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REVIEW PAPER

Experiences of Loneliness and Connection for Autistic Young People: A Systematic Review

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Abstract

Evidence suggest that autistic young people are vulnerable to feeling lonely, with detrimental consequences for their wellbeing. This systematic review sought descriptions of loneliness and connection by autistic young people. The findings summarise how loneliness has been conceptualised, measured and reported for autistic young people and offer a list of strategies that are personally meaningful and promote connection and wellbeing. Three conclusions are reached: first, there is a paucity of research on how this group experience loneliness; second, descriptions of feeling connected are mostly limited to neuronormative descriptions of friendship, which can judge autistic behaviours as inadequate; third, loneliness must be reconceptualised, and appropriate assessment tools developed. These developments should be supported by research with participation of the autistic community.

Keywords Loneliness · Connection · Autism · Autistic young people

Loneliness is conceptualised in diverse ways (Cramer & Barry, 1999; Motta, 2021). Essentially, loneliness can be understood as the absence of adequate social networks (social loneliness) or the absence of intimate relationships (emotional loneliness) (Weiss, 1973), with an accompanying negative feeling when social needs are perceived as not being met (Hawkley & Cacioppo, 2010). Both the number and the quality of relationships that a person has are important in these definitions. Furthermore, existential loneliness can be understood as a deep feeling of separation from others and the world, commonly accompanied by feelings of not being understood by other people (Baek et al., 2023; McKenna-Plumley et al., 2023). Although loneliness has been conceptualised in many ways, there is agreement that loneliness is part of human experience, and prolonged and persistent loneliness can be detrimental to health, mental wellbeing and cognition across the life span (Cacioppo & Hawkley, 2009; Deckers et al., 2017; Holt-Lunstad et al., 2015).

Experiences of loneliness are less well understood for autistic young people. Higher rates of loneliness are reported for autistic adolescents when compared with their peers (Deckers et al., 2017). High levels of anxiety have also been associated with loneliness (White & Roberson-Nay, 2009). Many autistic young people have expressed their desire to have and maintain friendships (Gallup et al., 2016; Myles et al., 2019; Murphy et al., 2017); however, some autistic young people describe pursuing friendships in order to be considered 'normal' (Berns, 2016). Bauminger and Kasari (2000) added further understanding to the complexity of the experiences of loneliness for autistic young people; they reported that having a best friend does not seem to lessen feelings of loneliness for autistic children, raising questions as to what contributes to meaningful experiences of relationships, connection and belonging.

Interventions that support social skills have been developed and widely used to support social connection for autistic individuals (D'Amico et al., 2015; Ghasemtabar et al., 2015; Koning et al., 2013; LaGasse, 2014; Lindsay et al., 2017). Although there is evidence that social skills training can reduce feelings of loneliness and can foster belonging (Gantman et al., 2012), other findings suggest that offering

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social skills training, or interventions to increase opportunities for social contact, can be inappropriate for autistic people (Bottema-Beutel et al., 2018). For some autistic young people, navigating expectations of neurotypical communication, such as initiating or reciprocating social interactions, interpreting non-literal speech or managing sensory processing sensitivities, can mean that efforts to imitate a particular way of socialising detract from their sense of self (Causton-Theoharis et al., 2009; Mesa & Hamilton, 2022). These social obstacles can contribute to experiences of rejection, exclusion and distress (Tierney et al., 2016). Some autistic young people respond to constant expectations to be more 'sociable' by masking or camouflaging to appear more like their neurotypical peers (Tierney et al., 2016), whilst others withdraw from social invitations (Wainscot et al., 2008). These coping strategies could be contributing to mental ill health, as they are described by autistic people as being 'exhausting and associated with feelings of anxiety, stress, sadness and identity confusion' (Cook et al., 2021, p.3).

Loneliness and connection might be experienced differently by autistic adolescents when compared with their non-autistic peers. This review sought to answer the following questions: (i) How do autistic adolescents describe loneliness? What do feeling 'lonely' and 'not lonely' feel like? (ii) How is loneliness measured and reported in research with autistic adolescents? (iii) What strategies are used personally by autistic young people to promote meaningful connection and wellbeing?

Methods

This study was pre-registered on PROSPERO [CRD42022374504], and the review followed the updated PRISMA guidelines (Page et al., 2021).

Community Involvement

Guided by the framework for emancipatory research (Chown et al., 2017), a patient and public involvement (PPI) group with members of the autistic community informed the research process. This consultation validated the research questions and refined the search strategy for the review. The absence of young people in the PPI group is considered to be a limitation.

Defining Adolescence

Adolescence is usually determined as being between 12 and 18 years of age (Dahl, 2004; Jaworska & MacQueen, 2015). Researchers apply age ranges inconsistently; therefore, the search strategy was broader than 'adolescent' search terms to allow full-text review. Studies with quantitative designs were excluded if participants were predominantly younger than 12 or older than 18 years old. For qualitative designs, when relevant quotes from participants could be identified as being from someone between 12 and 18 years of age, these studies were retained.

Eligibility and Information Sources

Initial searches were conducted in early 2023 and update searches in September 2024. Following good practice from previously successful systematic reviews (Francis et al., 2022) a scoping exercise was conducted by the first author to inform eligibility criteria. This preliminary search indicated that relevant studies had been published between 2000 and 2022. In addition, the pioneering research by Bauminger and Kasari (2000) became a hallmark in the field and, therefore a good starting point for relevant publications around the experience of loneliness for autistic young people. The review sought qualitative descriptions of loneliness and connection as experienced by autistic young people, authored by any stakeholder. Qualitative, quantitative and mixed-methods designs were included. Inclusion and exclusion criteria were developed from SPIDER concept maps (Boland et al., 2017), as shown in Table 1 (Online Resource 1).

Ten electronic databases (APA PsycINFO, APA PsycArticles, Child Development & Adolescent Studies, ERIC, CINAHL, EthOs, Dissertations and Theses A&I, Web of Science, BEI and ASSIA) were searched after consultation with a specialist librarian and by referring to systematic reviews on similar topics (Cook et al., 2021; Grace et al., 2022). All studies were in English.

Search Strategy

Key terms from the research questions were identified (Aromataris & Riitano, 2014) with the aid of the SPIDER table (Boland et al., 2017). The list of search terms was refined by discussions with the research team and PPI group. Boolean search strings were created and combined in three different searches that were used across all databases (see Table 2, Online Resource 2), except when adaptations were required by a particular database. Adaptations constituted of using the same combination of words without truncation.

Screening and Study Selection

The initial searches returned 24,040 titles. Titles were transferred to Refworks and then to Rayyan (Ouzzani et al., 2016). After automatic and manual deduplication, 15,058 titles were retained and submitted to title and abstract screening. The main researcher (LLW) and a collaborator (EMT) independently screened a random sample of 25% of titles and abstracts. Inter-rater reliability was substantial, $k = 0.68$

(95% CI 0.61–0.80). For the second phase of screening, 30 full texts were independently screened. Inter-rater reliability was moderate, $k = 0.58$ (95% CI 0.41–0.60). Disagreements during both phases were discussed in conjunction with the research team. Reasons for exclusion are detailed in the PRISMA diagram for the second phase of screening. After full-text screening, 41 titles were included in the review (Fig. 1). The update searches conducted in 2024 identified four further papers (Dean et al., 2023; Gerber et al., 2023; Schiltz et al., 2024; and Sumiya & Senju, 2023) that corroborate the findings around representations of loneliness in assessment tools.

Quality Assessment

The primary researcher (LLW) used the Mixed-Methods Appraisal Tool (MMAT) (Hong et al., 2018) to conduct quality appraisal in consultation with the research team. Titles were grouped and assessed according to the guidance: qualitative ($n = 24$), quantitative non-randomized ($n = 1$), quantitative descriptive ($n = 11$), mixed methods ($n = 4$). One title (Adamo, 2004) was not appraised as it did not fit any of the categories, but since it contributed personal voice from an autistic adolescent, it was deemed valuable and therefore included in the final sample. Most included titles were of excellent or moderate quality. Two of the mixed-methods titles were judged to be of poor quality as they failed to give enough qualitative evidence for the analyses and lacked clarity when reporting methodology. Quality appraisal was used to characterise how young people have been represented in research and to improve future research design. Given the infancy of this research area, it was important not to exclude young people's voices; therefore, all studies were included in the review.

Data Extraction

Data extraction was guided by the same SPIDER concept map used to generate search terms and inform the inclusion criteria. Extracted data consisted of title, author, year and type of publication, sample, phenomenon of interest, design, evaluation and type of research. Main findings and discussion of the suitability of methods or accommodations made for autistic participants were also extracted. All qualitative descriptions of loneliness, connection and belonging were extracted from primary quotations, excerpts and summaries offered by authors.

Synthesis

Qualitative content analysis was used. This is a flexible and content-sensitive method for the systematic analysis of texts (Elo & Kyngäs, 2008). The analytical process followed Kyngäs et al. (2020) guidance. As part of the preparation phase, the full-extracted dataset was read several times guided by the aims and research questions. The organising phase included open coding, which was performed inductively by the primary researcher (LLW). This round of open coding generated 293 codes, which were grouped together according to similarity. As part of the abstraction phase, groups of codes were revised twice, and each time they were grouped into broader higher order categories. These sub-categories were then finally grouped into five main categories which offer descriptions of the research topic.

Results

Study Characteristics

The 41 studies are summarised in Table 3 (Online resource 3). Research was conducted in 12 countries, the majority in the USA ($n = 18$), followed by the UK ($n = 9$), Australia ($n = 4$), Japan ($n = 2$), and Belgium, Canada, China, Denmark, Germany, Ireland, Israel and Italy, with one study each. There were 1952 participants overall, with 826 being autistic adolescents (all with a formal diagnosis of autism). Out of these, 623 were reported to be males, 157 females, one participant with gender fluid identity and 45 did not have their gender specified. Other participants were non-autistic adolescents ($n = 836$), participants with motor and/or sensory disabilities ($n = 50$) and participants who identified as disabled ($n = 8$). There were 178 family members reported as mothers ($n = 35$), fathers ($n = 9$), caregivers ($n = 7$) and parents ($n = 127$). There were 53 members of staff, including mentors ($n = 7$), teachers ($n = 23$), teaching assistants ($n = 7$), learning support assistants ($n = 5$), senior members of staff ($n = 1$), support worker (n = 1), head of resource provision ($n = 1$), mental health professional ($n = 1$), production assistant ($n = 1$), self-employed artists ($n = 2$) and volunteering students ($n = 2$). Two members of staff did not disclose their position.

Most studies represented autistic young people attending mainstream schools ($n = 11$), followed by mainstream schools with support services for children with special educational needs ($n = 8$), outpatient clinics and other groups dedicated to developing skills or offering activities specifically for autistic people ($n = 8$), online and in-person support groups ($n = 3$), special schools or units ($n = 4$), research participants ($n = 3$) and therapy clients ($n = 2$). Two studies (Bauminger et al., 2003; Danker et al., 2019) recruited participants from more than one setting.

Most qualitative studies provided descriptions of connection and belonging from the perspectives of autistic young people, with exploration of friendship development, social experiences, the understanding of belonging, how

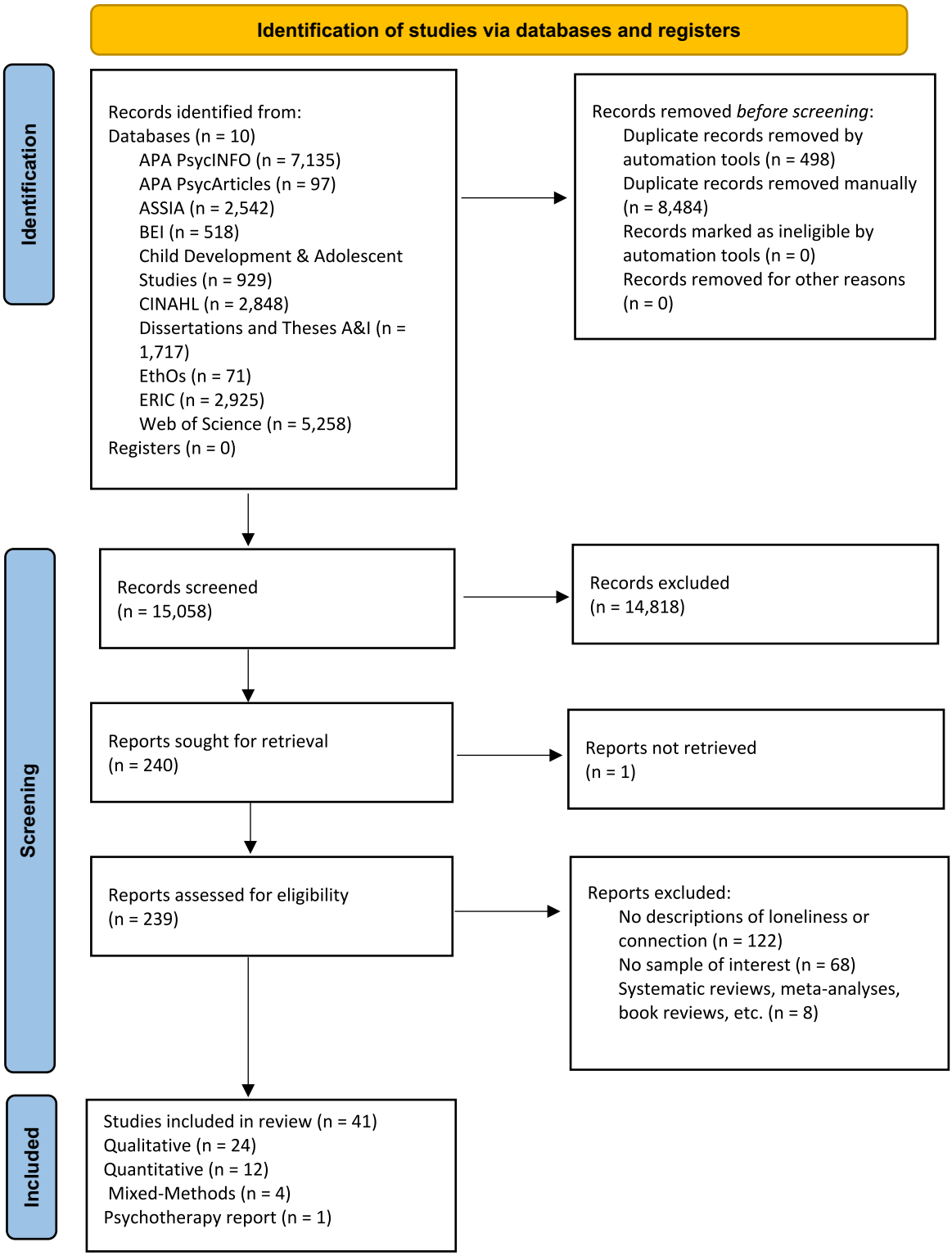

Fig. 1 PRISMA flow chart diagram

connection happens, peer relations and wellbeing. Half of the 24 qualitative studies asked autistic adolescents about their perceptions of these phenomena and half presented the perspectives of multiple stakeholders collectively. Therefore, the personal perspectives of autistic young people could be well represented in the analysis.

Data Synthesis

Based on the qualitative content analysis, five main categories were created: (1) descriptions of loneliness and connection; (2) desire and motivations to have and maintain friendships; (3) things that promote and prevent connection; (4) representations of loneliness in assessment tools; and (5) strategies used by autistic young people that promote connection and wellbeing.

(1) Descriptions of Loneliness and Connection.

Three studies gave descriptions of loneliness and isolation experiences by autistic adolescents, and one study (Berns, 2016) presented experiences of loneliness as one of its primary research topics.

Sumiya et al. (2018) explored emotions associated with friendships for autistic adolescents, who reported that loneliness was felt when they were excluded from activities or games: 'When we were playing tag together, other students didn't catch me and they didn't let me catch any one of them. I felt loneliness then' (Sumiya et al., 2018, p. 7). Goodall and MacKenzie (2019) asked how autistic young girls experienced mainstream school and reported experiences of bullying, prejudice and social pressures, which contributed to feelings of loneliness. An absence of close friends, or people to relate to, being excluded from activities or from meeting up after school and not fitting in also contributed to feelings of loneliness. The following quotes illustrate their findings: 'I found that I had no close friends I could talk to. I felt very lonely and often found myself without anyone to play with' (Goodall & MacKenzie, 2019, p. 507). 'I was isolated and separated, in like a bubble of depression and anxiety... but, I still felt the centre of attention with others looking at me and judging' (Goodall & MacKenzie, 2019, p. 507). Haegele and Maher (2022) reported similar findings. In their study, feelings of belonging were largely unavailable during sports lessons said to be imbued with typical conceptions of masculinity. Some autistic boys felt excluded from what was typically expected from them in this environment.

Berns (2016) provided an understanding of the experiences of friendship and loneliness for autistic boys. One participant defined loneliness as follows: 'To feel like you don't have a place, to not really have people to be with, to just feel a longing for something, like someone to talk to…' (p.125). Another participant defined loneliness as a negative feeling: 'It's kind of like being in a dark room. You can't see anything, and well, you don't know what's there, and you don't know what to do… and then paranoia starts to kick in a little bit. It's not fun' (p.126). Autistic young people in this study also mentioned the need for meaningful and genuine personal connection. They said that interacting with people whom they do not feel a legitimate connection with is almost as good as not having anyone: 'If you have no one who will talk to you (with) honest interest in what you're saying, then that's what I feel like it's lonely' (p. 126). Collectively, loneliness was described by autistic young people as a negative feeling that emerges from being excluded from social activities, and feelings of inadequacy (not 'fitting in').

Descriptions of belonging and connection were explored in seven studies (Berns, 2016; Bradley, 2016; Collier, 2018; Haegele & Maher, 2022; Hall, 2021; Halsall et al., 2021; Myles et al., 2019) and helped to address the question of how 'not lonely' might feel for autistic adolescents. Belonging was associated with having friends, being included, acknowledged and valued. Belonging was reported to be supported by social acceptance and self-acceptance, when young people felt that they were understood, fitted in, did not feel like an outcast and were with like-minded people. For example, autistic young people felt belonging in environments with simplified social interactions, such as friendships with peers in different age groups, which 'enabled them to explore relationships in safe and controllable situations' (Halsall et al., 2021, p. 2080). Friendships with pupils identified as having SEN (Special Educational Needs) were also reported to be positive, with 'reduced social interaction demands' (Halsall et al., 2021, p.2080). A peer mentoring programme that recognised autistic young people's academic strengths and placed them as mentors was evaluated by autistic adolescents as a way of contributing to feelings of belonging: 'It was good. Others don't normally like my ideas or listen to me in class, but they did in the group' (Bradley, 2016, p. 282). When in secure relationships with peers that provided emotional support and demonstrated empathy, young people said this companionship was a source of joy, happiness and entertainment. Such positive experiences entail young autistic people to be 'vulnerable with their friends and then experience the positive feedback of having friends accept and understand them' (Hall, 2021, p.134). Therefore, acceptance, understanding, acknowledgement, emotional support, empathy and inclusion, reportedly enabled autistic young people to contribute authentically, consequently reducing camouflaging and increasing wellbeing.

(2) Desire and Motivation to have and Maintain Friendships.

Nine studies with qualitative designs (Acker et al., 2018; Cage et al., 2016; Gallup et al., 2016; Hall, 2011, 2021; Kunz, 2009; Murphy et al., 2017; Myles et al., 2019; O'Hagan & Hebron, 2017) stated that autistic young people desire social relationships. Autistic young people personally described friendships as being valuable to them (Hall, 2011, 2021) and expressed wanting to have other people to 'hang out with' (Cage et al., 2016, p.17), or to 'actively engage in activities with or keep them entertained' (Hall, 2021, p. 104). Some young autistic people expressed a strong urge to make social connections, but also a worry that treasured relationships could be lost by 'messing things up with people' (Acker et al., 2018, p. 12). Friendships were described

as an 'antidote' to loneliness by some autistic young people (Murphy et al., 2017). However, a desire for friendships was variable across studies. Sumiya et al. (2018) reported that some autistic adolescents showed low levels of motivation to make new friends or to deepen existing friendships and Kunz (2009) reported that although autistic young people seemed to want to have social connectedness, 'none demonstrated overt anxiety or unhappiness regarding the fact that none had such a connection' (p.79). In addition, for some participants a motivation to have friends was not related to feelings of loneliness, but to social pressure (Berns, 2016). For these young people, making friends seemed to come from motivations to be seen as one of their peers, avoiding feeling shame or anxiety or experiencing low self-esteem for being different: 'I'm different, but I can still act normal. In elementary school and junior high, I didn't act normal that often, but I've been trying to act somewhat normal in high school…' (Berns, 2016, p.109).

For some autistic young people, motivation to make friends was said to be low because they have difficulties finding shared interests, or knowing what people might be like before seeking friendships: 'When I look around, I don't really see anything about a person that makes me think, 'Yeah, I wanna be friends with that person.'…' (Berns, 2016, p. 110).

In summary, the desire and motivation for establishing and maintaining social relationships, although present, is not universal amongst autistic young people.

(3) Things that Promote and Prevent Connection.

(i) Authenticity: Being Yourself Without Negative Judgment.

Authenticity was discussed by autistic young people in four studies as something that is needed to feel meaningfully connected (Foggo & Webster, 2017; Gallup et al., 2016; Hall, 2021; Murphy et al., 2017). When discussing aspects of friendships that they valued, some young people cited 'understanding, respect, honesty and the ability to be themselves without judgement' (Foggo & Webster, 2017, p. 79), or being accepted for who they are: '…it's just a matter of me being myself around other people and they accept me for who I am even though they have different personalities I still get along with them' (Hall, 2021, p. 102).

Self-esteem and self-confidence were briefly discussed as contributing to connection with peers, as 'these qualities are likely to empower students to initiate conversations with their peers' (Danker et al., 2019, p. 2929). This study also explored how building a positive self-image can be challenging for some autistic adolescents because they sometimes struggle with their own perception of how different they are from their peers. A teacher shared: 'Matt is not very comfortable with the fact that he's different and that he has additional needs, and that we support him. He's started to pull away a little bit' (pp. 2929–2930).

Some autistic traits, such as sensory issues, repetitive behaviours, the diagnostic label and behaviours used to manage emotions, were also voiced by participants as hindrances that make connection more difficult (Berns, 2016; Danker et al., 2019; Hall, 2021; Rossetti, 2007). Embarrassment due to rejection, fear of humiliation, fear of attracting negative attention, fear of judgement, not being accepted or liked and other negative feelings such as finding themselves different or strange can stop autistic adolescents from trying to connect to other people (Acker et al., 2018; Bradley, 2016; Danker et al., 2019; Kunz, 2009; Hall, 2011, 2021; Myles et al., 2019; Ryan et al., 2021). Less frequently mentioned were difficulty of letting go of their own routine (Hall, 2021), immaturity, lack of Theory of Mind (Berns, 2016) and shyness (Ryan et al., 2021). Some parents of autistic children believed that the barriers that keep their children from connecting meaningfully to others are their lack of social skills, their obsession with one topic, the absence of emotional ties and prevalence of shallow contact (Kunz, 2009). In addition, these individual characteristics were also frequently mentioned by participants as reasons for being excluded, bullied, teased or isolated by peers (Berns, 2016; Collier, 2018; Danker et al., 2019; Hall, 2021; Hurlbutt & LaPlante, 2010; Murphy et al., 2017; Myles et al., 2019; O'Hagan & Hebron, 2017; Rossetti, 2007).

(ii) Safe Spaces, Trust, and Reciprocity.

Eleven studies (Ashburner et al., 2018; Daniel & Billingsley, 2010; Foggo & Webster, 2017; Gallup et al., 2016; Glew, 2020; Hall, 2021; Hurlbutt & LaPlante, 2010; Murphy et al., 2017; Myles et al., 2019; Reynolds, 2017; Ryan et al., 2021) reported safe environments as being a fundamental requirement for connection. A safe environment was explained by participants to be a space that is free from bullying or judgement: 'I feel safe and not threatened, like when I see a movie and I write about it, and friends don't say mean things about my choices' (Watkins, 2016, p.111). Associated with safe spaces were trust and reciprocity (Adamo, 2004; Daniel & Billingsley, 2010; Foggo & Webster, 2017; Glew, 2020; Hall, 2021; Howard et al., 2006; Murphy et al., 2017; O'Hagan & Hebron, 2017; Reynolds, 2017; Ryan et al., 2021). Reciprocity was commonly linked to common interests by autistic young people, who said that spending time with like-minded people who enjoy the same things as they do, was a step towards feeling connected (Ashburner et al., 2018; Berns, 2016; Collier, 2018; Daniel & Billingsley, 2010; Haegele & Maher, 2022; Hall, 2021; Howard et al., 2006; Murphy et al., 2017; Reynolds, 2017): 'It's nice to have friends who understand what I'm going through for once' (Glew, 2020, p. 28).

Social barriers that prevent connection and were frequently mentioned by autistic young people included receiving different treatment, being bullied, ignored and judged (Acker et al., 2018; Gallup et al., 2016; Goodall & MacKenzie, 2019; Haegele & Maher, 2022; Hall, 2011, 2021; Myles et al., 2019; Reynolds, 2017; Watkins, 2016). Social pressure was felt by autistic adolescents when they had difficulty fitting in and by the prevalence of face-to-face interactions (Collier, 2018; Hall, 2011; Hurlbutt & LaPlante, 2010). The lack of inclusive practices and accommodations for autistic needs, also seen as lack of support, was said to result in situations being unpredictable, which can be difficult for autistic adolescents to deal with (Danker et al., 2019; Myles et al., 2019).

Occasionally, the ambiguity of social interactions (Acker et al., 2018), parents' negative attitudes towards disability (Danker et al., 2019), fast pace of changes (Haegele & Maher, 2022), lack of realistic academic and social expectations (Danker et al., 2019), misinterpretation of behaviours and speed of interactions (Rossetti, 2007) were reported as connection inhibitors.

(iii) Familiar People and Familiar Places.

Familiarity with people was described by autistic young people as getting to 'know each other a lot' and 'becoming a lot closer' (Hall, 2021, p. 105). Familiarity was said to help with the predictability of interactions and to facilitate engagement with peers (Hall, 2011, 2021; Glew, 2020). It 'reduced the degree of risk and discomfort associated with social interaction,' (Hall, 2021, p. 143). Feeling in control of interactions such as when autistic young people create imaginary friends (Adamo, 2004) or choose to have online interactions (Gallup et al., 2016) were said to help to avoid feeling dependent or vulnerable. Keeping regular contact with friends, being kind and honest with each other and sharing humour were each described by autistic adolescents as fostering connection (Adamo, 2004; Foggo & Webster, 2017; Hall, 2021; Howard et al., 2006; Murphy et al., 2017; Reynolds, 2017; Rossetti, 2007).

(iv) Supported Activities.

Seven studies (Cage et al., 2016; Berns, 2016; Danker et al., 2019; Foggo & Webster, 2017; Hall, 2021; Myles et al., 2019; O'Hagan & Hebron, 2017) mentioned emotional and practical supports as tools to foster connection. Three studies (Daniel & Billingsley, 2010; Howard et al., 2006; Rossetti, 2007) recognised family involvement as being valuable to promoting connection, whereby friendships develop from family acquaintances. Ashburner et al. (2018) found that interactions guided by adults such as mentorships can be helpful to promote connection. Rossetti (2007) also mentioned that modelling of social behaviours was appreciated by one young person in their study: 'I think it's so difficult to initiate conversation questions if you don't have a teacher in the introduction. I look to an adult to really make the bridge' (pp. 170–171).

Glew (2020) and O'Hagan and Hebron (2017) suggested that structured activities, where autistic adolescents are offered opportunities to socialise and the social initiation is led by someone else, can be positive to support connection. Additionally, Hurlbutt and LaPlante (2010) and Rossetti (2007) said that sharing understanding about autism works as an indirect tool that contributes to feelings of connection. Participants in four studies (Danker et al., 2019; Glew, 2020; Rossetti, 2007; Watkins, 2016) said that creating inclusive environments could mean changing the pace of social interactions to allow gradual participation of autistic young people in schools (Glew, 2020). This includes allowing extra time during supported social interactions to aid different communication styles (Rossetti, 2007). Less frequently discussed were ways to support communication in non-verbal ways, such as creating environments where verbal communication is not imperative (Myles et al., 2019) or by 'becoming adept with subtle, non-spoken prompts' that could help young autistic people during social interactions (Rossetti, 2007, p.194).

(4) Representations of Loneliness in Assessment Tools.

Loneliness was predominantly measured quantitatively using standardised loneliness scales. The most used questionnaire was the Children's Loneliness and Social Dissatisfaction Scale (Asher et al., 1984), used in its original form by four studies (Bohnert et al., 2019; Bradley, 2016; Dean et al., 2023; Locke et al., 2010). The Loneliness Rating Scale is a 24-item scale completed by children aged 8 to 12 years old to assess feelings of loneliness and social dissatisfaction (Asher et al., 1984). Adaptations of this scale were used by another six studies as follows: Bauminger et al. (2003) added six additional loneliness items to the scale, which explored the emotional and social aspects of loneliness, based on previous research with autistic individuals. For example, 'I feel very sad in class' and 'I feel bored during most of the free time in school' (Bauminger et al., 2003). This same modified version was used by Sumiya and Senju (2023) and White and Roberson-Nay (2009). Nomura et al. (2012) used a version of the Loneliness Rating Scale developed by Maeda (1995) to investigate loneliness and characteristics of social behaviour in peer-rejected children. Storch et al. (2012) used only 16 of the 24 original items in their adaptation of the measure and Schiltz et al. (2024) used the Asher and Wheeler (1985) a revised version of the original Asher et al. (1984).

The second most used measure of loneliness was the third version of the UCLA Loneliness Scale (Russell, 1996), developed in English for use with young adults (Maes et al., 2022). Six studies used versions of this measure, with De Gennaro (2015), Gerber et al., (2023) and Lasgaard et al.,

(2010) using the original scale with its 20 items. Chang et al. (2019) used a Chinese version, which contained eight items. Feldhaus et al. (2015) used a German version containing 20 items and Wendler (2018) used three items of the original scale.

Six out of the 12 items of the Loneliness and Aloneness Scale for Children and Adolescents (LACA) developed by Marcoen et al. (1987) were used by Bossaert et al. (2012). Whitehouse et al. (2009) opted for the original de Jong-Gierveld Loneliness Scale (de Jong-Gierveld & Kamphuis, 1985) which is a self-report questionnaire. Berns (2016) used the Peer Network and Dyadic Loneliness Scale (PNDLS: Hoza et al., 2000). Finally, Schiltz et al. (2024) also used modules three and four of the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000, 2012) as measures of loneliness.

Five studies considered the suitability of the measuring tools being used. Berns (2016) stated that the PNDL scale had not yet been used to investigate experiences of loneliness for autistic adolescents; however, the measure was used with the developers' permission. Schiltz et al. (2024) acknowledged limitation of the ADOS as a metric of loneliness. They also commented on the lack of psychometric validity of the revised Asher Loneliness Scale's for autistic people. Bauminger et al. (2003) adapted the Loneliness Scale (Asher et al., 1984) adding six items based on previous research with autistic children and Sumiya and Senju (2023) and White and Roberson-Nay (2009) chose to use this altered version in their research.

Ten studies compared the scores on loneliness scales for autistic and typically developing adolescents (Bauminger et al., 2003; Bossaert et al., 2012; Chang et al., 2019; De Gennaro, 2015; Feldhaus et al., 2015; Gerber et al., 2023; Lasgaard et al., 2010; Locke et al., 2010; Nomura et al., 2012; Whitehouse et al., 2009). In eight out of the ten studies, autistic adolescents reported feeling lonelier than their peers. De Gennaro (2015) did not find a statistically significant difference in reports of loneliness in their sample. Gerber et al. (2023) also found no difference in self-reported loneliness at the beginning of their study, but a small statistically significant decrease in self-reported loneliness for autistic participants. Schiltz et al., (2024) who compared autistic and non-autistic people with other neurodevelopmental disabilities, found similar levels of loneliness between both groups.

For autistic adolescents, high anxiety (Bauminger et al., 2003) and higher ratings of social impairment and difficulties with emotional control (Bohnert et al., 2019) were associated with reports of loneliness. Storch et al. (2012) reported that nearly half of their sample of 60 (48 males) autistic adolescents reported high levels of loneliness. In Wendler's (2018) study, autistic adolescents with increased social difficulties reported increased loneliness, whereas autistic individuals with growth mindset reported less loneliness. Both Schiltz et al., (2024) and Sumiya and Senju (2023) found that feelings of loneliness increase with age for autistic adolescents and Sumiya and Senju (2023) identified that loneliness is mediated by companionship (one aspect of friendship). Dean et al. (2023) found a significant relationship between being mutually involved in a social activity and loneliness.

(5) Strategies Used by Autistic Young People that Promote Connection and Wellbeing.

Strategies mentioned by autistic young people that allowed them to explore their identities and the dynamics of social interaction safely included engaging with fictional characters by watching shows, videos on the Internet or playing videogames (Berns, 2016) and exploring alternative realities by creating 'fantastical ideal universes' that can be joined with role-play, by engaging online or through comic books (Acker et al., 2018). 'Drama, video or studying English Language to learn about the social world without directly interacting with it' (Acker et al., 2018, p. 15) were also mentioned. Some autistic young people created imaginary friends to fulfil their need for companionship and intimacy (Adamo, 2004) or to explore and have control over relationships (Halsall et al., 2021). Spending time alone with personal interests (Goodall & MacKenzie, 2019; Hurlbutt & LaPlante, 2010), playing with pets (Berns, 2016) and mixing with younger children or with adults (Halsall et al., 2021, Hurlbutt & LaPlante, 2010) were also mentioned as strategies that promote wellbeing.

These strategies were discussed by autistic young people when asked about camouflaging (Halsall et al., 2021), their experiences of friendship and loneliness (Berns, 2016), their experiences of mainstream school (Goodall & MacKenzie, 2019), social issues surrounding autism (Hurlbutt & LaPlante, 2010), their experiences of anxiety (Acker et al., 2018) and as part of a therapeutic process (Adamo, 2004). Researchers' evaluations of these strategies were mixed. Imaginary friends, for example, were described by Adamo (2004) as a 'constant dilemma' in the therapy room. Although imaginary companions 'performed a vital function,' protecting the autistic person from 'an unbearable sense of emptiness, unconnectedness and deadness,' they also 'interfered with the possibility of establishing relationships with alive human beings, and they had a quality of addictiveness' (p. 276). Similarly, Acker et al. (2018) highlighted the 'possible detrimental effects' of imaginary friends or fantastical realities linked to special interests as they can 'become obstacles to meaningful relationships' (p. 16). However, Acker et al. also expressed the importance of investigating the role of fantasy for autistic young people due to its potential promotion of wellbeing. One parent of an autistic adolescent (Halsall et al., 2021) described imaginary friends as a compensation for the lack of real friends: 'I do

wonder if those (imaginary) friends are because she doesn't have that many real friends' (p. 2080).

Finally, three studies highlighted strategies that contribute to wellbeing and do not require connection with other people. Hurlbutt and LaPlante (2010) described 'spending time with own interests' as being 'extremely important to the adolescent with AS' (p. 91) and Goodall and MacKenzie (2019) described how one autistic young person 'ranked having friends as the least important aspect for making school more enjoyable' as 'she was happy spending time alone' (p. 508). Berns (2016) also said that engagement with animals or fictional characters as a strategy to promote wellbeing is a novel finding and investigation in this area should be extended.

Discussion

This review describes how loneliness and meaningful connection are experienced by autistic young people, as represented within academic literature.

Loneliness has been reported to be more commonly experienced by autistic young people when compared with their non-autistic peers (Bauminger et al., 2003; Chang et al., 2019; Feldhaus et al., 2015; Lasgaard et al., 2010; Locke et al., 2010). Loneliness has also been associated with higher anxiety (Bossaert et al., 2012; Chang et al., 2019; Nomura et al., 2012; Storch et al., 2012; Wendler, 2018; White & Roberson-Nay, 2009) and depressive symptoms (Whitehouse et al., 2009). However, loneliness has rarely been defined by autistic people, meaning these estimates must be interpreted with caution. This review demonstrates that measures of loneliness are predominantly based on a conceptualisation of loneliness that does not include autistic views and have been used with limited interrogation of their suitability. Consequently, assumptions represented within the reviewed literature limit experiences of connection and belonging for autistic young people mostly to social relationships, such as friendships with peers. These assumptions reflect a 'typical' way of understanding loneliness characterised by 'normalised' views of being with other people (Hawkley & Cacioppo, 2010), failing to recognise legitimate autistic experiences (Milton, 2012; Whitehead, 2023). Whilst possibly unintended, this representation of what constitutes connection and belonging reinforces a historical trend of defining autism based on social deficits (Milton et al., 2023). To truly understand and include autistic people in research literature, it is particularly important to challenge neurotypical frameworks that might determine what friendships or connection should look like (Rossetti, 2007).

Loneliness experienced by autistic young people has not yet been investigated as a main topic of qualitative research. Qualitative designs analysed in this review offered discussions of loneliness as part of wider domains, such as friendship (Berns, 2016; Daniel & Billingsley, 2010; Gallup et al., 2016; Hall, 2011; Hall, 2021; Howard et al., 2006; O'Hagan & Hebron, 2017; Rossetti, 2007; Ryan et al., 2021; Sumiya et al., 2018), relationships (Murphy et al., 2017), social experiences (Foggo & Webster, 2017; Hurlbutt & LaPlante, 2010; Kunz, 2009; Myles et al., 2019), anxiety (Acker et al., 2018), wellbeing (Danker et al., 2019; Glew, 2020), belonging (Haegele & Maher, 2022), camouflaging (Halsall et al., 2021), mainstream education (Goodall & MacKenzie, 2019), judgment from peers (Cage et al., 2016), school transition (Ashburner et al., 2018) and developing of social skills (Watkins, 2016). There is a need for research that focuses specifically on autistic young people's experiences of loneliness.

The second main finding of this review is that a desire to have social relationships, or to be socially connected to peers, is not universal amongst autistic young people. Cacioppo and Patrick (2008) explain that for some people, the motivation to connect socially can emerge from feeling lonely. The same research reports that loneliness can feel threatening and make an individual feel vulnerable, without protection or assistance from others. Although this model rings true for some autistic adolescents, a more detailed analysis expands this perspective. As Berns (2016) raised, some autistic young people are moved to grow social relationships due to social pressure. Their efforts to be socially connected seem to stem from a desire to fit into governing social standards rather than promoting feelings of connection and wellbeing that make personal sense. This can be a problematic strategy, as previous research suggests that trying to conform to non-autistic social demands can lead to reduced wellbeing (Grace et al., 2022). In this review, friendships were shown to contribute to feelings of humiliation and rejection for some autistic young people, who worried about doing and saying the right things. Gerber et al. (2023), for example, discusses how the effects of the pandemic might have given autistic youth increased flexibility in their daily social interactions, reducing anxiety, peer-victimisation and consequently reducing self-reported loneliness.

Alternative ways of feeling 'not lonely' were described personally by autistic young people and did not always include peer relationships. Strategies such as engaging with fictional characters, alternative realities, interacting with pets or imaginary friends should be better investigated as personal strategies that promote wellbeing and are meaningful to autistic young people. Autistic people emphasised feeling acknowledged, included and valued, with both social acceptance and self-acceptance, which might resonate with definitions of existential loneliness, more than loneliness as defined by the number or quality of relationships with other

people (Baek et al., 2023; McKenna-Plumley et al., 2023). It is, however, difficult to disentangle the meaningfulness of peer relationships from how accepting social contexts are.

Social environments can contribute significantly to identity construction (Mesa & Hamilton, 2022), the development of collective and personal self-esteem and psychological wellbeing (Cooper et al., 2017). This review has evidenced how social spaces can enable autistic young people to connect socially with others when they choose to. To feel connected, accepted and socially satisfied, autistic young people said they needed reciprocity, trust, authenticity and spaces free from bullying and judgement. The social model of disability emphasises such inclusive social contexts and the development of meaningful support, as it situates the problems faced by disabled people within society's disabling barriers rather than focusing on individual deficits and impairments (Oliver, 2013): the environment then becomes the focus of interventions. Instead of 'repairing' the individual, support comes from whole systems, shaped by enabling environments where all individuals can thrive (Pellicano & den Houting, 2022; Sonuga-Barke, 2023). This review identified strategies to create inclusive social spaces and meaningful support as described by autistic young people. They consisted of environments with flexible practices such as adopting a slower pace for social interactions or considering communication preferences, which can help with interactions and can facilitate social engagement. For young autistic people who want to develop social relationships, structured activities led by adults or family members can support social engagement. Finally, wider understanding about autism can inform better practices in autism research, education and training, media representation and how social spaces are planned. As discussed by Turnock et al. (2022), these not only promote inclusion of autistic people but contributes for reduced stigma and the creation of social environments that are free from bullying and judgement.

Historically, autism has been medically and scientifically framed as a disorder (Donvan & Zucker, 2016), which has led to predominantly negative perceptions of autistic people and camouflaging of their autistic status (Botha et al., 2022). This context also contributes to self-stigma and internalised oppression (Milton, 2012). In this review, some autistic young people, parents and people who work with autistic young people, mentioned individual differences, such as sensory sensitivities, behaviours used for self-regulation and different communication styles, as hindrances to establishing or maintaining social relationships. In creating inclusive environments, individual differences are not understood as barriers to be overcome by the autistic young person: 'Differences in neurology may well produce differences in sociality' (Milton, 2012, p. 886), which requires an ongoing interactive process for differences to be understood, accepted and accommodated. Self-acceptance and authenticity were discussed by autistic young people represented in this review as being essential underpinnings of meaningful social relationships and recognised in personal accounts from autistic adults (Gadsby, 2022; O'Toole, 2018; Poe, 2019; Prahlad, 2017; Price, 2022).

A closer look at individual items of existing loneliness scales reveals that some items may not appropriately reflect autistic young people's experiences of loneliness as summarised in this review. For example, the UCLA Loneliness Scale (Russel et al., 1978) states that 'having no one to talk to' and 'doing things alone' are indicators of loneliness. However, some autistic young people describe spending time alone with their interests as positive and important experiences (Berns, 2016; Goodall & MacKenzie, 2019; Hurlbutt & LaPlante, 2010). As another example, the Children's Loneliness and Social Dissatisfaction Scale (Asher et al., 1984) presents items such as, 'It's hard for me to make friends' and 'I don't have any friends,' which limit experiences of feeling 'not lonely' to having social relationships. In this review, desire for social connection varied across studies (Berns, 2016; Kunz, 2009; Murphy et al., 2017; Sumiya et al., 2018), showing that not all autistic young people pursue social relationships. Nor does difficulty making friends reflect a desire for friendship. Similarly, the de Jong Gierveld Scale (de Jong-Gierveld & Kamphuis, 1985) and the LACA (Marcoen et al., 1987) have items where lack of friendships indicate loneliness, such as, 'I miss having a really close friend,' 'I find my circle of friends and acquaintances too limited' and 'I think I have fewer friends than others.' Some autistic adolescents describe loneliness as a negative feeling that emerges from being excluded from social activities (Sumiya et al., 2018), from an absence of close friends (Goodall & MacKenzie, 2019) or people to talk to (Berns, 2016). However, other perspectives contradict this normalised notion of loneliness, raising concerns about the suitability of the current measuring instruments used for understanding the experience of loneliness for autistic people. Grace et al. (2022), in their systematic review of how loneliness has been conceptualised for autistic adults, offer a critique of how researchers have not fully examined the validity of measuring instruments, and when efforts have been made to develop measures, these have been without in-depth involvement of the autistic community. This review reports complementary findings: researchers frequently assume that definitions of wellbeing and its essential contributing factors are comparable for autistic and non-autistic people (Caruana et al., 2021; Cassidy et al., 2018a, 2018b; Milton and Sims, 2016). Autistic people have previously raised concerns over studies that use measuring tools that have not been validated by the autistic community (Nicolaidis et al., 2020). In this review, three studies considered the suitability of the measuring tools used. Although Bauminger et al. (2003) adapted the Loneliness Rating Scale

(Asher et al., 1984) following research with autistic individuals, it would be beneficial, as cited by Grace et al. (2022), to have included extensive consultation and collaboration with autistic people, like the work done by McConachie et al. (2018) in when studying quality of life.

Assessment tools will need to evolve from an updated definition of loneliness that comes from research with autistic people as partners (Whitehead, 2023). To expand the conceptualisation of loneliness and connection, future research should focus on qualitative investigations with the use of creative and flexible methods of data collection (Ridout, 2017; Stutterheim & Ratcliffe, 2021), within a participatory research framework (Chown et al., 2017). The suitability of traditional methods of inquiry should be examined before being used (Nicolaidis et al., 2020).

Limitations

Although the included studies were from many different countries, several populations have not been represented. Only participants with verbal communication and no learning disabilities were recruited with one exception (Rossetti, 2007). Representativeness challenges have been reported by other researchers in the field (Cook et al., 2021; Grace et al., 2022). This issue could partly be addressed by broadening the research scope and by developing methodologies that properly capture autistic narratives (Whitehead, 2023). Neurodivergent people with varying skill profiles have been included in research with the use of creative and flexible methods of data collection (Howe et al., 2023; Lewis et al., 2023; Ridout, 2017), with the study of blogs (Petty et al., 2023) and with the use of naturally occurring data (Drewett & O'Reilly, 2023). Titles were limited to publication in English. Loneliness was examined as part of broader domains; therefore, it is not possible to draw firm conclusions of how loneliness is felt by autistic adolescents. Finally, findings derived from studies that used standardised measures, which have not been designed nor validated by autistic people, should be treated with caution.

Conclusion

This systematic review has highlighted a paucity of qualitative descriptions of loneliness from autistic adolescents' perspectives. Investigations have mostly depended upon conceptualisations of loneliness and connection underpinning measuring instruments that have not had their suitability interrogated for autistic people. These findings reinforce the dominance of a 'typical' way of experiencing connection, and the need for autistic people to meet these expectations (Fletcher-Watson et al., 2019; Milton & Sims, 2016). Critically, a conceptualisation of loneliness that is without representation of autistic lived experience can lead to marginalisation and damage to wellbeing (Pellicano & den Houting, 2022) through the reinforcement of stigmatising views and internalised oppression (Milton, 2012). Research underpinned by the neurodiversity paradigm, with a strong participatory ethos, could enable researchers to redefine loneliness for autistic young people and develop measuring scales based on this new understanding. This review foregrounds emerging descriptions of meaningful connection for autistic young people to suggest routes for a reconceptualisation of loneliness.

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Data Availability Data related to this systematic review can be found in the supplemetary materials. Additional data is available on request by emailing the corresponding author.

Declarations

Competing Interests The authors declare no competing interests.

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