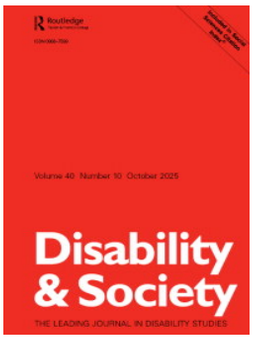

Disability & Society

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

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To cite this article: Chad Edery & Clare Harvey (2025) Narratives of siblinghood: exploring perspectives of adult siblings of autistic individuals, Disability & Society, 40:10, 2730-2756, DOI: 10.1080/09687599.2025.2455091

To link to this article: https://doi.org/10.1080/09687599.2025.2455091

Published online: 21 Jan 2025.

DISABILITY & SOCIETY
2025, VOL. 40, NO. 10, 2730–2756
https://doi.org/10.1080/09687599.2025.2455091

Routledge
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Narratives of siblinghood: exploring perspectives of adult siblings of autistic individuals

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ABSTRACT

Sibling relationships, one of the longest relationships in life, can be altered by the presence of autism. The paper explores the perspectives of adults who grew up with a sibling with autism. Little is known about this relationship from an adult perspective due to reliance on parental and child voices in the literature. Eight adults were interviewed on their retrospective and current experiences of their relationship with their sibling with autism. The data underwent an interpretive phenomenological analysis. The findings suggest a relationship characterised by an ebb and flow of a nuanced sibling dyad across siblinghood. Siblings move between moments of closeness and distance and engage in continuous complex meaning making of their sibling relationship, where their growth in understanding autism influences their interpretation of their experiences. These findings challenge rigid, absolute notions of siblinghood with autism and have implications for improving a sibling bond.

ARTICLE HISTORY
Received 21 November 2023
Accepted 8 January 2025

KEYWORDS
Adult siblings; autism spectrum disorder; disability; neurodevelopmental; neurodivergent; sibling relationship

Points of interest

- Adults offer detailed, long-term perspectives of their relationship with their autistic sibling.
- Sibling relationships when one sibling has autism move through times of closeness and distance.
- Navigating the relationship with an autistic sibling is not isolated to a specific developmental stage; rather, it is a continuous ever-changing process throughout life.
- Public responses to an autistic sibling negatively impacts the sibling relationship and the neurotypical sibling. There is a need for advocacy groups to raise awareness on autism.

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Introduction

Sibling relationships are among the longest relationships of an individual's life and a salient source of support, companionship, and influence on one's emotional, cognitive, and social development throughout one's lifespan (Beyer 2009; Diener et al. 2015; Morris et al. 2024). Since it is often the longest lasting of familial relationships, this relationship exerts considerable influence on each sibling during their lifetime (Guse and Harvey 2010).

Despite the significance of the sibling dyad, literature has largely focused on the parent-child subsystem (Noonan, O' Donoghue, and Wilson 2018). Whilst a shift in focus to the sibling-sibling subsystem has been noted, this research has traditionally depended on maternal reports, regardless of reported discrepancies between parent and child perspectives of the sibling relationship (Noonan, O' Donoghue, and Wilson 2018). Some strides have been made by including children's and adolescents' voices in the discourse, including when one sibling has a neurodevelopmental disability such as autism (e.g. Noonan, O' Donoghue, and Wilson 2018; Petalas et al. 2015).

A sibling relationship with a sibling with autism has been an area of exploration due to the dyad being a cornerstone for developmental influence. An individual's early learning and social experiences are typically encountered and shared with one's primary social partner(s) – siblings – and enacted based off observing one's sibling (Howe and Recchia 2014). As one ages so too does the sibling relationship, in that it shifts to meet the needs of a particular stage of development (Coffman et al. 2021). Consequently, the presence of autism within a sibling relationship may alter one's learning and developmental experiences (Howe and Recchia 2014).

Autism has its 'onset in the developmental period, [consisting of] deficits that produce impairments of personal, social, academic, or occupational functioning' (APA 2013, 31). Autism is characterised by persistent and pervasive 'deficits' in social communication and interaction, and restricted, repetitive patterns of behaviour, activities, and interests (APA 2013, 31). The global prevalence of autism is estimated to be between 1%-2% of the population (Bishop 2012; Zeidan et al. 2022).

Attempts to ensure a more comprehensive understanding of the sibling experience by including young voices of children and adolescents into the discourse, whilst substantial in enhancing the understandings of the sibling relationship, has also had some drawbacks. This is especially noteworthy in autism sibling research. Majority of the studies about individuals with a sibling with autism have focused primarily on neurotypical siblings' experiences and outcomes in childhood and adolescence (e.g. Gorjy, Fielding, and Falkmer 2017; Iannuzzi et al. 2022; Petalas et al. 2009; Ward et al. 2016). Whilst these findings have been considerable in enhancing understandings of nuanced sibling relationships with an autistic sibling, this particular experience from

an adult's point of view has been heavily negated (Doody et al. 2010; Hall and Rossetti 2018; Orsmond and Seltzer 2007). Consequently, rigid, absolute, and hypothesised narratives of siblinghood beyond childhood and adolescence have emerged. Studies exploring the sibling relationship with a sibling with autism from an adult perspective predominantly focus on the neurotypical adult sibling's caregiving responsibility, their relationship with service delivery, this sibling relationship in a combination of intellectual and developmental disabilities, or combined parental and sibling perspectives (Critchley et al. 2021; Hall and Rossetti 2018; Hamilton et al. 2024; Heller and Arnold 2010; Milevsky and Singer 2022; Orsmond and Seltzer 2007; Rum et al. 2024; Tozer and Atkin 2015). Few studies have focused specifically on adult perspectives and their reported relationship with their autistic brothers or sisters (Morris et al. 2023; Moss et al. 2019, Noonan, O' Donoghue, and Wilson 2018; Viswanathan, Kishore, and Seshadri 2022; Wright et al. 2022).

While some studies have indeed contributed to the literature by incorporating adult perspectives, they also exhibit notable limitations that underscore the importance of the current research. For example, Wright et al. (2022) examined the experiences and perceptions of young adults concerning their relationships with their autistic siblings, focusing on specific relational aspects at the individual, dyadic, and family levels. Although their findings offer valuable insights, the study's narrow scope constrained participants' accounts, allowing limited spontaneity and excluding broader relational dynamics. Consequently, the Wright et al. study provides only a partial, rather than a comprehensive and nuanced, understanding of these sibling relationships.

Similarly, Morris et al. (2024) employed a mixed-methods approach, focusing on two factors – knowledge of, and attitudes towards autism – to explore the adult sibling experience in autism. By comparing neurotypical and autistic sibling pairs, they aimed to illuminate differences in sibling relationships. While the study included qualitative insights into the lived experiences of participants with autistic siblings, it merely offered a brief snapshot of: future caregiving responsibilities (a theme in line with the predominant literature exploring adult experiences), a robbed childhood, and the impact of the autistic sibling on their own needs. However, it lacked contextual depth, failing to explore the origins of these perceptions and emotions, and knowledge learnt about autism (an aspect unrelated to understanding the siblings relationship with their autistic sibling). Consequently, the Morris et al. study offers a narrowly focused understanding of the sibling relationship from an adult perspective rather than a comprehensive, nuanced perspective.

Likewise, Moss et al. (2019) examined interactions influencing adult sibling outcomes, building on variables from studies focused on child siblings' perspectives. However, the current study critiques the reliance on these child-based findings as rigid, arguing that they predispose Moss et al.'s conclusions to some extent by failing to account for the dynamic nature of

sibling relationships over time, and the assumed dynamic nature of such variable outcomes. Like Morris et al. (2024), Moss et al. (2019) adopted a directive approach, basing their insights on responses to a few specific, categorical, and delineating questions. This method may have constrained participants' expressions, implicitly shaping their accounts of the sibling relationship and leaving little room for spontaneous thought or deeper exploration of why these perceptions exist or evolve.

In contrast, while Viswanathan, Kishore, and Seshadri (2022) employed an Interpretive Phenomenological Analysis' (IPA) methodology to explore the lived experiences of siblings, their participant age range of 15–36 years raises a critical issue, in that it remains unclear which findings pertain specifically to the adult participants' narratives of siblinghood. This lack of differentiation limits the study's ability to provide clear insights into adult sibling experiences. Noonan, O' Donoghue, and Wilson (2018) stands out as one of the few studies that effectively explored autistic sibling relationships from an adult perspective, offering valuable insights. However, its singularity and lack of retrospective exploration underscores the importance of the current study in further advancing this area of research, especially within a South African context. Subsequently, there is limited research exploring adult siblings' emotions, reactions, thoughts, and perceptions regarding the presence of autism within their sibling relationships, leading to an experience that is largely excluded and unknown.

An adult perspective is an essential part in enhancing the understandings of sibling relationships with a sibling with autism because adult sibling relationships evolve across the life course and offer a complex and nuanced perspective (Avieli, Band-Winterstein, and Bergman 2019). Thus, adults can provide retrospective and current accounts of their lived experiences of siblinghood. These accounts allow for descriptive and insightful understandings and representations as opposed to limited understandings of siblinghood derived from a specific focus on a time in one's life, such as childhood or adolescence. The inclusion of retrospective narratives enhances the study since it enables a broader context, offering insights into the emotional and relational foundations that shape current sibling dynamics. By reflecting on past experiences, thoughts, perceptions, and feelings, these narratives reveal how sibling relationships have been formed, solidified, or transformed over time. The strength of this approach lies in its combination of retrospective and current accounts, uncovering patterns and shifts that would be missed if relying exclusively on current accounts, thus offering a more nuanced view of autistic sibling relationships across the lifespan. Given the dearth of information surrounding the psychological experience of growing up with a sibling with autism, from the voices of adult participants, this paper refers to a study that intended to address this gap to add to the existing, predominantly child-based literature on this topic.

Moreover, this scope of research frequently adopts a quantitative paradigm, negating the rich accounts derived from exploratory, qualitative studies (Doody et al. 2010; Ward et al. 2016). Thus, the study employed an IPA framework to enable exploration into the lived experiences of adult individuals' sibling relationships with an autistic sibling, in their own voices.

In keeping with the recommendations by the American Psychological Association (APA 2022), person-first language – 'person with autism' – is used here. However, the APA (2022) also encourages identity-first language, such as 'autistic person' and thus both these terms are used interchangeably, and in doing so the participants and their disabled siblings are respected. This terminology is also in accordance with the neurodiverse community's preference for identity first language (Smith, Horton, and Fitzgibbons 2023). Additionally, the term 'disabled/autistic sibling' is used to situate disability within a social context, denoting that individuals with differences are disabled by harsh societal associations (Albrecht, Seelman, and Bury 2001; Hedlund 2000). This is in keeping with the social model of disability – which both authors are proponents of – which states that a person is disabled because of the environment around them and the way in which society is organised, rather than by one's difference or impairment (Shakespeare 2013). This is in stark contrast to the medical model of disability in which personal experiences are overlooked and impairment is located within the individual's body (Harvey 2019). Furthermore, the terms 'able-bodied' and 'neurotypical' – terminology used by the participants – are used as opposed to 'non-disabled'. Taken together, the above language is employed to appropriately manage the ethical dilemma of re-representation of reported ideas of disability and autism with sensitivity.

Method

The paper refers to a qualitative IPA study (Alase 2017; Peat, Rodriguez, and Smith 2019). IPA focuses on individuals' lived experience within the world (Alase 2017). Grounded in principles of phenomenology, hermeneutics, and idiography, IPA aims to explore individuals' meaning making related to certain experiences. Subsequently, individuals are viewed as active agents in the creation of their experiences and as experiential experts (Petalas et al. 2009; 2015). Thus, IPA was appropriate here to explore how siblings perceive, feel about, and experience their relationships with their autistic sibling across their siblinghood.

Individuals with a biological sibling with autism were interviewed. It was felt important to recruit biological siblings given the potential feelings that may arise in such a sibling dyad when one does not have a disability. Adults above 25-years-old were selected, allowing for the transition of the sibling relationship into an adult one, encouraging participants to provide rich,

descriptive, retrospective, and current accounts of their lived experiences of the sibling relationship (Arnett 2007; Hamilton 2016). The participants needed to have lived with their autistic sibling for all/most of their childhood, and their sibling needed to have been given an autism diagnosis by a medical professional (APA 2013). In keeping with IPA idiographic commitment to illustrate the lived experience of each participant rather than move to more general claims, participants were purposely sampled (Love, Vetere, and Davis 2020; Motta and Larkin 2023). This is a clear distinction from thematic analysis, a method which allows for generalisation and is also not limited to only exploring subjective lived experiences (Chatfield 2022).

Participants were garnered through an invitation posted on various social media platforms, including the first author's Facebook and Instagram accounts and Autism Facebook groups, as well as *via* professional services and schools for people with autism. Data saturation was reached after eight individuals were interviewed, an appropriate sample size for an IPA study, given its idiographic focus (Noon 2018; Saunders et al. 2018). All participants have been given pseudonyms.

Amy is a 26-year-old white, middle-class, married female. She has a thirteen-year-old autistic brother who she lived with for seven years. He was diagnosed at two years of age. Her parents are married and she also has a fifteen-year-old brother and a six-year-old sister. Another female participant, Khani, is black, middle-class, single and 25-years-old. Her parents are separated. Her autistic brother is ten-years-old and she has lived with him all his life. He was diagnosed at the age of four. Khani has another brother who is 32 years. Kim is female, white, upper-class, married and 37-years-old. She has a 34-year-old brother with autism who was diagnosed at 2 years. They lived together for 18 years. Her parents are married. She also has a 30-year-old brother. 33-year-old Nishka is female, Indian, middle-class and single. Her autistic sister is 10-years-old and was diagnosed at 22 months and they have lived together for 10 years. Her parents are married. Nishka also has a 28-year-old brother. Peter, a male participant, is 25 years, white, middle-class, single. His brother with autism was diagnosed at 5 years and is now 23 years. They lived together for 13 years. Peter also has an 18-year-old sister. The sixth participant is a female, 27 years, white, middle-class, engaged and is named Samantha. She has a father and one sibling, who is 29 years and who received a diagnosis of autism at 26 years. They lived together for 18 years. Participant seven, Terri, is female, Indian, middle-class, in a relationship and is 31 years. Her autistic brother is 21 years and was diagnosed at the age of three. They lived together for 15 years. Her parents are married and she also has a 30-year-old brother. Finally, Timothy, a 25-year-old male participant is upper-class, white and single. He has a 22-year-old brother with autism, who was diagnosed at 3 years. They lived together for 16 years. Timothy's parents are married.

Before the research process began, ethical clearance was obtained from X University's non-medical human research ethics committee. Aided by the tenets of IPA, the study employed semi-structured, one-on-one online interviews *via* Zoom (Peat, Rodriguez, and Smith 2019). Semi-structured interviews are a preferred approach by which to capture idiographic narratives since they allow for a real-time dialogue, enabling the researcher passage into the lifeworld of the participant (Love, Vetere, and Davis 2020; Smith and Fieldsend 2021). An interview schedule was designed by the researchers after reviewing relevant literature. The schedule served as a foundation but was not prescriptive or restrictive in the sense of disregarding the expressed interest of the participants or their ability to tell their own stories in their own words. Interviews varied between 60 and 90 min in length. Examples of interview questions:

What comes to mind when you think about your **childhood** growing up with a sibling with autism?
Can you recall any happy or unhappy times in particular?
What role/s do you think you played in your sibling relationship?
In what ways do you imagine your relationship is different to other relationships?
How would you describe your relationship with your sibling today, as an **adult**?
Looking back, how has your relationship with your sibling changed from when you were younger?
Has having a sibling with autism influenced your adult life? If so, in what ways?
Do you feel that autism impacted your sibling relationship in any way?

All participants signed informed consent to partake in the study. The first author conducted the interviews. The interviews were fully transcribed, anonymised, and supplemented by reflective process notes. The data were analysed by the first author and the second author verified this process *via* frequent discussions about the developing focus and structure of the analysis, as well as through feedback and reflections throughout the analysis. Verification in this instance was not to dictate a singular true account but to guarantee the integrity of the final interpretation (Brocki and Wearden 2006). Data were analysed according to IPA which interprets and heightens the lived experiences of research participants (Alase 2017; Petalas et al. 2015). The analysis followed the broad process outlined by Smith and Osborn, a process which goes beyond a standard thematic analysis (Smith and Fieldsend 2021). IPA's commitment to idiography entails coding themes individually for each data set before engaging in case-cross analysis (Brocki and Wearden 2006; Chatfield 2022).

Each interview transcript was read several times to become familiar with the content. Subsequently, transcripts were read line by line making note of descriptive comments with a phenomenological focus (e.g. initial interpretations, summaries of the meaning content, associations), as well as noting the semantic content which further elucidated the participants' meaning making (Motta and Larkin 2023; Petalas et al. 2015). Transcripts were then re-read with a focus on extracting the themes within the data. Connections across emergent themes were identified before the next participant account was

read and the emerging themes were tabulated and bracketed (Smith and Fieldsend 2021; Smith and Osborn 2015). Additionally, the second author reviewed the transcripts once themes were elicited to explore for any other possible emergent themes. Once all accounts had been analysed, patterns and differences across emerging themes were explored and superordinate themes that captured the experience of having an autistic sibling were created (Smith and Fieldsend 2021).

Consequently, the analysis moved beyond pure description towards interpretation to try and understand the participants making sense of their world (Peat, Rodriguez, and Smith 2019). Engaging in double hermeneutics rendered the authors active respondents in the research process (Shaw 2010). The researchers noted the potential for biases in the analysis since the onus of interpretation laid with them (Chambliss and Schutt 2010; Petalas et al. 2009). Thus, true to reflexivity being a fully integrated tenet of IPA research the authors kept a reflective journal noting impressions, emotions, and possible prejudices, due to their awareness that their positioning played a role in this study (Engward and Goldspink 2020). The first author is an able-bodied individual of able-bodied siblings and has had five years of experience working with autistic individuals (and their siblings), teaching developmental and academic skills and coping strategies. The second author is a physically disabled individual with dwarfism and has two able-bodied siblings. She researchers and publishes in disability studies.

Reflective notes were shared in supervision with the second author (who brought experience with qualitative research methods and familiarity with the standards of research ethics), to effectively navigate and engage with them, ensuring a more authentic and ethical study. Supervisorial dialogue strengthened the rigor of the study since it allowed for tracking of the opinions and insights back to the data, safeguarding the representativeness and transparency of the interpretations.

Discussion of findings

This study does not aim to define what an autistic sibling relationship looks like in adulthood. Instead, it seeks to uncover insights from adult perspectives, leveraging their unique capacity to critically reflect on siblinghood across the lifespan, moving beyond the limited narratives from specific life stages. Thus, adults offer a nuanced understanding of these relationships as they were experienced, perceived, and evolved over time. Subsequently, by integrating and oscillating between retrospective and current accounts, the section that follows serves as a visual roadmap, capturing the dynamic and continuous process of navigating and making sense of this relationship throughout one's life.

Relational ebb and flow

Participants' accounts of their lived experiences across their sibling relationship depicted a relational ebb and flow of feeling distant to achieving closeness between themselves and their sibling with autism. This relational movement is corroborated by general sibling literature that stresses that the experience of siblings is not fixed but rather is subject to change (Gorjy, Fielding, and Falkmer 2017), as well as the findings of Noonan, O' Donoghue, and Wilson (2018), who emphasised that individuals with an autistic sibling engage in nuanced oscillations of being distant and close.

'Chalk and cheese': awareness of the atypical sibling experience

Participants reported experiencing various degrees of distance from their sibling with autism. Early accounts of relational distance were sparked by confusion in trying to make sense of their sibling's autism-related behaviour:

> As a child…I couldn't understand why my brother acted the way he did at times (Samantha).

> …a lack of understanding…from my side as to why can't you just be normal? (Kim).

> We hadn't really heard about autism, we didn't really understand what it meant (Nishka).

The initial confusion surrounding autism, as identified by Viswanathan, Kishore, and Seshadri (2022), underscores a pattern where siblings of autistic individuals recognise behavioural differences early but often only achieve a deeper comprehension of autism later in life. Similarly, Morris et al. (2024) highlight how insufficient knowledge about autism can adversely affect sibling relationships, evident in many of the participants' early narratives resulting in a range of emotions and experiences such as distance, frustration, concern, and uncertainty.

Feelings of distance were evident by participants' desires for connection, as captured by Timothy:

> I just remember it being very difficult to connect with him and it being frustrating too…also it being very difficult to love him because of how like difficult and sometimes uninterested in any kind of affection he was…I think I got a bit burned out from trying.

This absence of an emotional connection is consistent with research which found that siblings of autistic children felt less emotional closeness compared to people with siblings without autism (Hall and Rossetti 2018; Tozer, Atkin, and Wenham 2013): 'we've not really had that emotional thing' (Kim).

Striving to understand one another is a prominent aspect in sibling relationships (Kuba 2011). Timothy illustrated how his relationship with his

brother in adulthood continues to be challenging due to communication barriers, yet expressed a desire to communicate with him, a finding corroborated by literature (Wright et al. 2022): 'Sometimes I just feel stumped when he's trying to tell me something and I'm not sure what he's trying to tell me…I feel it's quite important that we are able to communicate with each other.' This nuanced experience of navigating the relationality and boundaries of autism within the sibling relationship was expressed by many participants, particularly in reference to their communicational dynamic. The participants' awareness of difference within their sibling relationship because of autism and the repercussion such difference ensues corroborates existing literature (Hwang 2009; Noonan, O' Donoghue, and Wilson 2018; Tozer and Atkin 2015). Furthermore, Amy resonated with a sibling relationship characterised by distance when she expressed how altered means of communication with her brother continued into adulthood: 'I can't go make sarcastic jokes with him because he doesn't understand sarcasm so our conversations are different…I phone him…[but] he gets bored…so he would just hang up.' Wright et al. (2022) validate Amy's experience by highlighting that communication barriers can persist into adulthood, particularly due to reduced physical proximity between siblings, which diminishes the frequency of face-to-face interactions. The above experience, echoed by other participants, arguably stresses that patterns of communication within such a sibling dynamic are possibly predetermined and controlled largely by the inherent nature of autism, stressing a dynamic potentially void of flexibility, which may work against forming a sibling connection.

Interactions within these sibling relationships are generally oriented to the interest of the sibling with autism (Orsmond and Seltzer 2007; Wright et al. 2022). However, participants expressed how their attempts to grasp some form of connection by entering their sibling's way of being in the world only made such distance more apparent:

> There was definitely distance there because I couldn't find really any common ground to interact with him…it was generally me making compromises to find a way to interact with him (Timothy).

> …maybe when I was younger, we might have like, watched maybe a bit of TV together and that kind of thing, like cartoons, but then I kind of grew out of that and he didn't really… (Peter).

Distance is amplified with the awareness of difference and loss of an imagined sibling relationship, one characterised by togetherness and shared experiences. This finding is consistent within disability studies literature where the loss of the imagined, non-disabled child has been reported by able-bodied mothers (Harvey 2015).

Feeling despair due to a disconnect in the sibling interaction is also experienced in adulthood:

> Even now…he has his schedule and his routine every day and it doesn't really include us (Kim).

> A lot of the time…it still feels like we're strangers (Timothy).

This sombre sharing alludes to a lack of connection within adulthood for some of the participants' sibling relationships, leaving some feeling alone: 'Spending time it's non-existent, no interaction…so I'll spend most of my time by myself' (Peter). Solitude within such a sibling relationship results from the difficulty of neurotypical siblings having the responsibility of maintaining the sibling relationship (Kramer, Hall, and Heller 2013; Tozer, Atkin, and Wenham 2013).

Moreover, participants' reflections on their current and retrospective sibling interactions brought about awareness of the atypical sibling experience, an experience noted in existing literature (Hwang and Charnley 2010; Tozer and Atkin 2015; Viswanathan, Kishore, and Seshadri 2022). Peter described his relationship with his autistic sibling as *'chalk and cheese'*, a sentiment that signified feelings of disconnection, difference, envy, and loss shared by many participants:

> I was very aware that our dynamic wasn't the same as what my peers was… (Samantha).

> I would have loved to be able to like play video games with him…talk about nerdy stuff (Timothy).

> The thing that I do feel a little bit sad about is…I would always like that relationship where I could like…take her to the movies and like take her out like when I'm going out with my friends… (Nishka).

Consistent with research (Tozer, Atkin, and Wenham 2013; Tudor, Rankin, and Lerner 2018; Van der Merwe et al. 2017), participants indicated that feeling distant due to not being able to connect with their sibling was also created and amplified by their sibling's typical autism-related behaviour (APA 2013). Such behaviour may include autism meltdowns – an involuntary response because of nervous system overload, which presents as a tantrum (Autism Research Institute 2024). Learning to navigate this behaviour sparks difficult feelings (Ariel and Naseef 2005; Hwang and Charnley 2010; Iannuzzi et al. 2022; Moss et al. 2019; Viswanathan, Kishore, and Seshadri 2022) which some participants resonated with as a factor that largely affected their sibling relationship and reinforced feelings of distance, especially in childhood:

> Why are you suddenly not eating chicken now, now what must Dad make for supper or other weird things like that and that caused resentment from my side (Samantha).

> When he was like eight, he would have fits and it's so overwhelming and so emotionally overwhelming and frustrating, so you do kind of get angry with it (Timothy).

Although some distance from one's sibling in adolescence and young adulthood is common across sibling relationships (Petalas et al. 2015), behaviour inherent to autism can make such distance more pronounced (Angell, Meadan, and Stoner 2012; Pilowsky et al. 2004), with Viswanathan, Kishore, and Seshadri (2022) asserting that autism meltdowns pose a threat to the sibling relationship. Consistent with research (Hwang and Charnley 2010; Iannuzzi et al. 2022; Moss et al. 2019; Noonan, O' Donoghue, and Wilson 2018; Viswanathan, Kishore, and Seshadri 2022), distress and embarrassment noted by participants in their earlier years of their relationship with their sibling was largely resultant from bystanders' judgmental reactions towards their sibling's behaviour and the personal and emotional impact that such reactions caused. These experiences resulted in feelings of frustration and lack of control, deepening distance in the relationship: 'He's different and you often felt like people were just looking at you and your family…and that wasn't a great feeling' (Peter).

Some participants expressed that public perception became normalised yet indicated that these perceptions still left residual feelings of disconnection: 'Definitely embarrassing when we were in public, but it was also just something that had become normalised…there's definitely a very distinct sadness in my memories' (Timothy).

The above accounts emphasize Hwang's (2009) notion that the familiarity of living with an autistic sibling is disrupted and rendered unfamiliar and strange under the public gaze. This external scrutiny can frame the entire family as strange (Hwang 2009), potentially intensifying feelings of difference and fostering distance within the sibling relationship.

'Some kind of connection'

Participants' relational experience with their autistic sibling also brought about contradictory feelings of affection and genuine connection, as found by Noonan, O' Donoghue, and Wilson (2018). By following their sibling's lead and joining in on their various interests, some participants spent quality time with their siblings, both in later adolescence and adulthood: 'I try to like spend more quality time with her in terms of like doing things that she wants to do…' (Nishka). Whilst acknowledging some of the participants' childhood accounts that depicted frustration and anger from limited interactions or engaging primarily in their sibling's interest, this finding simultaneously captures the nuanced and dynamic nature of these sibling relationships across siblinghood. Participants were able to establish relationality in adulthood by joining in sibling-led interactions, contradicting their relational distance felt during their upbringing, akin to literature (Noonan, O' Donoghue, and Wilson 2018; Wright et al. 2022). This finding challenges literature that states adult sibling relationships are characterised

by reduced interactions (Braconnier et al. 2018; McHale, Updegraff, and Feinberg 2016; Orsmond and Seltzer 2007). Arguably, adulthood is a significant stage as a marker for potentially fostering connection within the autism sibling dyad.

Whilst reflecting on their lived experiences across their sibling relationship, several participants expressed how connection was achieved on their sibling's terms:

> He…asked me to tickle his back…he only asked me to do that… (Amy).

> When he gets particularly excited, he'll like grin and like grab your face and that always like, there's a lot of those memories dotted around. I always remember feeling happy with that, because it felt like I was getting some kind of connection with him that I'd been craving for a long time (Timothy).

> He sucks his thumb…and then I'll suck my thumb and we can hook our fingers together and we can like sit for like long periods of time like that because it's just comforting for him and it's almost like a moment where we can see each other (Terri).

These recollections of bonding experiences, whilst potentially uncharacteristic to other sibling dyads, stress that individuals with an autistic sibling have experiences that can foster a secure and compassionate sibling bond, a finding that is distinctive to both the current study and the work of Viswanathan, Kishore, and Seshadri (2022). Furthermore, communication barriers were evident within the participants' accounts of their experience of having an autistic sibling, however the above accounts are noteworthy since they stress that connection within sibling dyads with autism can still be achieved. Yet, this is a different connection, achieved through unique modes of relating that transcend words and phrases (Hwang 2009), a finding that challenges Wright et al. (2022) hypothesis that communication barriers may prevent siblings from forming meaningful connections. Notably, satisfaction of achieving a connection that was longed for, was recounted with positivity by some participants:

> Considering he doesn't like touch…when he came to me for affection that was quite special (Amy).

> I was getting some kind of connection with him that I'd been craving for a long time (Timothy).

> …a moment where we can see each other, it's I see you and it's okay to be who we are in this world (Terri).

Furthermore, with age some participants expressed closeness through realising and achieving pride for their sibling and their achievements:

> As I grew older, it became more of a I'm actually really proud of being the sibling of an autistic person (Kim).

> I'm very proud of like her growth (Nishka).

> There's a lot more respect for what he is actually capable of doing then I guess I would have had when I was younger (Timothy).

Admiration for their autistic sibling's accomplishment is consistent with literature (Angell, Meadan, and Stoner 2012; Petalas et al. 2009; Viswanathan, Kishore, and Seshadri 2022). Arguably, appreciating siblings and expressing pride can promote sibling bonding. Moreover, majority of the participants expressed feelings of genuine connection through increased acceptance of their *'different' (Timothy)* experience while they moved into late adolescence and adulthood stages of their relationship. Some achieved this through altering attitudes towards their autistic sibling:

> It's more my attitude towards him that's changed. So, I'm a lot more understanding than I would have been previously (Peter).

> I understand now that there's a lot more going on in his head than he lets on because he can't communicate it (Timothy).

> As I grow older and I know more, I get to understand why [brother] does certain things and so it [the relationship] has changed (Khani).

Siblings' perceptions of their sibling relationship are not fixed but rather change with age (Coffman et al. 2021; Hwang 2009; Noonan, O' Donoghue, and Wilson 2018; Viswanathan, Kishore, and Seshadri 2022). Positive perceptions of one's sibling with autism may serve a functional role in siblings' adaptation to growing up with an autistic sibling (Morris et al. 2024; Petalas et al. 2009). Thus, later life enables the development of changed perceptions of one's autistic sibling, facilitated by increased awareness of one's understanding of the sibling's circumstances and difficulties, increasing sibling connection. Participants attributed improved relationality to acknowledging who their sibling with autism was: 'I personally accepted the fact that this was my brother and now love him you know, regardless.' Samantha's account in adulthood supports the findings of Noonan, O' Donoghue, and Wilson (2018) who note a shift towards positive growth in adulthood. Thus, as participants mature so too do their sibling relationships, enhancing possibilities for connection.

Finding balance

Participants' accounts of their lived experiences across their sibling relationship reflected a process of navigating and discovering one's self, enabling a more balanced sense of oneself and the sibling relationship.

Some participants felt overlooked because their family focused on their autistic sibling: 'My mom said: "I'm sorry, if like, you feel like [brother] is getting more attention, but he actually does require more attention because he's not

neurotypical'" (Timothy). This account supports Viswanathan, Kishore, and Seshadri (2022) who found that siblings experienced their emotional needs being ignored as a result of inadequate parental attention. For some participants, this notion of being unseen extended to their sense of self. The boundaries between their collective self and their individual self were blurred and ill-defined. This is consistent with the literature, which indicates that through siblings' efforts to support their families by enacting various roles in an attempt to be seen, siblings often become detached from their own wants and needs (Dickey 2008; Morris et al. 2024; Noonan, O' Donoghue, and Wilson 2018; Viswanathan, Kishore, and Seshadri 2022). This dynamic was evident in Hwang (2009), where participants detailed differential standards that required them to suppress or downplay their personal needs. Identity is significantly based on the relationships and roles one embodies (McCall and Simmons 1978), with the participants' main source of identity becoming that of 'sibling'. This leaves them feeling unseen and unable to know themselves as individuals: 'I attached a lot of my identity and self-worth to that kind of nurture role…' (Terri). This account supports a notion in the literature where siblings navigate an intricate balance of being seen and unseen (Noonan, O' Donoghue, and Wilson 2018); a balance that Morris et al. (2024) note persists into adulthood with siblings often prioritising the needs of their autistic siblings over their own future aspirations (relocating or starting a family). However, Viswanathan, Kishore, and Seshadri (2022) caution that without proper support, siblings may become ambivalent about addressing their own needs.

There was a predominant perception that participants intrapsychically developed through their relationship with their sibling: 'Your life gets shaped so much by that experience…It's really shaped my way I think, the way I feel, the way I look at the world' (Terri). This finding supports a core aspect within the literature that having a sibling with autism results in individuals demonstrating improved psychosocial development and interpersonal perspectives (Macks and Reeve 2007; Morris et al. 2024; Wright et al. 2022). Similarly, when reflecting on the impact their siblings have had on their personal development and sense of self, some participants commented:

> It made me a lot more compassionate to other people and what people go through (Nishka).
>
> It fostered a greater sense of empathy in me (Peter).
>
> It's made me more resilient. It's made me more courageous (Terri).
>
> He's made me a much kinder person that I might have ordinarily been (Kim).
>
> He taught me a lot…a quieter leadership style, a listening leadership style… (Terri)

These accounts of enhanced emotional development reflect a dominant discourse in the literature, that of acknowledging the positive aspects of growing

up with a sibling with autism (Iannuzzi et al. 2022; Petalas et al. 2015; Viswanathan, Kishore, and Seshadri 2022; Ward et al. 2016; Wright et al. 2022). Participants made noticeable efforts to acknowledge the positive impact their sibling had on them, perhaps to balance out the more challenging moments, a coping strategy that was noted to be used by siblings in Viswanathan, Kishore, and Seshadri (2022).

Whilst participants expressed positive impacts on their personal development and sense of self, some expressed negative implications across their sibling relationship:

> [Brother's behaviour] caused me to be a bit introverted (Peter).

> Growing up I was very hard on myself and put an enormous amount of pressure on myself, which I believe is to overcompensate for [brother's] inability to do things (Timothy).

> Having to be very self-sufficient [as a child] is still something I carry to this day, and it has created a barrier in terms of me asking for help (Terri).

Although only three participants noted negative impacts on their personal development because of having an autistic sibling, such accounts depicted the polarities on personal development. Such dichotomous experiences of these types of sibling accounts are also evident in literature (Coffman et al. 2021; Johnson et al. 2020; Milevsky and Singer 2022).

Making meaning

Understanding and making sense of their lived experiences, central to their sibling relationship, was a core aspect of the participants' accounts. Three aspects emerged as vital components of participants' continuous meaning making.

Participants' accounts reflected a changed understanding of autism, an understanding that facilitated a meaning making process and aided the sibling relationship. During childhood and adolescence, when participants' siblings were diagnosed some participants expressed unfamiliarity with autism: '[I knew] pretty much nothing. I just knew that my brother was different… my perception of it was always, like quite a rudimentary one…I don't think I really understood really anything around autism until I was probably in my mid-teens.' Timothy's lack of knowledge, which echoed that of many of the participants' earlier experiences with autism, is consistent with research around childhood perceptions of autistic siblings. Literature highlights that these early understandings are possibly based on mannerisms and actions enacted by the autistic sibling (Coffman et al. 2021; Petalas et al. 2009). This finding was also evident here since some participants' understandings of autism were encapsulated by their sibling's presentation:

> When I was younger, I knew it was autism but…oh he's like 'Rain Man' [movie] (Kim).

> I would just explain…not exactly what autism was, but I would explain what [brother] does (Amy).

However, all participants expressed a changed understanding of autism as they matured, enabling meaning making and enhancing the sibling relationship. Coffman et al. (2021) as well as Viswanathan, Kishore, and Seshadri (2022) indicate that a deeper understanding of a sibling's diagnosis can foster empathy, mitigating some of the potentially negative effects of autism-related stressors on the sibling relationship. This association was captured by Samantha: '[improved understanding] impacted the sibling relationship…It enabled me to have a better understanding of my brother…which improved our relationship.'

Part of the participants' meaning making involved exploring the relationship between autism and disability. Although participants alluded to a possible connection between autism and disability throughout their accounts, directly exploring such connection was met with discomfort. This feeling is perhaps largely attributed to the commonly held nuances related to disability as negative in nature (Coleman, Brunell, and Haugen 2015). Exploring the relationship between disability and their autistic sibling – someone central to their lived experience – is perhaps difficult because 'disability' has largely been used to characterise individuals who are lacking or incomplete – a predominantly medical model perspective of disability (Meltzer 2018). In recognising an association between autism and disability, what might it mean for how participants view their autistic sibling? The sensitivity of exploring such connection was evident when most participants cautiously expressed that autism is a disability:

> I want to say the politically correct thing would be that no, it's not a disability, and people with autism can do everything that anybody else can do, but in reality, yes, it is a disability…a person with autism will struggle to do it and they may need extra assistance (Nishka).

> If I was answering for [my brother] specifically, I would say yes (Peter).

> I mean, my brother's case very much so. Like, I don't like the stigma around the word 'disability', but I would still consider it a disability (Timothy).

> I would say it is, but I don't, I don't want to like, I feel bad for saying it is (Khani).

> So, I don't see it as deficit, certainly not…I do see it as someone requiring support. So, to deny and say that it's not a disability is also wrong (Terri).

These accounts depict the ambivalence, shame, and agony some experience in labelling autism as a disability, due to the possible implication this may have for their view of their sibling. They also underscore the deep socio-cultural entrenchment of attitudes toward disability and the difficulty of challenging and overcoming such socio-culturally constructed beliefs (Hwang and Charnley 2010). As Goffman (2009) noted, having a stigmatised

quality such as a disability, diminishes an individual from their whole self because people only concentrate on their difference. Many participants attempted to justify a reason for a view of autism not being a disability, perhaps out of a protective sense towards their siblings. Others expressed guilt for having admitted their viewpoint, suggesting sadness and fear for what such connotations mean for their sibling, and highlighting a sense of disappointing them. Uneasiness with exploring such interaction highlights the complexity of meaning making undertaken by an individual with an autistic sibling, as captured by Kim:

> Gosh that's a tough one…it's hard because there is parts of it that yes would be a disability because that person would need full time care for the rest of their life…but I'm very scared of stepping on toes because of semantics…in terms of [brother], I would say disability…I would say if society was more accommodating and there was more understanding and more knowledge on it, then potentially not, however there isn't so because there isn't, I would have to say yes, I do have a disabled sibling.

Whilst disability studies are saturated with diverging views, the participants' hesitancy in exploring the relationship between autism and disability due to fear, guilt, and irreconcilable implications align with a dominant viewpoint that situates disability in the individual – postulating disability as substantial 'deficits' in functioning, and thus seeing disability through a medical model lens (APA 2013, 31; Nario-Redmond, Noel, and Fern 2013). This interpretation implies a negative experience and understanding of disability, fuelling stigma and discomfort. Contrasting this delineation is a view of disability as a contextual phenomenon, subjected to societal associations, attitudes, and responses around one's differences – a more social model of disability (Harvey 2019; Kara and Harvey 2017). This understanding was prominent within some of the participants' narratives which support and champion the thoughts put forward by Albrecht, Seelman, and Bury (2001) in that societal oppression and ignorance are a cornerstone for the experience of disability. Some participants expressed how viewing autism as a disability was socially constructed: 'In terms of societal expectation, yes…the difficulties that they face because of what is normal and because of the lack of knowledge, it does give them a disability within society…' (Kim). This account reiterates the necessity for acknowledging the socio-cultural underpinnings of disability and their role in shaping both the construct of disability and what is perceived and understood as disabling.

Perhaps participants' difficulties in stating whether they had a disabled sibling, despite indicating their views on autism as a disability, could be attributed to their identity of being an individual with a sibling who is viewed as disabled and the personal and social stigmas they may encounter as a result. This deduction concurs with literature which postulates that despite the degree of involvement in their sibling's lives, the challenges and stigma of disability are

prone to reach individuals of disabled siblings through association (Meltzer and Kramer 2016). Thus, siblings of a disabled individual are likely to be recipients of society's negatively tinged prejudices about disability. Thus, it is for this reason that Hwang and Charnley (2010) emphasize the importance of incorporating cultural understandings of disability, as these significantly influence how disability is perceived, experienced, and internalised.

Furthermore, apart from receiving negativity and the weight of judgment themselves, such difficulty of stating a view of whether they have a disabled sibling may also be a result of internal processes. Gomes (2020) indicates that such processes involve reflecting upon and questioning one's own ideas of, and relationality with, disability if one is to assume the identity of a sibling of a disabled individual. Subsequently, all dimensions of identity are interdependent (Jung and Hecht 2004). Thus, making meaning about autism and disability involves negotiating one's identity, and as Milevsky and Singer (2022) emphasise, this encompasses recognising the ongoing reciprocal influence siblings exert on one another.

'Find that connection'

Reflecting on their sibling relationship, participants expressed advice that they would provide others who have a sibling with autism. Attempts to understand their sibling's world, enabled participants to be empathic of the experiences of their autistic sibling:

> Try and empathise with what they're going through, and it will make you a lot more patient, a lot more understanding of them (Timothy).

> Be very aware of how terrifying everything is for them…everything is scary and if you think of how you feel when you're scared of something…put that to everyday situations and then that's how you can kind of understand them a little bit better (Samantha).

Although the implications of attempting an understanding of the experience of one's autistic sibling has been discussed (Coffman et al. 2021), this retrospective advice posits that such attempts are perhaps easier to obtain when one is older, since earlier sibling experiences may cloud the need to understand the other's perspective. The benefits of perspective taking are valuable in enhancing one's meaning making within the sibling relationship because perspective taking demonstrates consideration and empathy towards the other and allows one's sibling to be seen, and to an extent understood, enhancing the relationship.

Participants expressed the necessity of a neurotypical sibling enhancing their understanding of autism, a finding that has proven to enhance sibling relationships (Coffman et al. 2021): 'know about autism and understand symptoms' (Terri) and 'learn more about autism…' (Timothy).

Moreover, participants expressed the importance of finding a means to connect with their siblings, a way to make the sibling relationship meaningful:

> Try and build a connection with them because…you'll find that a lot more meaningful… (Timothy).

> I would tell siblings to get to know their siblings…find that connection…finding that connection where you can grow together and learn together and not seeing your sibling as any less than you (Terri).

Achieving a connection with one's sibling was a desire shared by most participants. Whilst barriers to accomplishing sibling connection have been explored here, the above accounts stress the poignance of not trying to connect with one's autistic sibling. Retrospective regret was evident in some participants' understanding of their experiences. Hence, there is value in living through various difficulties, relational barriers, negative feelings, and experiences of rejection, to strive for some resemblance of a sibling bond. Further, the importance of becoming acquainted with one's sibling, investing time and effort in finding means to communicate and connect, striving for shared experiences, and not viewing one's sibling as less than, all postulate potential components for establishing meaningful sibling relations. Conclusively, Terri expressed how the value of being comfortable in the ambiguous space aids one's understanding and experience of the sibling relationship:

> You can feel angry…you can fight…it could be chaos…you can feel lonely that's okay…it is kind of living in this ambiguous space…it's just about this is the way it is and how do I celebrate and find joy within that, how do I find joy within all of this that's going on within the difference.

This ambiguous space that is central to sibling relationships with a sibling with autism is nuanced and dynamic. For participants, having an autistic sibling entailed confronting mixed emotional and relational dynamics with themselves. Subsequently, perhaps part of one's meaning making of their experience with a sibling with autism is about embracing contradictory emotions. Engaging in comparisons of others' lived experience is postulated to result in skewed understandings and negatively impact the sibling relationship. Rather, sitting in, and experiencing the complexity of making sense of one's experience enveloped by difference, assists siblings to find happiness and celebrate their lived reality.

In closing

By including adult voices, and their retrospective and current accounts of their lived experiences of the sibling relationship, this paper contributes additional information to the sibling relationship discourse when one sibling has autism. Siblinghood with an autistic sibling is characterised by an ebb and

flow relationality, with an evolving and dynamic sibling relationship. Interestingly, later adolescence and early adulthood are moments of divergence, enabling opportunities to rediscover and redefine one's sense of self outside of the prevailing sibling self. Contrastingly, this is also a moment of reflection on how having an autistic sibling may have enhanced one's sense of self up to, and including in, adulthood, aiding connection and understanding within the relationship. Moreover, meaning making of one's sibling relationship is a continuous, dynamic process across one's life. Having a sibling with autism does not automatically delineate such a sibling dyad as negative or positive. Thus, this relationship is not fixed or determined by specific childhood or adolescent relational patterns or dynamics. Therefore, the study's findings suggest previous conceptions of 'outcomes' and the 'normative' standards against which sibling relationships with an autistic sibling are understood, require revision.

Limitations of the study

Perhaps the characteristics of the sample may be considered a limitation in the referred study. The gender imbalance within the sample (more females to males) and within the siblings with autism (more males to females) may pose a limitation. The sibling gender imbalance is representative of the diagnostic gender bias, wherein females are at a disparate risk of not receiving an autistic diagnosis because symptomatology and presentation is postulated to manifest differently to that reported in males with autism (Zhang et al. 2020). Although this study did not explore gender as a determining factor for siblings' experiences, accommodating an equivalent representation of gendered participants and their siblings may enable for different findings of the lived experiences of adult siblings with an autistic sibling. Furthermore, some participants were in early adolescence when their sibling with autism was born, and thus there is a large age gap between these individuals and their siblings. These participants would have a different experience to draw on to those who are close in age to their sibling with autism. Future studies could explore individual adult perspectives who have an autistic sibling who is closer in age. Another limitation to the study includes the limited demographic information regarding whether the sibling has a comorbid diagnosis that could have influenced the sibling relationship. Although this was not directly asked, no participant shared this information.

Future recommendations

Given the under-exploration of adult perspectives, specifically in autism sibling research, it is recommended that future research continue to explore this narrative to add to the extant child, adolescent, and parental voices within

the literature. Subsequently, there is room for expansion on this topic, such as exploring adult perspectives with a targeted sibling sample (sibling pairs with similiar age gaps or both in adulthood, individuals with older or younger siblings with autism, specific cultural, racial, or socio-economic groups) or exploring the determinants that mitigate or impact the sibling relationship from adult perspectives (gender, age-gap, birth order, having additional siblings or living situation). The benefits of current and retrospective accounts offered by an adult perspective are endless and enable a springboard to explore the multifaceted nuanced sibling relationship across the lifespan when one has autism. Furthermore, future research could elucidate the current findings by including the adult perspectives of both the sibling and the autistic sibling. A dyadic approach may yield different findings and a dynamic understanding of the sibling relationship across siblinghood.

With regards to implications for the support of adult siblings, there are benefits of experiencing various relational barriers, adverse feelings, and experiences of being rebuffed, to strive for some resemblance of a sibling connection. Although it may be overwhelming to continue working through these, the findings provide various components for establishing potentially meaningful sibling relations. Firstly, one should understand the importance of becoming acquainted with one's sibling – getting to know their sibling, their personality, and interests. Secondly, one should invest time and effort in finding means to communicate and connect, opposed to using conventional means that may not be optimal for one's autistic sibling, or abandoning efforts when rejected. Thirdly, one should strive for shared experiences, since this may lead to shared growth and development, encouraging a more collaborative and relational sibling dyad. Lastly, one should not view one's sibling with autism as less than. Such disparity in perception can limit one's understanding of their sibling, put them in a box, undermine their capabilities, cause resentment, and impose feelings of inferiority onto one's autistic sibling. Therefore, it is hoped that individuals with autistic siblings can view these findings as guidelines to achieve a sibling bond and to avoid future regret, as well as to understand the benefits of surviving the difficulty to arrive at a place of closeness and connection.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This paper received no funding support.

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Data availability statement

Data is available upon request from the corresponding author.

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