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“Bigger lows, but higher highs”: A qualitative exploration of the similarities and differences in quality of life of middle-aged and older autistic and non-autistic adults

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ABSTRACT

Background: Autistic adults often report lower subjective quality of life (QoL) than non-autistic adults. Despite older age also often being associated with lower QoL, little is known about the first-hand experiences of, and influences on, QoL for middle-aged and older autistic adults compared with their non-autistic peers.

Method: Thirty-three participants (autistic n = 15, non-autistic n = 18) aged 50–89 years completed semi-structured interviewed that explored their QoL. Responses were thematically analysed, and themes were compared to identify similarities and differences between groups.

Results: Both autistic and non-autistic groups reported similar QoL experiences, but with subtle differences. Social support from family and friends was important for both groups. Both noted shrinking social networks with age, but the non-autistic group was often less satisfied with their social lives. Concerns about health and sleep changes were common, but autistic participants often mentioned persistent mental health issues affecting their wellbeing. Autistic individuals also highlighted sensory sensitivities and difficulties with change. Receiving their autism diagnosis was significant for autistic participants, aiding self-acceptance. Acceptance of age-related changes was common in both groups, but the autistic group was more willing to seek support, while the non-autistic group often saw asking for help as losing their independence.

Conclusions: These findings highlight similarities and differences in aspects relevant to QoL for middle-aged and older autistic and non-autistic adults. While many similarities were found, the autistic group reported subtle differences in their experiences. Experiences such as social connectedness and coping with change could be targeted to improve the QoL of ageing autistic adults.

1. Introduction

Autism Spectrum conditions (henceforth simply ‘Autism’) are a set of lifelong neurodevelopmental conditions that are

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characterised by differences in social communication and restrictive-repetitive behaviours and interests (American Psychiatric Association, 2022; Happé & Frith, 2020; Keating et al., 2023). Despite being a lifelong condition, due to changes in the conceptualisation of autism across time, as many as 90 % of older autistic people (> 50 years old) are likely to be undiagnosed or misdiagnosed with another condition (O'Nions et al., 2023). As a result, there is a scarcity of research that explores the experience of middle-aged and older autistic adults and their quality of life (Mason et al., 2022), with older autistic people being described as a 'lost generation' (Lai & Baron-Cohen, 2015). Given the high rates of mental health problems (e.g., Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Lever & Geurts, 2016; Stewart et al., 2020b), poorer life outcomes (Mason et al., 2020), experiences of loneliness and isolation (Stewart et al., 2024; Umagami et al., 2022), high rates of PTSD symptoms and trauma (Quinton et al., 2024; Stewart et al., 2021), and high rates of suicidality in autistic populations (Cassidy et al., 2022; Stewart et al., 2022), improving the quality of life of middle-aged and older autistic people is of vital importance.

Quality of life (QoL) is defined by the World Health Organisation as a multi-faceted subjective construct that pertains to an individual's satisfaction with the current state of their life, taking into account their past experiences, goals, standards, and concerns (Harper et al., 1998). There is a growing body of research that highlights that autistic children and adults have been found to report lower subjective QoL than non-autistic peers (Ayres et al., 2017; Mason, Mackintosh, et al., 2019; van Heijst & Geurts, 2015). However, despite older age often having a negative influence on QoL (Zaninotto et al., 2009), only a few studies to date have explored QoL in middle-aged and older autistic populations (Mason et al., 2022). The first study of subjective QoL in a middle-aged and older autistic adult sample was a quantitative study by van Heijst and Geurts (2015), who examined group differences in self-reported QoL scores between 24 autistic adults (aged 53–83 years, mean = 63 years, male n = 19) and an age, gender, and IQ-matched non-autistic comparison group. The autistic group were found to report lower QoL than the age-matched comparison group. A similar pattern of results was found by Mason et al. (2019), in their larger sample of 69 autistic people aged 55 years and older (mean age = 61.5 years, male n = 48). A recent qualitative study by Viner et al. (2024) highlighted a range of autism-specific factors that influenced quality of life in their sample of 16 middle-aged and older adult participants (mean age ~52, male n = 9). These factors included the importance of receiving their autism diagnosis, the challenge of maintaining social relationships as an autistic person, and having autonomy over their own time.

Despite the dearth of information about QoL in midlife and older autistic adults, lower QoL has more generally been linked to mental health difficulties (Ayres et al., 2017; Charlton et al., 2022; Mason et al., 2018; Mason, Mackintosh, et al., 2019), which are common in autistic populations across adulthood (Croen et al., 2015). These high rates of mental health problems have also been found in middle-aged and older autistic adults (Bishop-Fitzpatrick & Rubenstein, 2019; Lever & Geurts, 2016), and middle-aged and older adults with high autistic traits (Lodi-Smith et al., 2021; Stewart et al., 2020a, 2020b, 2021, 2022).

Other age-related factors may also play an important role in QoL for autistic people. As midlife and older age represents a period of health and lifestyle changes, healthcare needs often increase (Abdi et al., 2019). Autistic people have been found to experience barriers to accessing healthcare across their lifespans, often resulting in unmet support needs (Bradshaw et al., 2019; Mason, Ingham, et al., 2019; Nicolaidis et al., 2015; Walsh et al., 2020). Due to the scarcity of research exploring autism in midlife and older age, it is not currently known whether middle-aged and older autistic people have disproportionately unmet healthcare needs, which could in turn impact their QoL.

Social support can also change in later adulthood and has been shown to be an important predictor of QoL for middle-aged and older autistic adults. A recent quantitative study by Charlton, McQuaid, and Wallace (2022) explored links between social support and QoL in 388 autistic people (aged = 40–83 years, mean = 52.2 years, 41 % male). This study reported that better subjective social support (i.e., feeling their needs were listened to) significantly predicted higher overall QoL for middle-aged and older autistic adults. Additionally, while objective social support (i.e., the quantity/availability of support, social connectedness) did not predict overall QoL, it was found to be important for the social and environmental subdomains of QoL.

To the authors' knowledge, despite autistic people in midlife and older age having high rates of social isolation (Stewart et al., 2024), few studies have explored the influence of having low social connectedness (i.e., social isolation) on QoL for middle-aged and older autistic people. A qualitative study by Hickey, Crabtree and Stott (2018) explored the experiences of 13 older autistic people (aged = 51–71 years, male n = 10) using semi-structured interviews to discuss how being autistic has influenced their lives. Many of the participants highlighted that they had experienced social isolation and loneliness throughout their lives. While these experiences had a detrimental impact on their wellbeing, some found that this isolation represented a state of solitude and helped them manage their social anxiety (Hickey et al., 2018). Furthermore, a quantitative study conducted by Yarar et al. (2022) compared QoL in 38 younger and 41 older autistic adults (age range = 19–71 years, male n = 61). This study found an age-effect in social QoL, with older autistic adults rating their social QoL significantly better than the younger autistic adults, suggesting that social aspects of QoL may improve with age (Yarar et al., 2022).

Younger autistic people often report feeling socially isolated and lonely, which has been found to have a profound negative impact on mental health and quality of life (Hedley et al., 2018; Lamport & Zlomke, 2014; Mazurek, 2014; Umagami et al., 2022). While social isolation and loneliness can occur at any age (Office for National Statistics, 2018), the experiences become more common as people get older (Courtin & Knapp, 2017; Donovan & Blazer, 2020), with over 2 million people aged 50 + in the UK having poor social contact (AgeUK, 2018). Stewart et al. (2024) documented that 1 in 10 autistic people over 40 had no family or friend contact within the past month, highlighting that lack of social connections may greatly impact autistic people as they age.

In sum, many factors may have an impact on a person's QoL as they age, and research is needed to identify areas that could be targeted for interventions and support to improve QoL in later life for autistic people. To address the scarcity of research that examines quality of life in midlife and older age for autistic people, the present study explored the factors that influence QoL in middle-aged and older autistic and non-autistic adults using a semi-structured interview protocol. After consulting with middle-aged and older autistic and non-autistic adults, an interview protocol was developed to explore several key areas, including social life, health, support needs, and coping with age-related change. Thematic analysis was used to analyse the interview responses. Comparisons between developed themes were then made to identify any 'autistic-specific' influences on QoL in later life.

2. Method

2.1. Study design and participants

Participants were recruited through study adverts on social media, in older adult independent-living residential communities (i.e., private or local authority-run independent-living communities for people over a certain age), in community centres in London and southeast England, and through existing participation databases held by the authors, forming a convenience sample. Individuals were eligible to take part if they were 50 years of age or older and lived in the UK. Participants who responded to the study advert or invitation email had a brief telephone call with a researcher (GRS, DF, DH) to confirm their interest in being interviewed, and to agree on a convenient time to conduct the telephone interview. The participant was then sent a letter by post or an email that included an information sheet and informed consent form, as well as a set of brief demographic questions and a set of quantitative questionnaires. Prior to the interview, participants were also asked to spend 30-minutes reflecting on their lives and what has influenced their QoL. At the time of the interview (either via video call, telephone, or in-person), participants were asked to verbally reaffirm their consent for participation. Participants were offered regular breaks during the interview, and the researcher answered any queries that participants had during the sessions. Interviews were conducted between October 2019 and February 2020, prior to the onset of the COVID-19 pandemic. Participants were reimbursed for their time with a £ 40 gift voucher. Full ethical approval was received for this study through the King's College London PNM Research Ethics sub-committee (RESCM-19/20–14313).

In total, 33 participants were recruited to this study (aged 50–89 years, female n = 20 (60 %)). All participants lived independently in their communities (i.e., not in a care or residential home). The participants were separated into an autistic group (n = 15, 60 % female) and a non-autistic comparison group (n = 18, 61 % female). The autistic group included those who have an autism diagnosis (n = 12) or self-identify as autistic (n = 3). All autistic participants were diagnosed with Autism or began to self-identify as autistic in adulthood; specific data on the age of Autism diagnosis/self-identification was not collected. Due to high rates of underdiagnosis of Autism in midlife and older age (O'Nions et al., 2023) and that the self-identified participants reported comparably high autistic trait scores to the diagnosed participants, the two groups were merged into a combined autistic group. Few differences were found between the demographic characteristics of the autistic and non-autistic comparison group, with the exception being education history. Overall, the autistic group had a higher level of education than the non-autistic comparison group. Specific data on race/ethnicity and socio-economic status were not recorded. See Table 1 for demographic characteristics of the sample.

2.2. Materials

A semi-structured interview protocol was developed for this study, to ensure standardisation between interviews while still allowing for participants to express their own experiences. The protocol included broad open-ended questions related to factors known to influence QoL in midlife and older age, specifically 1) family life and friendships, 2) physical and mental health, 3) sleep quality, 4)

Table 1
Demographic characteristics of autistic and non-autistic groups.

		Non-Autistic Group (n = 18)		Autistic Group (n = 15)		Group Difference	Effect Size
Age (years)	M (SD)	68.1 (12.5)		61.5 (9.30)		*t*(31) = 1.69	0.59
	[95 % CI]	[61.9–74.3]		[56.4–66.7]		*p* = .102	[−0.11 - 1.29]
	Range	51–89		50–78			
Gender	male: female	7:11		6:9		χ2 = .01,	0.03
	%	38.9 %: 61.1 %		40.0 %: 60.0 %		*p* = .794	[−0.68 - 0.75]
Living arrangement	Supported housing^	2	11.8 %	0	-	χ2 = 4.43,	0.83
	Living alone	4	22.2 %	3	20.0 %	*p* = .489	[0.06 - 1.61]
	With sibling(s)	0	-	1	6.7 %		
	With spouse/partner	7	38.9 %	9	60.0 %		
	With children	4	22.2 %	2	13.3 %		
	With spouse/partner and children	1	5.6 %	0	-		
Education history	School to 16	7ǂ	38.9 %	3ǂ	20.0 %	χ2 = 9.06,	1.32
	School to 18	5ǂ	27.8 %	1ǂ	6.7 %	*p* = .028 *	[0.46 - 2.17]
	Undergraduate	5	27.8 %	4	26.7 %		
	Postgraduate	1ǂ	5.9 %	7ǂ	46.7 %		
Current employment status	Employed	6	33.3 %	6	40.0 %	χ2 = 7.26,	1.13
	Unable to work due to health	0	-	4	26.7 %	*p* = .064	[0.36 - 1.95]
	Unemployed	1	5.6 %	0	-		
	Retired	11	61.1 %	5	33.3 %		

Note: ǂ Cells with significant proportional difference. Effect size calculated with Cohen's d. * $p < .05$
^ Here, supported housing refers to people in an independent-living older adult community with a call alarm for emergencies.

cognitive changes, 5) support needs, 6) coping with personal changes, 7) travel and sensory difficulties, 8) hobbies and interests, and 9) any other factors not covered. Each topic would open with a description (e.g., "To start the interview, I'd like to speak about your family life…") which would then lead into a set of questions (e.g., "Families come in all shapes and sizes. Can you tell me a bit about your family?"). Some topics also included questions only asked to autistic participants (e.g., "Do you have any friends or people who you keep in touch with that are also autistic?"). Pre-determined prompts would occasionally be used to help facilitate conversation. At the end of each section, a question would be asked to capture any influences not yet covered, ensuring that the participant could freely discuss their experiences (e.g., "Is there anything else about your family life or friendships that you would like to talk about?"). See Supplementary Materials for the full Interview Protocol.

While not the primary focus of this study, additional standardised questionnaires were also used to contextualise the characteristics of this sample. Autistic traits were measured using the Autism Quotient (AQ-10; Allison et al., 2012). Symptoms of current depression and anxiety were measured using the Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001) and the Generalised Anxiety Disorder questionnaire (GAD-7; Spitzer et al., 2006). Current subjective quality of life was measured using the WHOQoL-BREF (Harper et al., 1998). The autistic group self-reported significantly higher autistic traits, more symptoms of current depression and anxiety, and lower quality of life than the comparison group. The same pattern of group differences in QoL scores were found when accounting for education history. See Table 2 for group questionnaire summary scores.

2.3. *Community involvement in research*

The topics that were discussed in this study were influenced by a series of patient and public involvement (PPI) interviews with 12 middle-aged and older autistic adults conducted prior to the commencement of this study by GRS in 2019. Three older adults (two autistic, one non-autistic) reviewed the final protocol to ensure the questions were clear, accessible, and appropriate.

2.4. *Positionality of researchers*

The five authors of this study are non-autistic. All authors have a background in Psychology and Autism research, with experience ranging from being intercalated medical students (DF and DH, at the time of the study), to being senior researchers with decades of experience (RAC and FH). All authors share a neurodiversity perspective that recognises that the different way in which autistic people process the world can be disabling in a society designed by and for non-autistic people. Authors also view ageing through a positive lens.

2.5. *Data analysis*

Demographic characteristics and questionnaire data were analysed using t-tests and chi-square analyses (using SPSS v28; IBM Corp., 2021). All interviews were recorded and transcribed verbatim, with any identifiable information being removed to ensure confidentiality/anonymity. DF and DH quality checked the manual transcriptions to ensure they were accurate. Due to overarching themes (e.g., the influence of mental health) being found throughout almost all discussion topics, transcripts were viewed and coded as a whole, rather than as responses to individual topic prompts. Transcripts were individually thematically coded using a reflexive deductive approach (Braun & Clarke, 2006, 2019a, 2019b) by DF and DH (using Nvivo Pro 12; QSR International, 2018), with GRS reviewing all transcripts and coding to ensure appropriate theme identification. Reliability meetings were held to discuss the individual coding, and to identify any areas of coding disagreement between DF and DH. Coding agreement was high between DF and DH, and any disagreements were resolved between DF and DH with GRS prior to the finalisation of the themes identified. Comparisons were made between the themes identified from the autistic and non-autistic participant groups, with similarities and differences being

Table 2
Questionnaire summary of autistic and non-autistic groups.

		Non-Autistic Group (n = 18)	Autistic Group (n = 15)	Group Difference	Effect Size
Autistic Traits	M (SD)	2.71 (2.28)	6.77 (2.45)	$t(31) = 4.68$,	1.72
(max score = 10)	[95 % CI]	[1.53 - 3.88]	[5.29 - 8.25]	$p < .001$***	[0.88 – 2.57]
Depression	M (SD)	6.88 (4.78)	13.92 (5.07)	$t(31) = 3.89$,	1.43
(max score = 27)	[95 % CI]	[4.42 - 9.34]	[10.86 - 16.99]	$p < .001$***	[0.63 – 2.24]
Anxiety	M (SD)	3.88 (3.74)	8.77 (5.53)	$t(31) = 2.89$,	1.06
(max score = 21)	[95 % CI]	[1.95 - 5.81]	[5.43 - 12.11]	$p < .004$**	[0.29 – 1.84]
QoL Physical	M (SD)	13.30 (1.38)	10.62 (1.98)	$t(31) = 4.54$,	1.58
(max score = 20)	[95 % CI]	[12.61 –13.98]	[9.52 –11.73]	$p < .001$***	[0.79 – 2.36]
QoL Psychological	M (SD)	13.48 (1.64)	11.44 (1.59)	$t(31) = 3.58$,	1.24
(max score = 20)	[95 % CI]	[12.66 –14.29]	[10.56 –12.32]	$p < .001$***	[0.50 – 1.99]
QoL Social	M (SD)	15.88 (2.32)	11.46 (4.03)	$t(31) = 3.94$,	1.37
(max score = 20)	[95 % CI]	[14.74 –17.04]	[9.23 –13.70]	$p < .001$***	[0.61 – 2.13]
QoL Environmental	M (SD)	14.98 (2.60)	12.45 (3.12)	$t(31) = 2.54$,	0.88
(max score = 20)	[95 % CI]	[13.69 –16.27]	[10.72 –14.18]	$p = .008$**	[0.16 – 1.59]

Note: Autistic traits (AQ-10), Depression (PHQ-9), Anxiety (GAD-7), QoL (WHOQoL-BREF). Effect size calculated with Cohen's d. ***$p < .001$, **$p < .01$

highlighted.

3. Results

Four main themes were identified in the thematic analysis of the semi-structured interview transcripts. Each theme is listed below, with illustrative quotes from the autistic and non-autistic participants. Quotes maintain the original phrasing used by the participant, but some have been altered for confidentiality or for context using square brackets.

3.1. Theme 1: The importance of family and friendships

Several similarities and some differences between the autistic and non-autistic groups were found in what participants said about family, friendships, and social activities. See Fig. 1 for 'the importance of family and friendships' thematic map.

Many autistic and non-autistic participants said that their social circles (including their family networks) had decreased with age. This decrease was often associated with feelings of loneliness. Family bonds in middle and older age were an important factor that influenced quality of life, as they offered a source of companionship and support, but also as source of longing when in a small family.

"I'm the only child of older parents, so I don't have much family left now… it can be quite lonely not having that familial camaraderie" – Autistic male, mid-60s.

For some autistic participants, however, the intensity of family relationships could be taxing to their mental health

"[The family member] wants a very close relationship with me, and I can't handle that. I feel responsible for their happiness, but I want to be my own person." – Autistic female, mid-50s.

Some differences were found; while many autistic and non-autistic participants found their social circled had decreased, only the non-autistic participants said they were dissatisfied with this. Some autistic participants felt that their social lives were already at

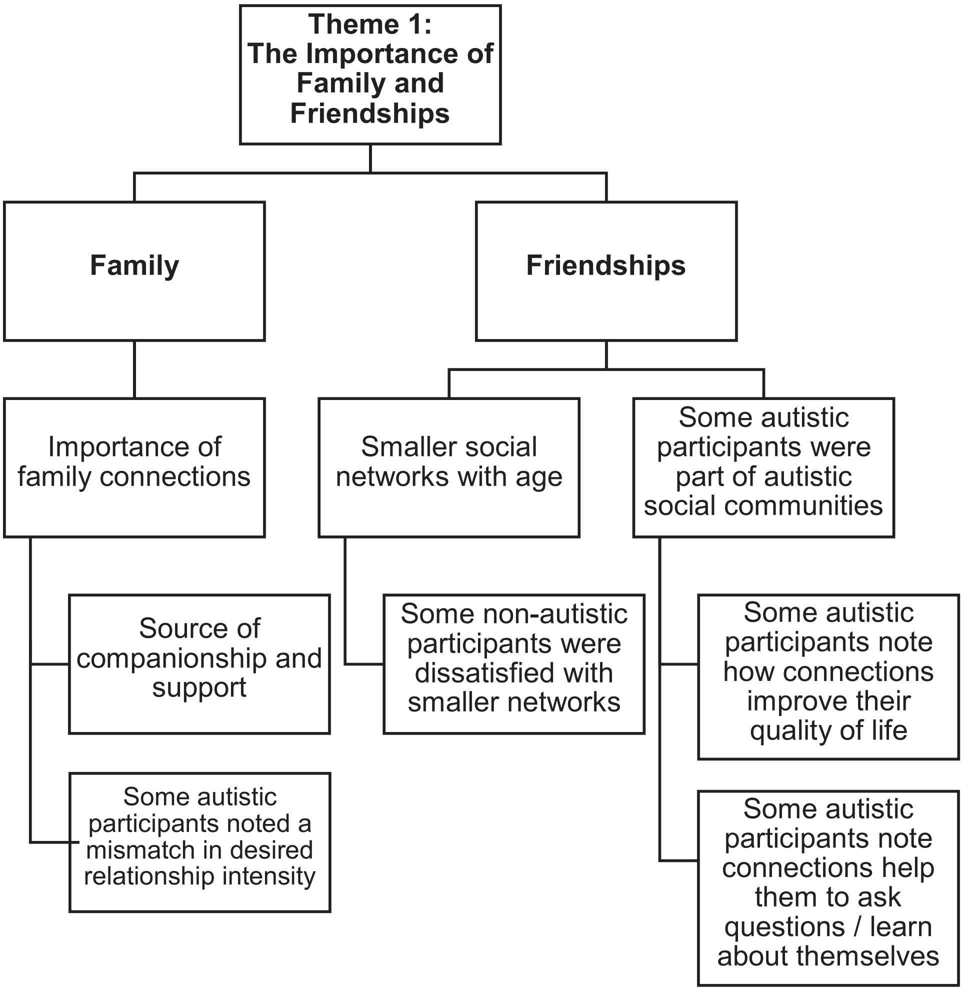

Fig. 1. 'The Importance of Family and Friendships' thematic map.

capacity, despite feelings of loneliness. Furthermore, several autistic adults were engaged with internet social groups for autistic people, whether as a member or as an organiser. Involvement in these groups was felt to be a positive influence on their quality of life and offered the opportunity for learning more about themselves through conversations with others. One autistic person noted, however, that they wouldn't consider the people they meet online to be friends but 'contacts'.

"[My social life] is probably as much as I can cope with, but I still get lonely." – Autistic female, late 50 s.

"I am satisfied [with my social life]; I am not a social person, so I'm happy not to have [too many] friends." – Autistic female, mid-50s.

"I'm not really satisfied [with my social life]. I could try harder if I'm honest. I think I could find the energy to do more. It's quite easy to sit and think "I just can't be bothered". Socialising more would be brilliant." – Non-autistic female, late 50 s.

"Being part of an autism community has definitely added to my quality of life. They gave me answers to things that I didn't even know were part of autism. In fact, I wouldn't have got my own answers without those first ideas from online friends." – Autistic male, early 60 s

3.2. *Theme 2: Health and identity*

Several similarities and some differences between the autistic and non-autistic groups were found in what participants said about their health (i.e., physical and mental health, sleep experiences, and whether their cognitive abilities have noticeably changed). Additionally, the autistic participants also noted that gaining insight into who they are and their identity through being diagnosed as autistic was a significant influence on their quality of life. See Fig. 2 for 'health and identity' thematic map.

Subtheme 1 – Health. Most participants in the autistic and non-autistic groups reported that their physical health had deteriorated with age, ranging from an increased rate of general aches and pains, to some having developed longstanding physical conditions.

Despite this increased rate of physical health problems reported, a key difference between the autistic and non-autistic groups was that mental health was seldom mentioned by the non-autistic participants, even when prompted. Autistic participants, by contrast, often expressed that they had experienced many mental health issues throughout their lives, which was still the case in midlife and older age.

"Yes, [my health] has had a detrimental effect [on my quality of life]. All the different physical and psychological things combine to close down my life. I do fewer things; I stay close to home." – Autistic female, late 50 s.

Subtheme 2 – Sleep. Some similarities between groups were found in sleep experiences; several autistic and non-autistic participants mentioned that their sleep duration had decreased as they aged, and this was often attributed to changes in their physical health. Both groups also reported that general aches and pains caused their sleep to become more disturbed as they have aged.

However, a key difference between the groups was that only autistic participants reported that their noise sensitivity has impacted on their sleep, leading to several autistic participants stating that they now have shorter sleep durations due to being awoken by external noises.

"[My sleep] has got shorter and [I've] been waking earlier. I can't really pinpoint when that started changing though. I've always had quite

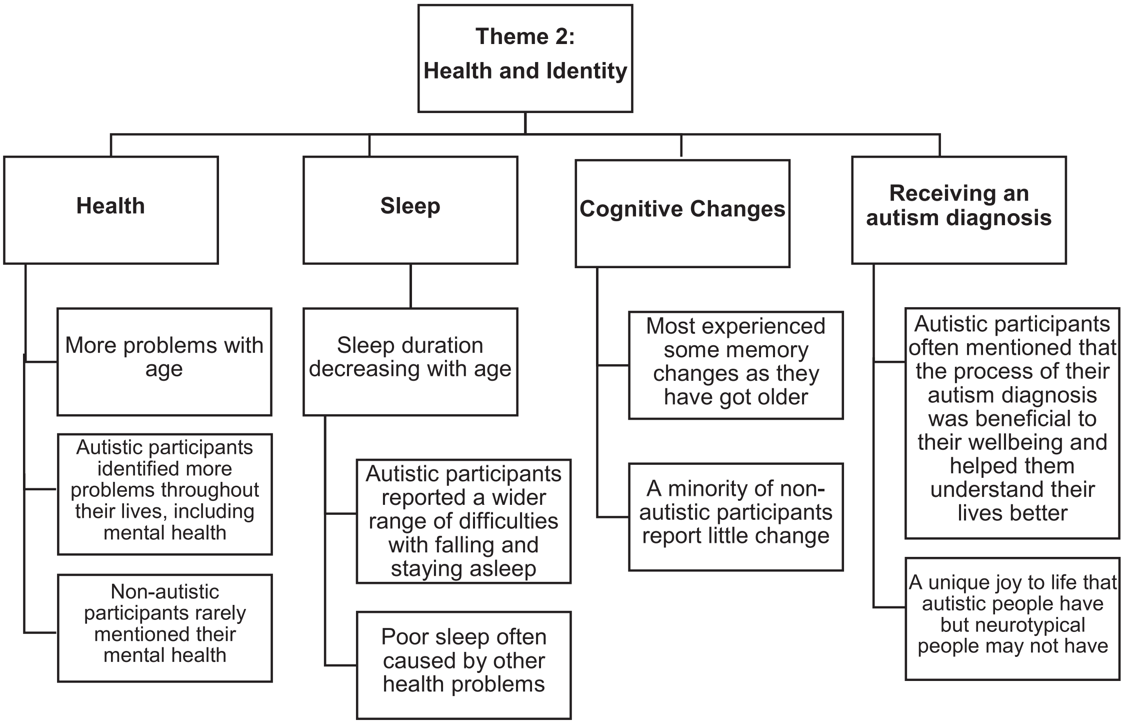

Fig. 2. 'Health and identity' thematic map.

broken up sleep but it's definitely getting worse [as I get older]." – Autistic male, mid-70s.

Subtheme 3 – Cognitive Changes. Several autistic and non-autistic participants mentioned that their memory had become worse with age, typically manifesting in being more forgetful or losing their train of thought when doing something.

"My memory is getting worse. I forget names more than before, lose my train of thought mid-sentence, take longer to finish what I'm saying and sometimes struggle to find the word I'm looking for. I can describe what I mean and know the approximate 'shape/sound' of the word but take a while to get to it." – Autistic female, early 50 s

"I think definitely as you get older [...] you wander upstairs, and you think 'what am I here for?'. Then you go back downstairs, and you realise what it was... but it's not disturbing at all. I don't sit and worry about it [...] I think you accept it as a part of getting older." – Non-autistic male, mid-70s.

However, a minority of the non-autistic group (n = 4) commented that they felt their cognitive abilities had not considerably changed as they aged, although minor forgetfulness was still common. This lack of change was not mentioned by any of the autistic participants.

"Not much has changed cognitively, and I don't have any major memory issues. I do sometimes forget small things, but it's not disruptive." – Non-autistic female, early-80s.

Subtheme 4 – Receiving an autism diagnosis. Several autistic participants noted that the process of identifying as autistic, and subsequently receiving an autism diagnosis, helped with their quality of life and wellbeing, and receiving better support for their health.

"It's been a journey of self-discovery, but the 'label' has opened more doors than it has closed. I feel far better supported with my health now I can put my finger on it.' – Autistic woman, mid 50 s

Some autistic participants also noted that it helped them 'make sense' of their past experiences

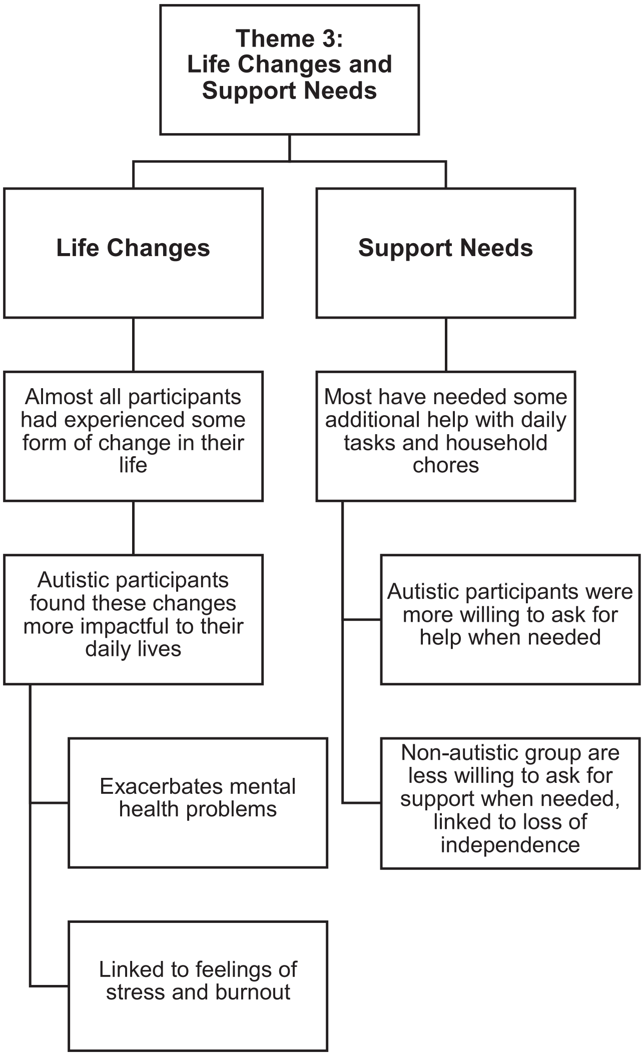

Fig. 3. Life Changes and Support Needs thematic map.

"The diagnosis gave me a strong sense of who I am. That I'm not broken, I don't need fixing. This is how I'm meant to be. It's how my neurology works. That has given me so much more certainty and an ability to draw boundaries around what I will and won't accept." – Autistic woman, late 50 s.

One participant also noted that they felt that they had an outlook on life that was something uniquely experienced by autistic people. They also noted that, despite experiencing highs and lows, they were joyful and enthusiastic about life.

"I feel I still have a joy and enthusiasm for life that I think a lot of neurotypical people don't seem to have. I think with being autistic you have bigger lows, but higher highs as well." – Autistic woman, early 60 s.

3.1. Theme 3: Life changes and support needs

Once again, several similarities and some differences between the autistic and non-autistic groups were found in what participants said about how life changes and their support needs impact their quality of life. See Fig. 3 for Life Changes and Support Needs thematic map.

Subtheme 1 – Life Changes. While similarities in life events and transitions were common (e.g., experiencing bereavement, retirement), some of the impacts of these differed between the groups. Almost every autistic and non-autistic participant expressed that they had experienced positive and negative change throughout their lives. However, autistic participants often reported that any life change that impacted their general daily routine resulted in an exacerbation of pre-existing mental health problems. They also said that change often resulted in increased stress levels. Some autistic participants felt this contributed to the experience of burnout. Additionally, some autistic participants mentioned that parents had been a stabilising presence throughout their lives, with very detrimental impact when a parent died. See Fig. 3 for Life Changes and Support Needs thematic map.

"I don't really know [how well I cope with change] I'm being honest. Things tend to happen, but not sure how good or bad I actually cope with it. I really dislike change." – Autistic male, late 70 s.

"[A parent] controlled my life so much it stopped me breaking down. Straight after [they] died, I had burnout and needed hospitalisation." – Autistic female, mid-60s.

Subtheme 2 – Support Needs. Similarities were evident in the common need for support, but the two groups had a different view on asking for the help they needed. Many autistic and non-autistic participants over the age of 60 mentioned they have needed some

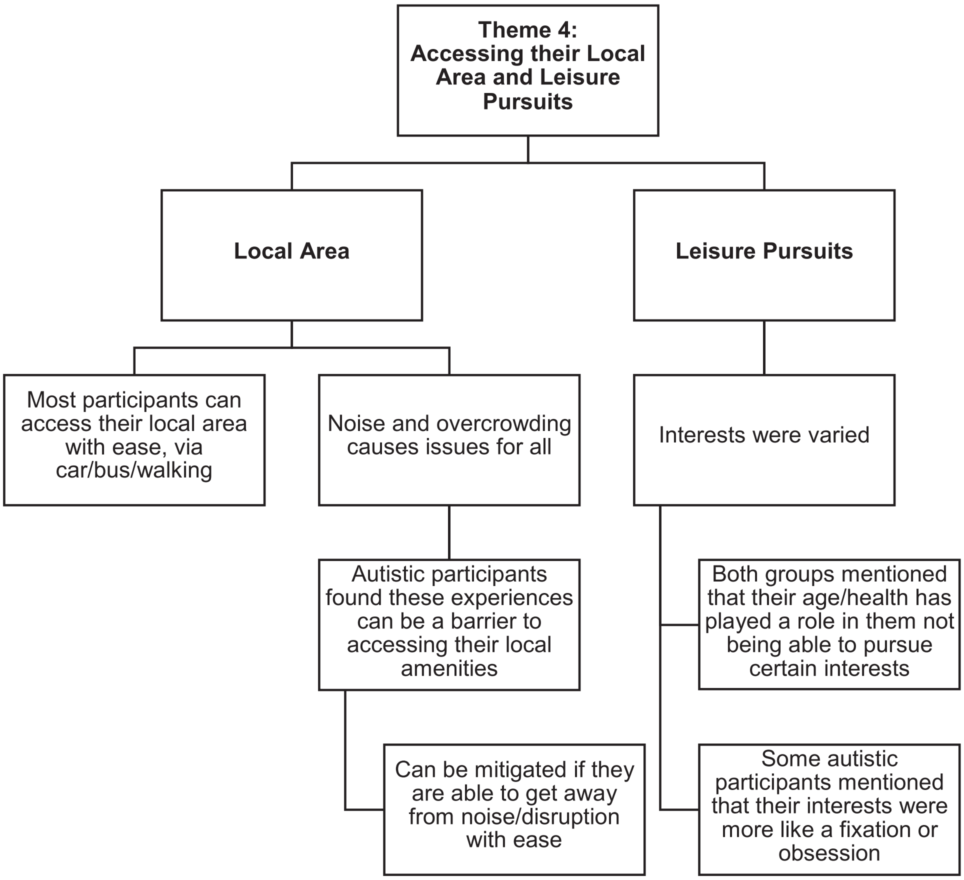

Fig. 4. Accessing their Local Area and Leisure Pursuits thematic map.

form of additional support as they have got older from their spouse, family members, friends, or from a more formalised support person (e.g., a support worker). This varied from help around the house, to assistance with shopping, organising the payment of bills, to being assisted with larger issues like health maintenance or planning for later life. However, a key difference between the groups was the willingness to ask others for help. Several non-autistic participants were often reluctant to ask for help and support that they needed, as they felt it reflected a loss of their independence. The autistic participants did not express this reluctance.

"I do everything else myself. … People say I shouldn't, but I want to. I can do it myself; you know?" – Non-autistic male, mid-70s.

"I've given myself permission to [ask for the help] I need, I suppose. Maybe that's an age thing, enough self-confidence and experience to not worry about what others might think." – Autistic female, early 70 s

"The kids do help out with the shopping, but I'd say I'm very independent." – Non-autistic male, early 60 s.

3.2. *Theme 4: Accessing their local area and leisure pursuits*

Several similarities and some differences between the autistic and non-autistic groups were found in what was said about accessing their local area, their sensory experiences, and what they like to do as leisure pursuits. See Fig. 4 for Accessing their Local Area and Leisure Pursuits thematic map.

Subtheme 1 – Accessing their local area. Again, several similarities and differences were found in how the groups accessed their local areas and whether they experienced any sensory barriers to doing so. Similarities were found in the ways in which participants travelled around their local area, with many travelling by car, bus, or on foot. Several people mentioned that they had free bus passes, which they used frequently.

"I have my bus pass. It's a fairly good service so I am happy with that. And I do like to walk. I'm not as quick as I used to be but it's good exercise." – Autistic female, mid-70s.

Another similarity was that participants from both groups felt that intrusive noise (e.g., high traffic roads, busy bus routes, supermarket noises) had a negative impact on their quality of life, particularly when they could not get away from the source of the noise. While some non-autistic participants felt more bothered by the external noise as they have got older, many autistic participants expressed that this sensitivity is something they have experienced for their whole lives. Most autistic participants also identified that busy/crowded areas and bright supermarket lighting overstimulated their senses, creating barriers to them accessing their local amenities, but some non-autistic people also shared these experiences.

"I notice a lot of small noises, which become irritating, I tend to avoid the school rush." – Autistic female, mid-70s.

"All those things [noise, crowding] narrow down what I can do, where I can go, or at least limit how long I can do a particular thing for." – Autistic female, late 50 s.

"I'm not very good with high pitch [noises]. I don't like noisy shops, especially the music. And I can't be in crowds or shut in anywhere." – Non-autistic woman, late 50 s.

Subtheme 2 – Leisure pursuits. Again, both similarities and differences emerged in what autistic and non-autistic participants said about whether their hobbies and interests have changed with age, and the influence on their quality of life. Autistic and non-autistic groups had a broad range of interests, such as making and appreciating art, reading, writing, cooking, crafting, gardening, and learning. A small number of autistic participants referred to their hobbies and interests as fixations or obsessions, while no non-autistic participants did. Several people from both groups expressed that their age and health has limited their access to certain hobbies. Furthermore, a small number of autistic participants were engaged in 'autism-related causes', such as consulting on research or being involved in their local council as an autism specialist advisor.

"I tend to dabble a lot with craft things, and bread making. I read a lot and spend a lot of time online, going down rabbit holes as I call it. I love learning about things and understanding the details of any given thing that interests me." – Autistic female, mid-70s.

4. Discussion

Using rich qualitative semi-structured interview data and standardised questionnaire data, this study documents the similarities and differences in the factors that influence quality of life for middle-aged and older autistic and non-autistic adults. From the qualitative data, four main themes were identified to be key factors that influence quality of life; the first related to social life (including the importance of family and friendships), the second focused on health (including sleep and cognitive changes) and identity, the third explored support needs, and the fourth concerned their local environment and their leisure pursuits. Overall, the middle-aged and older autistic and non-autistic adults had many shared experiences, but there were nuanced differences – particularly experienced by the autistic participants – that appear to play an important role in their quality of life. Some of these differences were evident in both interview and questionnaire data, for example, 1) the high rates of mental health problems that they experienced. However, other differences, such as, 2) difficulties with finding social opportunities that fit the individuals' needs, and 3) having appropriate support during transition phases of their lives were identified through the interview responses. These three broad areas of difference could be targeted by interventions to improve the quality of life for autistic people.

In the first theme, describing the importance of family and friendships, the autistic participants (like their non-autistic comparisons) noted that their relationships were an important source of companionship and support (a finding similar to Viner at al., 2024). However, the autistic participants placed emphasis on how their relationships could be both a positive and a negative, particularly when there is a mismatch in the desired intensity of the relationship and that they felt responsible for their relative's wellbeing. These negative aspects could be linked to the 'double empathy problem' (Milton, 2012), where holding divergent viewpoints can result in a breakdown in mutual understanding, e.g., the autistic participant enjoys solitary activities while their (often non-autistic) family member enjoys group activities, resulting in a mismatch of wants. Furthermore, as middle-aged people often form a 'sandwich generation', they often have caring responsibilities for their ageing parents and their own children, resulting in additional life pressures and responsibilities. While this has yet to be studied specifically in autistic populations, it could be particularly challenging for autistic people due to high rates of mental health and other support needs.

For differences in friendships, the autistic participants also often noted that, since beginning their autism diagnosis journey, they had joined autism-specific community groups. These groups provided them with an additional source of companionship and offered the opportunity for self-learning and a safe space to ask questions. Creating social networks and connections with other autistic people for self-discovery has previously been described as part of a 'group of fellow travellers who understand' (Crompton et al., 2022). As a later-in-life autism diagnosis can often lead to a broad range of life changes and recontextualizations of previous events (Hickey et al., 2018), fostering relationships with other likeminded autistic people can be beneficial to quality of life and wellbeing (Charlton et al., 2022), particularly as people enter older age and may be more susceptible to social isolation and loneliness (Stewart et al., 2024).

In the second theme, describing health and identity, the autistic participants (like their non-autistic peers) noted that they have experienced a wide range of health, sleep and cognitive changes with age. For health, most participants noted they currently had some health problems, however, the autistic participants noted that they have had health problems throughout their entire lives. Furthermore, mental health problems were often discussed by the autistic participants, while the non-autistic participants mostly discussed physical conditions. Mental health problems have been commonly identified as being experienced at higher rates in autistic populations across their lifespan, including older age (Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Lever & Geurts, 2016), which in turn impacts their QoL (Ayres et al., 2017; Charlton et al., 2022; Mason et al., 2018; Mason, Mackintosh, et al., 2019). The qualitative findings of this study further contextualise the impact of mental health on QoL in autistic populations in midlife and older age. Furthermore, these findings highlight the importance of supporting autistic people with their mental health, addressing any unmet healthcare needs.

Further to the influence of health in the second theme, an autism-specific influence on QoL centred around receiving their Autism diagnosis and the impact of this on their identity. Most of the autistic participants noted that they felt receiving their Autism diagnosis was beneficial to their wellbeing and helped them understand themselves better. Some participants noted that the discovery of their Autism gave them a unique joy that only autistic people experience, which one autistic participant described as 'bigger lows, but higher highs'. Previous studies (e.g., Hickey et al., 2018; Kiehl et al., 2024; Leedham et al., 2020; Viner et al., 2024) have discussed the impact of receiving an Autism diagnosis later in life, particularly in relation to recontextualising life experiences and impacts on sense of self and identity, as well as the ability to access support for healthcare needs.

In the third theme, describing life changes and support needs, the autistic participants (like their non-autistic comparisons) noted a range of experiences throughout their lives (e.g., bereavement, divorce) that had impacted their QoL, and that their support needs had changed with age. For life changes, the autistic participants did note that these changes often had a substantial impact on their general functioning, exacerbating their mental health problems, and linked to periods of stress and burnout. Raymaker et al. (2020) describe the experience of burnout in autistic populations as the manifestation of chronic exhaustion, loss of skill, and reduced tolerance to stimuli after a period of stress. Burnout can vary in duration and severity and has been associated with having a negative impact on health, capacity for independent living, and quality of life.

For support needs, the autistic group reported that they are often aware of their needs and are willing to reach out to others for help and support when needed, regardless of how that is viewed by others. Conversely, the non-autistic participants were more reluctant to ask for help and support and viewed this as a loss of independence. Subjective, rather than objective, social support was identified as an important predictor of QoL by Charlton et al. (2022). This suggests that it is the feeling of being able to ask for help and support that is important and influences QoL. As such, improving the access that autistic people have to general advisory services may be an ideal intervention target for improving autistic people's quality of life as they age. Given that the current study recruited community-dwelling middle-aged and older adults that could engage with a verbal interview, autistic people with intellectual disability and/or who communicate in other ways are not represented within the current sample. As people with intellectual disability often have higher support needs, future research should consider ways to integrate the experiences of autistic people with intellectual disability, for example using methods like photo-voice (Chinn and Balota, 2023).

In the fourth and final theme, describing access their local area and pursuing leisure activities, the autistic and non-autistic participants talked about many similar issues. Most participants were able to access their local area through walking or other means of transport. Both groups also noted that noise and overcrowding detracted from their enjoyment of public spaces, however, the autistic group found this to be something that prevented them from accessing local amenities at certain times, particularly if they were unable to distance themselves from the source of the problem. Some autistic participants noted that their sensory sensitivities had increased with age, which created further barriers to accessing local amenities. Sensory processing differences are common in autistic populations, particularly hypersensitivity to noise (Hazen et al., 2014). However, few studies have specifically examined sensory problems in older age. Chen et al. (2024) noted that sensory processing problems are found to continue into midlife and older age in autistic populations and are associated with symptoms of poor mental health. As such, supporting autistic people with their sensory experiences continues to be important later in life, and may have widespread impact on inclusion and involvement in local communities. Due to the far-reaching impact of sensory difficulties, it is important that future research considers sensory processing differences, and the influence of person-environment fit when considering mental health and quality of life in autistic populations.

For leisure pursuits, both groups expressed interests in a wide range of hobbies, including solitary pursuits and group activities. Both groups felt that their health sometimes impacted their ability to pursue their hobbies. A key difference between the autistic and non-autistic group was that some autistic participants described that they sometimes feel that their interests become fixations (e.g., exploring topics online in very fine detail as a special interest), however, this was not viewed as being a negative or impactful to their enjoyment. While being able to engage in special interests has been associated with higher subjective wellbeing in autistic populations, high intensity engagement has been found to be detrimental to their wellbeing (Grove et al., 2018). This highlights that engagement in hobbies and interests can be an important influence on quality of life, but the intensity of this may be an important consideration for autistic people when planning their leisure time.

4.1. Strengths and limitations

A key strength of this study is that data was collected from semi-structured interviews involving a demographically varied population of autistic and non-autistic adults in midlife and older age, including those from residential communities who were not internet users. Additionally, the interview topics and prompts used in this study, which were developed through a series of PPI consultations with autistic people, encouraged the participants to reflect on a broad range of aspects of their lives and to share their experiences in their own words. This provided rich qualitative data that contextualises the lived experiences of the participants.

However, it is important to note limitations of this study. First, this study was advertised through research networks, social media, older adult independent-living residential communities, and community centres in London and southeast England. While efforts were made to diversify recruitment, our study only included autistic people who received an autism diagnosis in adulthood, meaning that we are still unlikely to have recruited participants who are representative of autistic people who have longstanding autism diagnoses from childhood or those with intellectual impairments or higher support needs; further research involving these groups is needed. Additionally, while efforts were made to balance the gender ratio in the current study, more women/females participated than men/males in both autistic and non-autistic groups. Given that men/males are more often diagnosed with autism (approx. 3:1 ratio; Loomes et al., 2017), the current study may be over-representing the experiences of autistic women/females rather than autistic men/males. Despite this, no clear gender differences emerged in the themes identified in this study, suggesting similar factors influence quality of life for middle-aged and older people, regardless of sex or gender. Previous studies have found that older adults who engage in research typically are physical well and mentally able, which may impact generalisability of findings (Golomb et al., 2012). Second, we did not collect specific data related to socio-economic status or financial security, which may be an influential factor in quality of life in older age. While no participant mentioned financial hardship in the interview, it is a topic that requires further attention. As many autistic people are unemployed or unable to work due to health (including in the current study), they may experience financial hardship when retiring (Davies et al., 2024) and in later life. It is important that studies take financial stability into consideration in the future when exploring quality of life in midlife and older age. Finally, the coding and development of themes were conducted by the study team, who are all non-autistic (although some have other forms of neurodivergence). Involving autistic people in the coding may have resulted in different themes being developed.

4.2. Conclusion

This qualitative study identifies four themes that highlight both the similarities and differences in the factors that influence quality of life for middle-aged and older autistic and non-autistic adults. The autistic participants often expressed subtle differences in their lived experiences, particularly in relation to their mental health, social support needs, and difficulties with change. These differences may present possible targets for intervention to improve quality of life for middle-aged and older autistic adults. For example, mental health support could be tailored towards their needs as older autistic people or interventions like social prescribing could be adapted to be more appropriate for autistic people who are lonely and socially isolated. As support needs often change with age, the lived experiences of middle-aged and older autistic adults should be considered when creating future support services tailored towards this large, under-studied, and under-served population.

Author contributions

Authors RAC, FH and GRS conceived the current study. DF, DH and GRS designed the online survey and materials. DF, DH and GRS conducted interviews. DF and DH coded transcripts, with GRS providing inter-rater feedback and calibration. All authors finalised thematic structure of coding. GRS wrote the manuscript, with DF, DH, RAC and FH reviewing and editing drafts. All authors have read and approved the final manuscript.

CRediT authorship contribution statement

Hershman David: Data curation, Formal analysis, Writing – review & editing. **Francis Dayna:** Data curation, Formal analysis, Writing – review & editing. **Stewart Gavin R:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Software, Supervision, Validation, Visualization, Writing – original draft. **Happé Francesca:** Conceptualization, Data curation, Methodology, Supervision, Writing – review & editing. **Charlton Rebecca A:** Conceptualization, Data curation, Methodology, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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In this manuscript, we opt to use identify first language (i.e., autistic people) over person-first (e.g., people with autism) or neutral language (e.g., people on the autism spectrum) - while recognising that language preferences vary. This choice was made through consultation with our autistic colleagues, steering groups, and through preferences expressed by autistic people in wide-scale surveys (e.g., Keating et al., 2023).

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.reia.2025.202533.

Data availability

The authors do not have permission to share data.

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