clarke, 2006). This approach is considered "creative, reflexive and subjective, with researcher subjectivity understood as a resource rather than a potential threat to knowledge production" (Braun & Clarke, 2019, p. 591). Phases 1–6 were conducted by one researcher, and reviewed by a second, who affirmed the resultant themes though offered an alternative (more informative) title for one of them. The aim was to identify items at both the semantic and latent level to ensure quality and credibility in the process (Terry et al., 2017). In phase two, 32 codes were identified (for example, 'strain', 'postponing dreams', 'importance of awareness') which were refined during phases 3–5 through grouping codes of similar definitions together to form the final four themes. Although it may be argued that the themes could overlap, the research team are confident that each is independent and apparent enough within the data to warrant being discussed as a theme individually. Indeed, according to Braun and Clarke (2019), the data within themes should cohere meaningfully together, while there should also be identifiable distinctions, which we are satisfied there are.

## Results

### Attitude Score Statistics

All data were checked for normality and showed normal distribution. The independent *T* test showed there were no significant differences for the attitude total scores of matched ( $M=52.5$ ,  $SD=4.73$ ) and mixed ( $M=51.1$ ,  $SD=5.62$ ) sibling types;  $t(107)=1.400$ ,  $p=0.164$ , indicating that participants who have autistic siblings do not differ from participants who have neurotypical siblings in terms of attitudes towards autism.

A Pearson's correlation showed that there was no significant relationship between attitudes and total knowledge scores for matched sibling type ( $r=-0.11$ ,  $p=0.935$ ). Likewise, there was a marginal negative non-significant correlation between attitude and total knowledge scores for the mixed sibling type group ( $r=-0.269$ ,  $p=0.059$ ). These correlations showed that there was no relationship between knowledge and attitudes in both participant groups (i.e. those who have autistic siblings and those who have neurotypical siblings), indicating that both groups possess positive attitudes towards autism and similar knowledge of autism.

Finally, a simple multiple linear regression was carried out to determine if the knowledge domains on the KCAHW could predict attitude scores. The results of the regression indicated that the model explained  $R^2=0.039$ , (3.9% of the variance), with none of the domains predicting attitude scores. The model was not significant  $F(4, 108)=1.062$ ,  $p=.379$ , again indicating that knowledge does not predict sibling's attitudes towards autism. Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern (Domain 1, Tolerance = .66, VIF = 1.51; Domain 2, Tolerance .84, VIF = 1.19; Domain 3 Tolerance = .74, VIF = 1.35; Domain 4, Tolerance .81, VIF = 1.24). Additionally, the data met the assumption of independent errors (Durbin–Watson value = 2.15). Lastly, the standardised residuals indicated that the data contained approximately normally distributed errors. The regression results are shown in Table 3.

### Knowledge Score Statistics

Table 4 shows the mean and standard deviations for the total scores of knowledge towards autism for each sibling type. The *T* test suggests that the mixed sibling type scored higher ( $M=14.46$ ,  $SD=2.90$ ) on knowledge total than the matched ( $M=13.16$ ,  $SD=3.70$ ) sibling type, indicating that those participants who had autistic siblings showed higher levels of knowledge compared to participants who had neurotypical siblings. This was also found across all individual domains of knowledge. An independent *T* test showed a

**Table 3** Domain-related knowledge and sibling attitudes towards autism

Variable	<i>B</i>	SE <i>B</i>	$\beta$	<i>p</i>	95% CI
Intercept	55.55	2.14		.01	[- 51.22, 59.61]
Domain 1	.02	.34	.01	.94	[- .65, .70]
Domain 2	- 1.84	1.42	- .14	.20	[- 4.66, .99]
Domain 3	- .61	.60	- .11	.31	[- 1.8, .57]
Domain 4	- .07	.42	- .02	.88	[- .89, .76]

Domain 1 (max score 8, min score 0): Assesses individual's knowledge about impairments in social interaction. Domain 2 (max score 1, min score 0): Assesses individual's awareness of impairment in communication and language development. Domain 3 (max score 4, min score 0): Assesses knowledge of impairments in behavioural development found in autistic children. Domain 4 (max score 6, min score 0): assesses individual's understanding on basic information about autism such as the possible co-morbid conditions and onset of autism

**Table 4** Mean and standard deviation for the four KCAHW domains & total knowledge scores for each sibling type

Domains	Possible score	Matched Mean (SD)	Mixed Mean (SD)
Domain 1	8	6.06 (1.88)	6.56 (1.69)
Domain 2	1	0.81 (0.39)	0.84 (0.37)
Domain 3	4	3.13 (1.10)	3.56 (0.73)
Domain 4	6	3.15 (1.32)	3.56 (1.34)
Total knowledge score	19	13.16 (3.70)	14.46 (2.90)

marginal significant difference in the total knowledge scores of Group;  $t(107) = -1.994$ ,  $p = 0.049$ , suggesting that those with autistic siblings were more knowledgeable of autism.

A mixed ANOVA with a between subjects factor of group (matched  $\times$  mixed) and a within subjects factor of Domain (Domain 1, Domain 2, Domain 3, Domain 4) was carried out to examine the domains and group and a significant main effect of group was found  $F(1, 107) = 4.36$ ,  $p = 0.04$ . This is shown in Table 4. Planned comparisons independent *T* tests across the knowledge domains showed a significant difference between groups for Domain 3 only;  $t(101.5) = 2.39$ ,  $p = 0.02$ . Suggesting that participants who had an autistic sibling were better at identifying obsessive and compulsive behaviours than participants who had neurotypical siblings were.

## Thematic Analysis

As a result of the qualitative research question, *what are the lived experiences of having an autistic sibling?*, the following four themes were identified: (1) Robbed Childhood, (2) Sibling over Self, (3) Concerns for the Future, and (4) Autism Awareness; obtained from the participants

with autistic siblings only. An overview of each theme, with illustrative quotes, is presented below.

### Theme 1: Robbed Childhood

This theme focussed on participants' perceptions of their childhood being taken away in order to care for their siblings:

I had to grow up a lot faster than my peers as I had a lot of responsibility at a young age, I didn't have time to go out with friends as I was looking after him (Participant 56, age 22)

Growing up way too fast...I have almost been a parent to him (Participant 104, age 30)

Both participants here acknowledged they have grown up faster than their peers, highlighting that they have taken on responsibilities at a young age, and as such have sacrificed friendships to assist with caring for their sibling. Through participants' understanding of the responsibilities they had at a young age to be 'like a parent', it can be suggested the participants' childhoods had been robbed from them in order to take on the caregiving role. This is similar to previous research that reported high levels of sibling-focussed parentification (i.e. caregiving responsibilities, Hooper & Doehler, 2011; Nuttall et al., 2018).

However, this is not necessarily a negative. Consider the following from participant 56:

I have been (the) main caregiver for my brother since I was 10...we are very close still even though I do not live with him anymore (Participant 56, age 22)

Participant 56 discloses that from a young age they were a main carer for their sibling which has resulted in them maintaining a close relationship, so even though childhoods may feel robbed, this may be countervailed in adulthood and is supported by research that has shown sibling-focussed parentification predicts positive sibling relationship attitudes (Tomeny et al., 2017).

### Theme 2: Sibling over Self

The second theme expands upon the notion of experiencing a robbed childhood by detailing the ways in which they put the needs of their siblings over their own. Consider the following quotes:

It makes me want to stay closer to home, instead of moving to (Country X) like I'd been planning (Participant 53, age 21)

I sometimes don't feel like I have the freedom that others have. I have put off having kids because I want

my sister to find a good long-term housing placement first (Participant 38, age 26)

In these examples, the participants demonstrated how their own wants and needs have been put aside in favour of their siblings', whether in terms of halting moving plans or starting a family; both typical developmental milestones in life. This is in line with similar research that reports neurotypical participants will indicate a strong intention to continue to look after their autistic siblings throughout adulthood (Nuttall et al., 2018). Of interest is that both participants here talked about this as their choice: they "want" to stay close to home and prioritise their siblings' needs as opposed to feeling like they have to. In addition, some participants referenced the extreme lengths they will go to, putting their siblings' needs before their own:

If I had to give up plans for my own future to help him in any way then I will (Participant 107, age 23)

Here, we see participant 107 expresses that they would surrender their own future plans for their sibling, which portrays the dedication individuals have to their siblings, and the extent to which their needs are put first.

### Theme 3: Concerns for the Future

The next theme focussed on the future of siblings and the worries this brings. Consider the quotes:

I know that one day I will most likely need to become the carer of my autistic sibling in the future (Participant 99, age 46)

I have to be in an area where I can be near him & I have limited options to make future plans (Participant 100, age 26)

Research has shown that siblings tend to display anxieties about the future when their parents are no longer able to provide care (e.g. Benderix & Sivberg, 2007), and here the participants assume that they will still be involved in their siblings' care 'in the future' demonstrating not only the longevity of the role, but that it is something that will encompass their whole life, impacting their ability to make future plans for themselves. In addition, participants detailed how their role in their sibling's future may specifically impact their relationship with their partner:

I worry about my husband and I having to financially support her... I worry about it causing emotional difficulty for my husband (Participant 38, age 26)

This participant has shown how their care role has not only continued into adulthood, but has extended into their own personal life demonstrating the challenge of balancing future commitments to siblings and the strains this may place on

other family members. The participant also mentioned possible future financial and emotional stressors that come from caring for their sibling, suggesting that those who take on a primary caregiving role need to consider the impact this may have on their own families. This perspective has been highlighted in the previous literature as individuals were shown to worry about what their role would be in their sibling's future (Petalas et al., 2012).

### Theme 4: Autism Awareness

Finally, theme four relates to the importance of autism awareness within society: how much the participants have learned based on their life experience growing up with a diagnosed sibling, and how much their knowledge and awareness of autism would differ if they did not have this experience. Consider the following quote:

I believe it should be brought up in schools about disabilities (Participant 82, age 32).

Participant 82 here identifies the importance of discussing disability at school level, indicating not only the value of spreading awareness of disability, but doing so for children at a young age. However, research has shown that giving information about autism to raise awareness is not enough to change attitudes (Dillenburger et al., 2017), and perhaps real-life interaction is more important, as detailed below:

Most people who haven't grown up understanding autism don't know how to act around those with special needs (Participant 107, age 21)

Of interest here is this participant's suggestion that being around an individual with autism involves some form of act; something that is a learned skill, that they have developed due to their years of experience. This is in line with the social model of disability which posits that autistic people may be disadvantaged in social interactions not only due to their own differences but also by other's understanding and accommodation (Hutchison, 1995). In addition, participants describe the importance of their life experience and the positive impact this has on their own awareness:

I would not have the knowledge of what autism is and how it can impact people in many different ways. The only perspective I had previously was of that perceived on the TV (Participant 86, age 24)

The participant emphasised that without their own experience, their perception of autism would be based on how the media portrays autism. However, portrayals of characteristics of autism in film are often unrealistic, suggesting that people are receiving a false idea of what autistic individuals are like which results in establishing a negative or incorrect awareness (Nordahl-Hansen et al., 2018a, 2018b).



Conversely, the use of TV and media to spread awareness of autism would be of educational use if portrayed correctly (see Nordahl-Hansen et al., 2018a, 2018b).

In summary, the themes of Robbed Childhood, Sibling over Self, Concerns for the Future and Autism Awareness, together, have demonstrated the key lived experiences for this cohort of participants, of having an autistic sibling.

## Discussion

### Quantitative Findings

The study explored attitudes and knowledge of autism based on sibling experiences. The results showed that those with matched sibling types (neurotypical sibling + neurotypical sibling) scored slightly higher, on attitudes (identifying a stronger positive attitude towards autism), compared to the mixed sibling types (autistic sibling + neurotypical sibling), suggesting that both sibling types had a positive attitude towards autism (i.e. scored 31 and above on the SATA). Despite these findings being non-significant, this could be explained by a high proportion of participants having prior contact with autistic individuals—e.g. through volunteering and employment—with the majority also reporting to have an autistic family member (not sibling) as shown in Table 2. These results conflict with the previous literature as the current study showed that in adulthood regardless of sibling type, all adults appeared to have positive attitudes towards autism. In contrast, the previous literature reported that those with matched sibling types show higher levels of negative attitudes towards their autistic peers (e.g. Woods, 2017). It should also be noted that the sample of participants were relatively young, with the majority being in young adulthood, and a minority being in mid adulthood. Therefore, participants may be more likely to have been exposed to awareness campaigns and inclusive schooling. The importance of including children with disabilities in mainstream school was highlighted in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) and as a consequence, younger adults may have a more positive attitude.

Following on from this, there was no significant relationship between attitude and total knowledge scores for either mixed or matched sibling types, and the domains in the KCAHW did not predict attitudes. This is reflected in a study by White et al. (2019), who also found that there was no significant relationship between knowledge of autism and attitudes towards autism, and that attitudes remained stable and resistant to change. Indeed, within our current sample of participants, a positive attitude towards autism was reflected, which may be due to the majority of people having some experience with autism (albeit not necessarily a sibling—see

Table 2). The current study did not have sufficient power to examine whether exposure does impact attitudes towards autism and research should explore this further. As mentioned previously, the social model of disability proposes that the autistic individual's differences and challenges, coupled with societal barriers such as neurotypical negative attitudes towards autism, may lead to break down in social functioning and interaction (Hutchison, 1995). Recently, research has shown that neurotypicals' perceptions and first impressions of autistic people impact social interactions regardless of levels of exposure (Sasson et al., 2017), which may also suggest that attitudes are informed not only by knowledge but other initial social judgements.

The results also showed that siblings from the mixed sibling type scored significantly higher in both Domain 3 (obsessive and compulsive behaviours) and total knowledge scores, compared to siblings from the neurotypical matched groups, indicating that those participants that had autistic siblings were more knowledgeable about autism. It is interesting that knowledge about obsessive and compulsive behaviours was higher in participants who had autistic siblings. This may be due to these behaviours often being viewed as the most difficult to manage by families (Lecavalier et al., 2006; Ludlow et al., 2012), therefore, it would make sense that family members pay increased attention to such behaviours and how they present. These findings also further support the previous literature that found an increased awareness of autism indicated more knowledge of the condition (e.g. Cage et al., 2018), whereas members of the public with no prior experience or awareness of autism showed little to no knowledge of the condition (Woods, 2017); leading to misconceptions (Campbell et al., 2019). The findings also support the suggestion that to improve knowledge of autism in the community, those who have experience of autism need to share their knowledge to help increase awareness in others (Kuzminski et al., 2019).

### Qualitative Findings

The qualitative data explored the lived experiences of siblings of individuals with autism. Participants reported how their sibling relationship differed from a typical sibling relationship; theirs felt more like a parent-child relationship as opposed to a sibling relationship due to additional caring responsibilities, leaving feelings of a childhood robbed. Ferraioli and Harris (2009) demonstrated that autistic siblings can be a restriction towards a neurotypical sibling's ability to have friends, potentially due to the fact that they are more likely to be parentified as children. Petalas et al. (2009) reported a similar aspect of relationship change where individuals were able to recall their caregiving duties beginning in childhood, leaving participants with a negative attitude towards autism during

childhood due to becoming parentified. However, results from the current study also showed that this could result in a closer relationship between siblings which offers a more optimistic perspective of the autistic–neurotypical sibling relationship (e.g. Seligman & Darling, 2017; Tomeny et al., 2017).

The analysis went on to demonstrate the extent to which a close adult relationship was maintained, showing how participants would put their siblings' needs before their own. This has been identified in the previous research as adult siblings tend to negotiate other commitments when offering support to their disabled sibling (Moss et al., 2019; Orsmond & Seltzer, 2007), potentially due to a feeling of needing to protect them from vulnerability (Tozer & Atkin, 2015).

Although the results support previous work that indicates that participants freely choose to be so committed to their autistic sibling, other work has shown the negative impact that prioritising siblings can have on family and social life (Moss et al., 2019), and this was evidenced in the third theme. Aligning with past research (e.g. Heller & Arnold, 2010; Nuttall et al., 2018; Yacoub et al., 2018), participants assumed that they would become the primary caregivers, and would have to structure some of their life choices around that. In addition, there was the mention of worry about the impact such caring responsibilities would have on their own relationships, as detailed in the previous work (Sonido et al., 2020). These findings conflict, however, with the previous research as Corsano et al. (2016) found siblings did not feel worried or pressured into becoming a caregiver as it was presumed their autistic sibling would lead an independent life. Differences between these studies may have been caused by differences in the autistic siblings' capabilities, with lower levels of capabilities and increased support needs leading to increased pressure on the neurotypical siblings (Meyer et al., 2011).

Finally, the data also identified a need for increased autism awareness in sectors including education and the media in order to create a realistic portrayal to prevent misconceptions of autistic characteristics, leading to unwanted stereotypes. Research has shown that neurotypical individuals who have autistic siblings have dealt with negative attitudes and little understanding of their sibling even from their peers (Kovshoff et al., 2017; Sasson & Morrison, 2017), so there needs to be more developed awareness and understanding of the condition in society. Previous literature has identified that direct contact such as buddy systems or peer mentors can improve attitudes towards autism (Mavropoulou & Sideridis, 2014), which would be beneficial for society to raise awareness about ways to support an autistic individual, as other research has shown that general society is unsure how to communicate with autistic individuals (Dean et al., 2013), potentially at least partly due to misconceptions displayed in the media (Nordahl-Hansen et al., 2018a, 2018b).

## Implications

The current study furthers our understanding of autistic adult sibling relationships. The quantitative data had highlighted certain disparities in knowledge levels between siblings who have neurotypical siblings compared to those who have autistic siblings, however, there were no differences in attitudes. This is a novel line of enquiry since it is the first study to apply a mixed approach by combining quantitative data on knowledge and attitudes with qualitative data to provide a richer understanding of what these relationships mean to the neurotypical sibling. Attitudes from the quantitative data appear to be positive in both matched and mixed sibling groups, however, the themes from the qualitative component illustrates how participants would put their sibling's needs before their own. Finally, both the qualitative and quantitative data had shown that there needs to be greater awareness of autism from the general public, which is reflected both in the increased knowledge scores of the mixed sibling group and the emergent theme of autism awareness.

A number of limitations are associated with the current study. Only 6 participants had little to no contact with an autistic person, and so it could be speculated that it was those knowledgeable of and interested in autism, and with a positive attitude towards it, that were motivated to take part. Indeed, Jun et al. (2017) found that if a study was considered boring or irrelevant to the participant, they were more likely to drop out in an online study. Additionally, the severity of siblings' autism was not measured, despite this being an important factor in sibling psychological adjustment (Benson & Karlof, 2008; Meyer et al., 2011) and whether sibling relationships are viewed as positive or negative (Petalas et al., 2012). Considering different capability levels in autistic siblings is an important line of enquiry that warrants further research since the level of support an individual needs will impact family members and relationships (Pellicano et al., 2022). Another limitation is around gender since the majority of the current participant sample is female and it is documented that more caregiving responsibilities are absorbed by females in the home (Burke et al., 2012; Cridland et al., 2015), therefore, caution must be taken when linking the current findings to research in both male and female neurotypical siblings. Given that gender will influence both the sibling dynamic and relationship, this should be explored in conjunction with levels of autistic capabilities in future sibling research. The family context was also not recorded, such as the number of siblings in the family, the educational level of the participants and their siblings, and the family structure. These are important as they can determine the care taking role in older age, and factors such as economic pressures. However, as Moss et al. (2019) reported, most neurotypical siblings achieve many of the normative outcomes of their peers without an autistic

sibling, and many achieve better psychological outcomes such as higher empathy and perspective taking skills (Shivers et al., 2019). Lastly, demographic limitations include the study failing to identify where participants lived despite the study being shared world-wide through social media platforms. This prevented the exploration of possible cultural differences which is another crucial factor in the formation of attitudes towards and knowledge of autism.

## Conclusion

The current study has shown that autistic sibling types in adulthood maintain being more knowledgeable overall of autism than those with neurotypical siblings, specifically in obsessive and compulsive behaviours. Despite positive attitudes being present when a neurotypical sibling of an autistic person is knowledgeable of autism, all individuals in the current study, regardless of sibling type or degree of knowledge, appeared to have a positive attitude towards autism. Furthermore, becoming a main carer for an autistic sibling has created feelings of concern and fear due to strain being placed on the sibling and the constant conflict between their sibling and their relationships with others in society. The study has identified the need for increased autism awareness within society to allow for the public to understand autism and not use stereotypical media misconceptions. From this it can be suggested that having a sibling diagnosed with autism can predict knowledge of autism and have mixed experiences within adulthood.

*Note* In this article, we use identity-first language (e.g. “autistic person”) as opposed to person-first language (e.g. “person with autism”) to respect the preference of the majority of autistic people (see Gernsbacher, 2017; Kenny et al., 2016).

## Appendix: List of Free-Text Questions

1. What is the age of your sibling?
2. What is the gender of your sibling?
3. How long has your sibling been diagnosed with Autism Spectrum Disorder?
4. How would you describe your relationship with your autistic sibling?
5. What are the difficulties you face having an autistic sibling?
6. What are the positives to having an autistic sibling?
7. In what ways has having an autistic sibling had an impact on your daily living?
8. How has having a sibling with autism influenced your life choices (employment, children, living arrangements)?

9. In what ways does having an autistic sibling have an impact on your decisions as an adult?
10. Do you feel responsible for your autistic sibling in adulthood? If so, in what aspects?
11. Does having a sibling with autism prevent you from doing things you would do if your sibling was not diagnosed with autism? If so, please provide examples.
12. How has your experience having a sibling with autism impacted on your perspective towards others with autism?
13. Do you believe your current perspective on individuals diagnosed with autism would differ if your sibling was not autistic, if so, why?
14. In what ways does your sibling’s future influence your own future plans?

## Declarations

**Competing Interests** The authors declare that they have no competing interests.

**Ethical Approval** The work received ethical approval from the School of Education and Social Sciences, University of the West of Scotland.

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