“I’m not mad, bad, and dangerous … simply wired differently”: Exploring factors contributing to good quality of life with autistic women

Document Version
Submitted manuscript

Link to publication record in Manchester Research Explorer

Citation for published version (APA):
Paricos, A., Sturrock, A., Twomey, K., & Leadbitter, K. (in press). “I’m not mad, bad, and dangerous … simply wired differently”: Exploring factors contributing to good quality of life with autistic women. *Research in Autism Spectrum Disorders*.

Published in:
Research in Autism Spectrum Disorders

"I'm not mad, bad, and dangerous … simply wired differently": Exploring factors contributing to good quality of life with autistic women

Arianna Paricos[1] & Dr Alexandra Sturrock[2]* (co-first authors)
Dr Katherine Twomey[2]
Dr Kathy Leadbitter[1]

[1] Division of Psychology & Mental Health & [2] Division of Psychology, Communication & Human Neuroscience at The University of Manchester

Author note

*Correspondence concerning this article should be addressed to:
alexandra.sturrock@manchester.ac.uk
Division of Psychology, Communication & Human Neuroscience,
The University of Manchester, Manchester, M13 9PL

Acknowledgements

We thank the Autism@Manchester expert-by-experience group for their valuable input in the study design and materials and for the positive response to the study. We also thank the interviewed autistic women for their participation in this project.

Declaration of Conflicting Interest

The Authors declare that there is no conflict of interest.

Acknowledgment of funding

This work was supported by the ESRC International Centre for Language and Communicative Development (LuCiD) [ES/L008955/1, ES/S007113/1]. KL also acknowledges funding from the National Institute for Health and Care Research Health Technology Assessment Board (Ref: 17/80/09).

Abstract

Background: There is increasing recognition of under-representation of autistic women in the academic literature and the impact of this on understanding, diagnosis, and support. Previous research has suggested that autistic women have poorer quality of life (QoL) than the general population. However, these findings have been established through use of QoL measures based on non-autistic norms and priorities.

Methods: This qualitative study used bottom-up, reflexive thematic analysis methods to explore how ten autistic women defined good QoL, and the factors identified as key to achieving this, using individual semi-structured interviews.

Results: Findings indicate four main themes that represent routes to good QoL: *positive sense of self; feeling supported; autonomy; inclusion.* Participants noted that being autistic itself was not a determinant of reduced QoL. Instead, participants' QoL was underpinned by the extent to which participants understood themselves, others understood and accommodated their needs, and the person-environment fit.

Conclusions: The findings of this study align with a positive approach to neurological difference and have implications for diagnosis, post-diagnostic support and applications of current QoL measures for autistic women.

Keywords

Autism, quality of life, qualitative, women, neurodiversity

“I’m not mad, bad, and dangerous … simply wired differently”: Exploring factors contributing to good quality of life with autistic women

Introduction

Autistic women and girls: a distinct group

Autistic women and girls have been found, at group level, to manifest a distinct phenotype when compared to autistic men and boys (Lai et al., 2015). Core diagnostic features, such as areas of intense interests (Allely, 2019), levels of social motivation (Sedgwick et al., 2019) and social communication (Sturrock et al., 2019a), have all shown sex/gender-distinct features. It is likely that differences in these observable behaviours have contributed to the known disparity in autism diagnosis between males and females (3:1; Loomes et al., 2017) and later age of diagnosis (Rutherford et al, 2016). Lack of accurate diagnosis is a barrier to accessing appropriate clinical services (Kanfiszer et al., 2017) and forestalls the process of self-validation and autistic peer-engagement associated with better emotional well-being (Leedham et al., 2020). Further, autistic women are more likely to camouflage their autistic traits in social situations compared to men (Hull et al., 2017). This decreases the identification of autism (Bargiela et al., 2016). It can also bring additional implications for wellbeing: while particular skills in camouflaging may contribute to ‘passing’ as non-autistic and result in certain levels of attainment, the pressure of doing so can have exponential costs for the wellbeing of the individual (Cage et al., 2018).

While the profile of autistic women and girls can look different to autistic males, this group is also distinct to non-autistic females, for example, in terms of friendship quality (Head et al., 2014) and social communication (Sturrock et al., 2019a/b). Heterogeneity is a defining characteristic in autism (Lombardo, et al., 2019), and variation between individual women and girls is anticipated. However, there exists broad commonalities in terms of autistic presentation, barriers to diagnosis, social motivation, ability to mask difficulties and implications of all the above on mental health. For these reasons, it is likely that the group may offer collective insight into describing and defining their hopes, ideals, apprehensions and ambitions (i.e., Quality of Life). These commonalities may be informative when developing targeted support to the group and establishing future research questions.

Quality of Life measurement for autistic groups

Quality of life (QoL) refers to the standards of well-being, happiness or comfort experienced by an individual or group. Established measures, such as the WHOQOL-BREF (WHOQOL Group, 1998), covering domains of physical health, psychological health, social relationships, and environment, have consistently demonstrated poorer QoL for autistic individuals (Ayres et al., 2018). However, while both self-report and proxy (parent/carer) respondents estimate autistic individuals' QoL to be lower than non-autistic peers, proxy reporting typically yields poorer scores and seemingly over-estimates low QoL for autistic individuals (van Heijst & Geurts, 2015). This may contribute to mis-interpretation of the autistic experience (Kim, 2019). For example, Hong et al. (2016) explored both the proxy and self-reported scores of QoL for autistic individuals, and found discrepancies in the social relationship domain. This exposes the distinct possibility that a non-autistic individual might view an autistic person's relationships as less fulfilling than the individual themselves, based on normative expectations.

Even when autistic individuals self-report QoL, there is concern that traditional measures reflect non-autistic priorities and aspirations (Ayres et al., 2018), and this could contribute to the lower outcomes reported in the literature. Research with autistic men has demonstrated how alternative priorities, such as focus on a special interest can improve outcomes in employment, aligned with increased motivation and passion (Webster & Garvis, 2020). In an attempt to reflect different priorities, McConachie et al. (2018) collaborated with autistic people to add nine questions to the WHOQOL-BREF for an Autism Specific QoL measure (AsQoL). Although this measure had some advantages in positively recognising autistic difference, a psychometric evaluation suggested that wording and scoring of the AsQoL generated lower scores for autistic women compared to men, which was not reflective of their actual QoL (Williams & Gotham, 2021).

Autistic women, like their non-autistic counterparts (Orfila et al., 2006), typically score less well than men on QoL measures (Kamio et al., 2013; Graham-Holmes et al., 2020). Factors attributable to the female experience more generally, such as greater likelihood of precarious and temporary employment (Menendez-Espina et al., 2020) may coalesce with those more specific to the autistic woman's experience (e.g., coming to terms with later-age diagnosis, lack of access to dedicated services and camouflaging autistic features in work or social spheres; Cage et al., 2018; Hull et al., 2017; Leedham et al., 2020). In fact, intersecting demographic factors, such as being female and part of a minoritised group, have been found to exert an exponentially adverse effect on QoL (Washington & Randall, 2022; Saxe, 2017). Poorer outcomes according to sex-gender are most pronounced for autistic adults, but not replicated with autistic children (Kuhltham et al., 2010) or the elderly (Totsika et al., 2010). Although it is unclear why this might be, autistic women may be a particularly important group to consult with, in order to explore contributing factors to their QoL.

Exploring factors contributing to good quality of life

Understanding factors contributing to QoL for autistic women and girls has been identified as a research priority, which can contribute to much needed service development (Halliday et al., 2015). As QoL is individually and internally constructed, first-hand perspectives, rather than second-hand evaluations of externalised 'behaviours', are critical to our understanding. Additionally, by asking open questions on QoL themes (rather than collecting responses to closed questions in a survey format), we can shift away from non-autistic assumptions and biases in order to explore what autistic people themselves consider is (and is not) important in achieving good QoL. As some studies have shown that autistic women and girls may have advantages in self-awareness compared to autistic males (Lai et al., 2011; Sturrock et al., 2019b) these methods may offer a particularly advantageous opportunity when exploring the autistic experience.

A positive psychology framework, consistent with the neurodiversity paradigm, may be an appropriate lens through which to explore these phenomena. Historically, autistic traits have been pathologised, by being researched and treated in the context of a medical disorder (Robertson, 2010). However, the 'deficit' model is strongly contested, with detractors arguing that neurological, cognitive and behavioural variation is a natural and valuable part of human diversity (Kapp, 2020). Aligned with this, taking a positive psychology standpoint means it is possible to prioritise an individual's strengths (Peterson, 2008), namely, thoughts, feelings, experiences and influences which contribute to a positive state of being. In this way, focus moves away from the assumption that suffering is a certain consequence of autism (Kapp, 2020). The neurodiversity framework has also placed emphasis on the person-environment fit, for example promoting the benefits of inclusive adaptations (Krzeminska & Hawse, 2020). Therefore, by focusing on positive life experiences, it may be possible to uncover improvements in QoL attributable to environmental adjustments.

This study is focused on autistic women, Assigned Female at Birth (AFAB). We recognise that this is an arguably narrow definition of 'women' and that many autistic people do not identify their gender with their sex assigned at birth. Indeed, binary gender identities are less common in the autistic versus non-autistic population (Warrier et al., 2020). While there are likely to be many areas of shared experience between gender-diverse individuals and autistic women AFAB (e.g., complex pathways to diagnosis and limited access to appropriate services: Strauss et al., 2021), people with minoritised and marginalised gender identities can face prejudice and discrimination over and above those experienced by women AFAB (Black et al., 2023). For this reason, we chose to focus this study on women AFAB but fully acknowledge the need for further research into QoL of people of all genders.

In summary, to fully understand the factors, which contribute to good QoL in autistic women, it is important that we explore the perspectives of individuals from this distinct group. Positive psychology approaches can focus data collection on individuals' strengths, thereby offering a neurodiversity-affirming reflection on their experiences. From this perspective, the current study seeks to address the following gaps in our understanding:

(i) How do autistic women define good QoL?
(ii) What factors described by autistic women are key to achieving good QoL?

Method

This study aimed to reflect the genuine views and experiences of autistic women with respect to their QoL. There are concerns that the autistic experience will be misunderstood or miscommunicated by non-autistic researchers (Milton, 2012) and this may be especially problematic when studying the lived experiences of a minoritised group such as autistic women. To mitigate these types of misinterpretation, an autistic female researcher (KT) was central to all stages of research design, including generating research questions, designing study procedures and analysing data. Additionally, all materials and procedures were reviewed by autism@manchester, expert-by-experience group, in line with best practice in community engagement (NIHR, 2015). Co-production leads to a more authentic representation of participants' accounts (Fletcher-Watson et al., 2018) and can ensure autistic perspectives remain prioritised throughout the research cycle (Nicolaidis et al., 2019).

Recruitment

Study adverts were disseminated through relevant social media (e.g., posts to autism@manchester Facebook page and Twitter account). By carefully explaining this study's focus on women AFAB, advertisements aimed to clearly outline and explain the inclusion criteria at the outset of recruitment and thereby minimise the potential for distress through individuals being later excluded from research for which they believed they were eligible (Austin & Goodman, 2017). Prospective participants contacted the research team, after which they received an information sheet and interview schedule. Participants were asked to confirm they met inclusion criteria. At the start of each interview, eligibility was verified and informed consent obtained.

Participants

Eligibility was determined by the following inclusion criteria: (1) ≥18 years old; (2) autism diagnosis from a certified professional/institution; (3) identifying as a female and AFAB; (4) UK Citizen; (5) fluent English speaker; (6) without an intellectual disability (self-defined). These constraints allowed deep exploration of the specific experiences of the target group, without undue influences from other factors. Importantly, autism diagnosis is known to affect an individual's self-perception and feelings of inclusion within community groups (Crompton et al., 2022). For this reason this study targeted diagnosed (rather than a mixture of diagnosed and self-identifying) autistic interviewees.

Participant recruitment was responsive to the iterative stages of data analysis, that is, it continued until the researchers determined that there was sufficient detail to address the pre-determined research questions. To this end, ten autistic women were recruited before data collection was deemed sufficient. Group characteristics are shown in Table 1.

Table 1 approx. here

Table 1: Participant characteristics shown at group level

Characteristics	Sample	M(*SD*)
Age when interviewed (range in years)	22-64	41.9(*14.75*)
Age at autism diagnosis (range in years)	13-62	37.9(*16.65*)
Number of years since diagnosis (range in years)	0-10	4(*3.53*)
Ethnicity n (%):		
- White British	7(70)	
- White Irish	2(20)	
- Other White	1(10)	
Occupation/employment status n (%):		
- In employment	5(50)	
- Student	2(20)	
- Housewife	1(10)	
- Unemployed	2(20)	
Additional confirmed neurodevelopmental and/or mental health diagnoses n (%):		
- Depression	4(40)	
- Anxiety	3(30)	
- Attention Deficit Hyperactive Disorder	1(10)	
- Anorexia	1(10)	
- Post-Traumatic Stress Disorder	1(10)	
Suspected additional neurodevelopmental and/or mental health conditions – undiagnosed n (%):		
- Attention Deficit Hyperactive Disorder	5(50)	
- Anxiety	2(20)	
- Dyspraxia	2(20)	
- Dyscalculia	1(10)	
Highest level of education n (%):		
- GCSE/equivalent	2(20)	
- A Level/equivalent	2(20)	
- Undergraduate degree/equivalent	1(10)	
- Postgraduate qualification	5(50)	

Procedure

The primary researcher (AP: female AFAB, aged 24 years, White British, non-autistic) conducted interviews using whichever communication method was preferred by the interviewee. Six participants chose on-line video-call, two chose telephone and two chose internet text-exchange. Video-call and telephone interviews ranged from 36 to 71 minutes (*M*=56.13, *SD*=12.02), and text-exchanges were approximately 90 minutes.

During the interview, a semi-structured approach was undertaken, allowing the interviewer flexibility to discuss responses and probe points of interest raised by participants (Bearman, 2019) in response to the schedule (see below). The interviewer made notes, representing their initial interpretation of content.

Due to the potential for eliciting sensitive subject matter, a distress protocol was put in place. The first stage of this protocol was followed in three interviews, specifically, a break was offered due to tearfulness. However, all interviews were resumed and completed within a single session, resulting in ten transcripts.

Following the interview, all participants were debriefed and offered a lay summary of the findings at study completion. There was no financial compensation for participants.

Interview schedule

An interview schedule was developed to address primary research questions. It focused on four key areas of QoL, as previously identified in the WHOQOL-BREF (WHOQOL Group, 1998), specifically, physical health, psychological health, social relationships, and environmental health. Unlike the WHOQOL questionnaire, open questions were devised which could elicit responses on the key areas without pre-empting specific content, for example, ‘What aspects of physical health are important for your QoL?’ Question development was also informed by the existing autism literature. For example, rather than asking about support received from friends (WHOQOL Group, 1998), the interview asked, Q7 ‘What kind of relationships are important to you?’ and Q8 ‘When you need support from other people, are you able to get it?’ By so doing, any preconception about the centrality of friends in support networks was removed and interviewees were able to define this in their own way (Sedgewick et al., 2019). A final draft of the interview schedule was then evaluated by autism@manchester advisory group, who made recommendations on question format and procedure. For the full interview schedule, see Appendix A.

Ethical approval was granted by The University of Manchester, Research Ethics Committee for all stages of recruitment, data collection and analysis.

Data Analysis

The analysis method was inductive and idiographic, focusing on the unique lived experience of each participant, following Braun and Clarke's (2006, 2021) guidance. The process was led by the primary researcher (AP). The rest of the team (all female, AFAB, aged 39-46 years, one autistic, two non-autistic) took part in specific analytic activities.

AP exported text-transcriptions of interviews from the conferencing platform then manually checked transcripts against audio recordings and notes. In the first phase of analysis, all researchers independently became familiar with one transcript by reading, re-reading and documenting initial ideas, then conducting line-by-line analysis and independently generating codes. The first team meeting, led by AP, encouraged reflexive thinking on this process, to ensure alternative interpretations were explored by the team and reflective thinking was undertaken (Braun & Clarke, 2021). Differences in interpretation were resolved through debate and team consensus, taking into account the notes taken by AP during the interviews. At the close of the initial meeting, a provisional coding scheme was produced. This was applied to a second transcript by all researchers, during the next round of independent reading and coding. In a second meeting, the team reflected on the existing codes in light of the second transcript. They also began to cluster related codes into a provisional set of hierarchically organised main and subordinate themes. The process of refining the codes and thematic framework continued in a third phase of independent analysis. At this point team discussion reflected on whether the research questions were well represented by the data and made minor adjustments to the existing thematic framework to ensure these findings were transparent. In a final phase, AP continued independent analysis of a further seven successive transcripts. Minor adjustments to the thematic framework were undertaken in consultation with the team via email. At this point, the team were satisfied that the data successfully answered the research questions and offered sufficiently rich data to corroborate the thematic analysis. The final set of themes was tabulated (Appendix B). The remainder of the research team reviewed the resulting thematic framework and supporting quotations, and agreed that it was a good representation of the data.

Results

Four main themes and 17 subordinate themes were generated (Table 2) providing rich data to answer our research questions. The four main themes were identified in all ten transcripts. These were: positive sense of self, feeling supported, autonomy, and inclusion. Figures provide detail on the composition of all main and subordinate themes. Themes directly addressing research questions are discussed in the text with supporting quotes. Pseudonyms are used throughout.

Table 2 approx. here

Table 2: Main and Subordinate Themes from 10 autistic women answering interview questions on achieving self-reported good quality of life

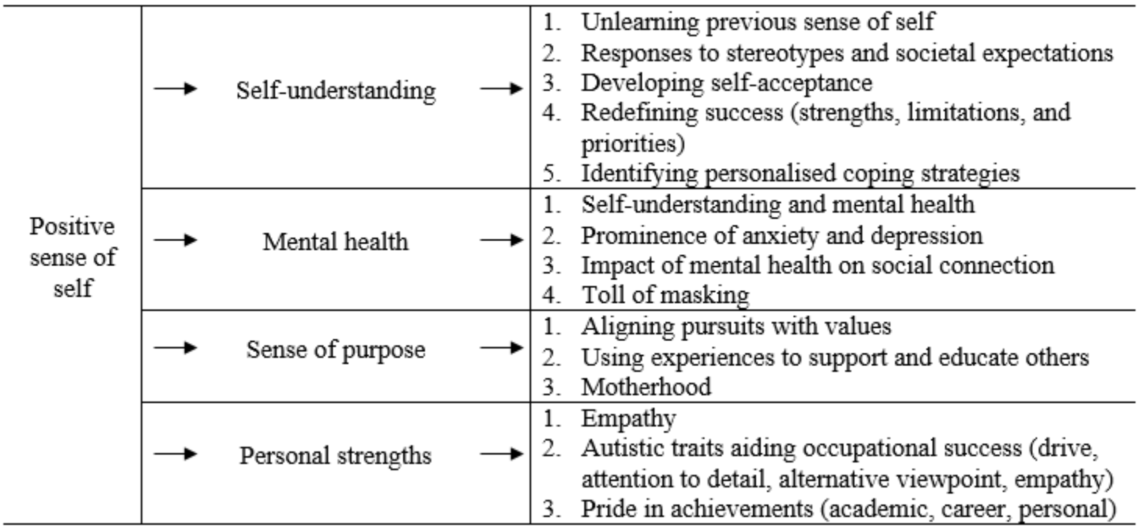
1. Positive sense of self	2. Feeling supported	3. Autonomy	4. Inclusion
a. Self-understanding	a. Autistic community	a. Creating the ideal environment	a. Non-autistic understanding of autistic experience
b. Mental health	b. Family	b. Physical health	b. Communicating needs
c. Sense of purpose	c. Understanding from professionals	c. Self-accommodations	c. Accommodations
d. Personal strengths	d. Romantic relationships	d. Special interests	d. Accessibility of services
	e. Friendships		

Main theme 1: positive sense of self

All participants described how a positive sense of self aligns with QoL. Figure 1 denotes the themes alongside data-driven codes.

Figure 1: Positive Sense of Self: Main Theme, Subordinate Themes, and Codes

Figure 1: Positive Sense of Self: Main Theme, Subordinate Themes, and Codes



Positive sense of self	→ Self-understanding →	1. Unlearning previous sense of self 2. Responses to stereotypes and societal expectations 3. Developing self-acceptance 4. Redefining success (strengths, limitations, and priorities) 5. Identifying personalised coping strategies
	→ Mental health →	1. Self-understanding and mental health 2. Prominence of anxiety and depression 3. Impact of mental health on social connection 4. Toll of masking
	→ Sense of purpose →	1. Aligning pursuits with values 2. Using experiences to support and educate others 3. Motherhood
	→ Personal strengths →	1. Empathy 2. Autistic traits aiding occupational success (drive, attention to detail, alternative viewpoint, empathy) 3. Pride in achievements (academic, career, personal)

Many described diagnosis as improving self-understanding (1.a). This was partly due to diagnosis legitimatising difficulties and allowing a shift from self-blame towards positive self-acceptance and thereby better well-being.

"There are a lot of things that…I was blaming myself for, but then I realised there's an actual reason behind why I don't understand certain things…so that was just like a massive weight off my shoulders" (Chloe)

However, some participants acknowledged that achieving this shift was challenging.

"*Self-acceptance is definitely a continuing path. You think you've got there, and then you're like, oh no...I want to change this about myself"* (Bethany)

The journey to self-acceptance was often seen as non-linear, and reliant on the individual's ability to self-reflect and desire for personal growth.

Self-understanding and diagnosis were also discussed in relation to mental health (1.b). Several participants described how, prior to diagnosis, they had experienced mental health difficulties without understanding why.

"Prior to [diagnosis] there would be so many outbursts and silences where I just couldn't say a word…I now know these were shutdowns and meltdowns" (Jackie)

Diagnosis supported self-understanding and was associated with recognising the source of mental health difficulties.

"I realized that I'm not mad, bad and dangerous…simply wired differently" (Freya)

It was also associated with getting appropriate support that met both the individual's mental health and neurotype needs.

"Other therapists have given…more general advice, [with the autism specialist] it's more targeted to the way that I think" (Chloe)

A sense of purpose (1.c) was commonly reported in relation to developing a positive sense of self. For many 'helping others' was key to this; for example, Lisa compared her previous work in a sales team to her preferred occupations.

"It was just so meaningless…I just had no motivation, like I didn't care if they sold their [items] or anybody else did or if nobody sold any, it just didn't matter to the world. So, yeah, things that make the world a better place I guess, being able to do some of that" (Lisa)

In many cases, personal strengths (1.d) were associated with sense of purpose. Therefore, being good at something and able to enact that, through employment or volunteering, improved participants' sense of self. Interviewees identified drive, attention to detail and having an alternative viewpoint as underpinning their personal strengths. Empathy was also identified and linked to a having a purposeful occupation.

"If I don't have that deep level contact, if I'm not really feeling like I'm…just connecting with people…through my job, helping people…then there's something missing in my life" (Eve)

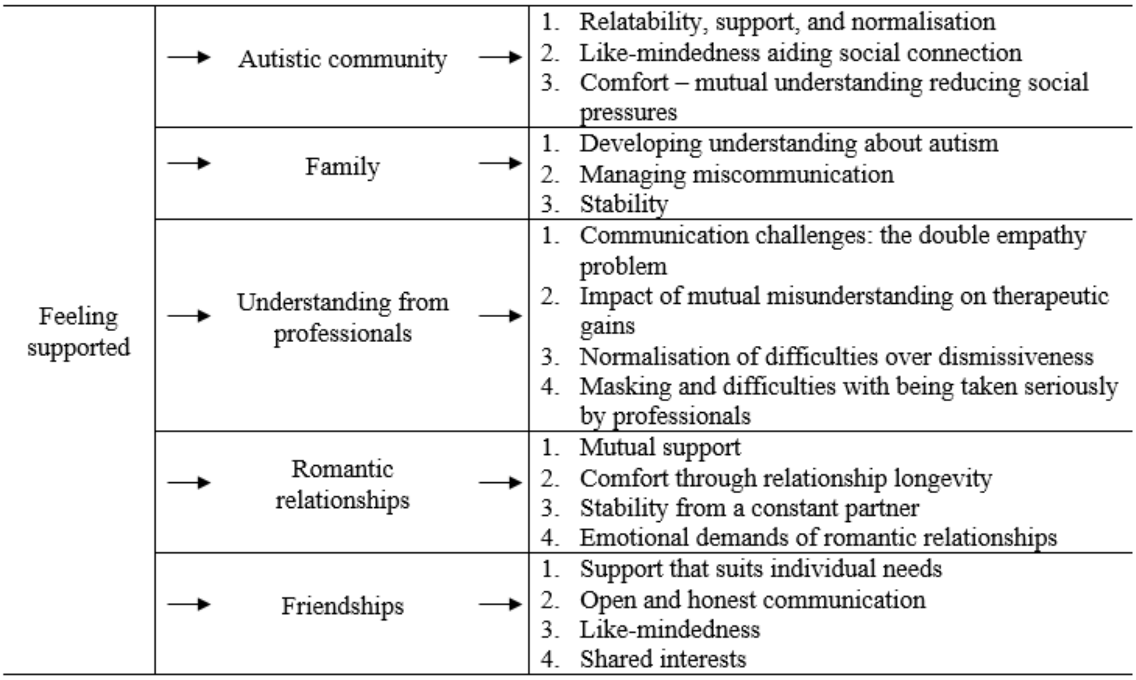
Engagement in autism advocacy and activism also offer a meaningful sense of purpose.

Main theme 2: feeling supported

QoL was improved by feeling supported. This theme was unanimously described by interviewees. Figure 2 highlights themes alongside codes.

Figure 2: Feeling Supported: Main Theme, Subordinate Themes, and Codes

Figure 2: Feeling Supported: Main Theme, Subordinate Themes, and Codes



Feeling supported	→ Autistic community →	1. Relatability, support, and normalisation 2. Like-mindedness aiding social connection 3. Comfort – mutual understanding reducing social pressures
	→ Family →	1. Developing understanding about autism 2. Managing miscommunication 3. Stability
	→ Understanding from professionals →	1. Communication challenges: the double empathy problem 2. Impact of mutual misunderstanding on therapeutic gains 3. Normalisation of difficulties over dismissiveness 4. Masking and difficulties with being taken seriously by professionals
	→ Romantic relationships →	1. Mutual support 2. Comfort through relationship longevity 3. Stability from a constant partner 4. Emotional demands of romantic relationships
	→ Friendships →	1. Support that suits individual needs 2. Open and honest communication 3. Like-mindedness 4. Shared interests

A key source of support discussed in several transcripts was the autistic community (2.a).

"It's like coming home, it's like finding your people, you know, suddenly people think like you do, you're not having to explain things to them" (Grace)

Several participants reiterated how safety and comfort were derived from supportive relationships with like-minded others. However, it was also clear that interviewees valued the effort made by non-autistic people.

In particular, family members (2.b) who embraced the new diagnosis were integral to the individual feeling supported.

"I am so grateful to my family for this, once they knew…my brother in particular, researched it a lot, they listened to me. They listen to what I need" (Vicky)

Where the interviewees' families did not accept or embrace the new diagnosis, individuals felt less supported.

"It's been very sad that they haven't necessarily wanted to support me in the way that I've needed them to, just by trying to understand about neurodivergence and by that token understand me in a different way" (Rachel)

Understanding from professionals (2.c) regarding an individual's autistic or specific needs was seen as critical to participants feeling supported. For example, Lisa described how poor understanding of her communication needs resulted in a breakdown in support from her mental health team.

> *"[They] wouldn't explain to me what the options were. And then I said, 'well if you can't tell me what the options are, then I can't tell you what you can do for me'. So they were like, 'oh, shall we just leave then'. So then they just left"* (Lisa)

This description shows how mutual misunderstandings can occur between autistic and non-autistic individuals within professional interactions. Importantly, however, the negative consequences were more significant for the autistic person due to lack of access to services and impact on well-being.

Interviewees commented on how romantic relationships (2.d) contributed to feeling supported. They were very important to some, for example, Eve described her husband as her *primary* relationship,

> *"We are very much, best friends and do a lot of things together and support each other and help look after our families together"* (Eve)

There was a sense that long-term relationships could improve a person's sense of security and stability (Lisa). They could also offer a space for where it was acceptable to be true to oneself.

> *"I didn't have to pretend to be someone else, I didn't have to be smiley, or chatty…, or make eye contact, or know when to speak and when not to. I could say what I liked"* (Jackie)

However, this was not unanimously agreed upon and some interviewees identified a need to 'be on my own' (Freya).

Friendships (2.e) were universally seen as beneficial to QoL, and were also commonly linked to feeling supported. Friends offered a deep connection with another person, namely, being able to discuss thoughts and feelings and getting through difficult life events. For some, it was the sense that you could be open and honest.

> *"If I get the text that says, 'how are you?'…I can actually say 'I'm feeling bloody awful, this is happening'" (Rachel)*

For others, friendships were based on like-mindedness and/or shared neurodivergence. This could entail recognising each other's support needs

> *"There's also something about both of us being quite careful with our own self-care…I know that if I ring him up and say look, can you listen or can you sort this, if he can't he'll say so, and he knows the same with me."* (Freya)

Equally, sharing joy over specific interests was seen as important to good QoL:

> *"The best thing is talking to another autistic person with the same special interest because you can just talk endlessly about it" (Grace)*

Main theme 3: Autonomy

Having autonomy was integral to better QoL as described by all participants. Figure 3 shows themes and codes.

Figure 3: Autonomy: Main Theme, Subordinate Themes, and Codes

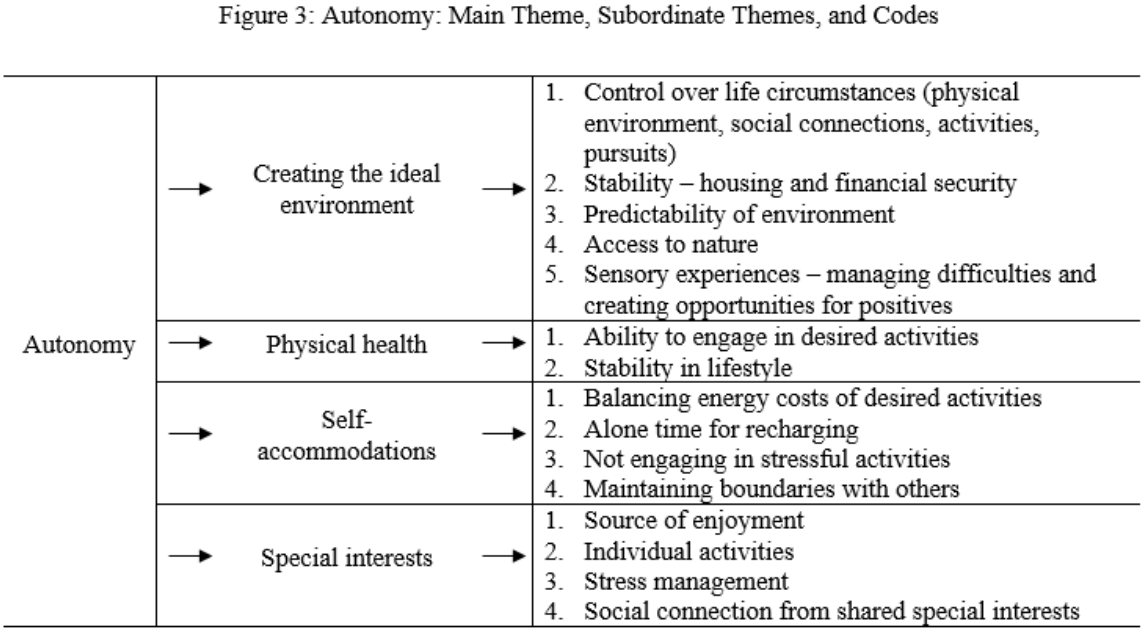


Figure 3: Autonomy: Main Theme, Subordinate Themes, and Codes

Autonomy	→ Creating the ideal environment →	1. Control over life circumstances (physical environment, social connections, activities, pursuits) 2. Stability – housing and financial security 3. Predictability of environment 4. Access to nature 5. Sensory experiences – managing difficulties and creating opportunities for positives
	→ Physical health →	1. Ability to engage in desired activities 2. Stability in lifestyle
	→ Self-accommodations →	1. Balancing energy costs of desired activities 2. Alone time for recharging 3. Not engaging in stressful activities 4. Maintaining boundaries with others
	→ Special interests →	1. Source of enjoyment 2. Individual activities 3. Stress management 4. Social connection from shared special interests

Several participants identified how autonomy interacted with creating the ideal environment (3.a). Freya described how her QoL was improved by cultivating a lifestyle in tune with her preferences.

"Living where I want to, how I want, doing my dream job…having my cats, my harp, my friends...it's something I've created" (Freya)

Autonomy meant individuals could make and enact choices, thereby managing their environment and their own well-being. Home ownership and financial security were strongly associated factors. For example, when asked about things that make her feel good about herself, Vicky stated:

"*Having paid off the mortgage"* (Vicky)

Where housing and financial security were not established, individuals felt less autonomous and less able to manage their environment, which contributed to lower QoL. For example, Lisa discussed the lack of control experienced whilst being in receipt of government benefits.

"The insistence on [having]…reassessments after certain periods…that means that there's no stability in my life. Because I could be going into crisis at any point" (Lisa)

Participants also discussed physical health (3.b) as important for maintaining one's chosen lifestyle.

"I'm quite scared if something happens to me physically because I'm so used to…having the ability to do everything, it would really scare me [to be dependent], because it would be such a change in my life" (Eve)

The ability to enact self-accommodations (3.c) was commonly associated with a strong sense of autonomy. For example, several interviewees described how they pro-actively balanced participation in preferred activities with the associated costs to their energy levels.

"[alone time is] very important, it's the space of it, not having to perform, just to be. It's really important after socialising because it takes a lot of quiet time to get over" (Jackie)

By doing this, individuals could feel in control of their effort expenditure. They could also prioritise time spent engaging in special interests (3.d).

"The beauty of being autistic is that…if we enjoy something, we can really get into it…so I think it's just sort of nice to allow yourself to do that" (Chloe)

The ability to prioritise special interests was associated with autonomy and contributed to feelings of enjoyment and, thereby, QoL.

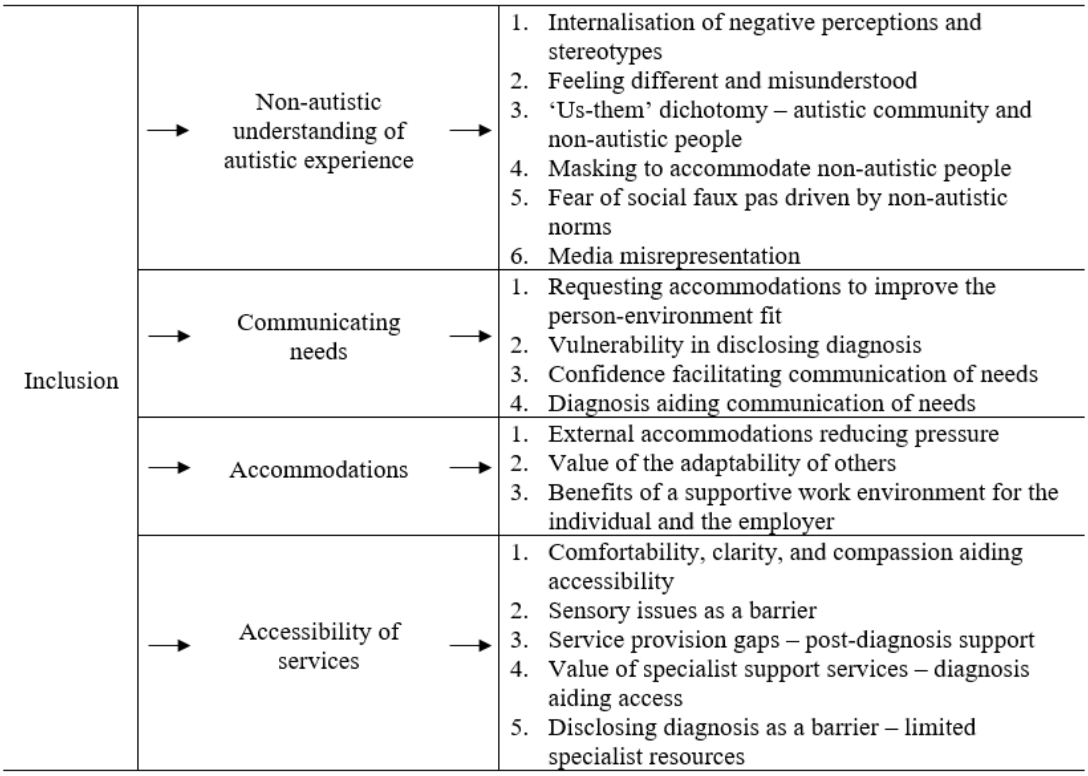
> *"They have a life of their own, if I don't make time for them, they force me to, attention-wise, and that keeps me going, because the enjoyment is elation with a special interest"* (Alice)

Main theme 4: inclusion

All participants discussed how inclusion (or lack of it) influenced their QoL. Figure 4 displays themes and codes.

Figure 4: Inclusion: Main Theme, Subordinate Themes, and Codes

Figure 4: Inclusion: Main Theme, Subordinate Themes, and Codes



Inclusion	→	Non-autistic understanding of autistic experience	→	1. Internalisation of negative perceptions and stereotypes 2. Feeling different and misunderstood 3. 'Us-them' dichotomy – autistic community and non-autistic people 4. Masking to accommodate non-autistic people 5. Fear of social faux pas driven by non-autistic norms 6. Media misrepresentation
	→	Communicating needs	→	1. Requesting accommodations to improve the person-environment fit 2. Vulnerability in disclosing diagnosis 3. Confidence facilitating communication of needs 4. Diagnosis aiding communication of needs
	→	Accommodations	→	1. External accommodations reducing pressure 2. Value of the adaptability of others 3. Benefits of a supportive work environment for the individual and the employer
	→	Accessibility of services	→	1. Comfortability, clarity, and compassion aiding accessibility 2. Sensory issues as a barrier 3. Service provision gaps – post-diagnosis support 4. Value of specialist support services – diagnosis aiding access 5. Disclosing diagnosis as a barrier – limited specialist resources

The subordinate theme, 'non-autistic understanding of autistic experiences' (4.a) was reported as an influential factor contributing to feeling included in social activities or not. Participants reported how difficulties navigating the non-autistic world could lead to feeling like the odd one out.

> *"It feels like I'm a left-handed person in a right-handed person's world"* (Eve)

Negative perceptions and misconceptions about autism were also identified as a barrier to inclusion. Several participants described concerns about disclosing their autism to others for fear of negative judgement.

> *"I don't want them making judgements about what I can do because they've got a stereotype in their head about what an autistic person is"* (Grace)

Effectively communicating needs (4.b) was critical for establishing an inclusive environment. Where this occurred participants described benefits to their QoL.

> *"I said, very nervously, I'm afraid I can't work in an internal room, because of the light, and they said that's fine, we'll just swap you round to a room with natural light"* (Freya)

Where an individual felt enabled or supported to communicate their needs, these could be met successfully. Other individuals, for various reasons, felt dis-enabled or unsupported in making those requests, affecting feelings of inclusion and overall QoL

Pro-active accommodations (4.c) on the part of others were helpful in creating a sense of inclusion. These could reduce feelings of 'pressure' (Chloe), and result in better outcomes for all, for example, in the workplace,

> *"If you're forced to try and work in a way that involves a lot of your weaknesses and doesn't play to your strengths, you're not going to achieve as much. But if you allow someone to work in their strengths, they could be your most outstanding employee" (Eve)*

Interviewees described feelings of acceptance and improved self-worth due to other people's accommodations. Inclusion also contributed to the individual's QoL by interacting with other themes: feeling supported and positive sense of self.

Inclusion relating to medical services (4.d) was also discussed. Some services demonstrated inclusive practices

> *"The people make you feel very at home…They explain everything to you, they give you all the information…they were nice, I think is the main thing"* (Bethany)

However, others did not. Interviewees noted barriers to accessing general practitioner surgeries and hospitals, namely, sensory issues related to noise, crowds and unclear communication of information.

Lack of knowledge about autism or dismissive attitudes towards autistic needs were also noted as barriers to services and this extended to lack of post-diagnostic support. In some cases, the autistic diagnosis perversely reduced access to services,

"I shouldn't have mentioned I was autistic really, because I could have got counselling…they said that they didn't think that their service would be able to support me because I needed a more specialized service" (Bethany)

In contrast, where autism was better understood, support was more appropriate.

"I found like a new therapist who specialises in…autism…and also I found like quite good support through my university, they have a really good disability team" (Chloe)

Overall, variation in inclusion practices contributed to variability in the individual's QoL.

Discussion

This study offers new insight into how autistic women define good quality of life and which factors they consider key to achieving better outcomes. Four main themes were identified from the data: positive sense of self, feeling supported, autonomy, and inclusion. While these themes differ from headings currently existing within established measures of QoL (WHOQOL Group, 1998), there is considerable overlap in terms of the content. For example, both describe the importance of physical and mental health, self-perception, security and financial stability, access to meaningful occupation and leisure activities, independence, autonomy and validations from friends, family and partners. However, the differences are in the details. What this study brings, in particular, is a better understanding of how autistic women prioritise themes relating to QoL, and how they interpret their own success in each area. The findings have significance for any individual offering practical or emotional support to autistic women and those engaged in developing much needed support services.

The first main theme showed positive sense of self as a key factor for good QoL. Like findings from Webster and Garvis (2017), participants indicated that diagnosis enabled improved self-awareness and confidence. Previous research has shown how autistic adults' QoL self-ratings improved in response to interventions encouraging autism awareness and acceptance on the part of the autistic individual (Hesselmark et al., 2014). Therefore, later age of diagnosis (Lai et al., 2015) and subsequently delayed acceptance of the autistic-self may have a significant effect on QoL for autistic women and points to benefits from early diagnosis. This mirrors findings from other clinical groups, where diagnosis provides the individual with self-knowledge, access to strategies and support, ultimately improving QoL (Connell et al., 2012). Positive sense of self-aids autistic women in being active agents in creating their own good QoL through embracing rather than repressing autistic traits. Like autistic men (Webster & Garvis, 2020), identifying personal interests and strengths, such as 'drive' and 'attention to detail', allowed individuals to align their pursuits accordingly. However, unlike previous research into autistic men, women in the current study also *frequently* identified their ability to be empathetic and altruistic as a personal strength, challenging 'lack of empathy' stereotypes often associated with autism (Harmsen, 2019).

The second main theme highlighted feeling supported as a key factor for good QoL. This theme reflects commonly identified predictors of better QoL, in both autistic (Mason et al., 2108) and non-autistic clinical groups (Connell et al., 2012). For autistic women, the autism community itself was identified as a source of support, thus allowing individuals to experience acceptance and mutuality. In previous research, engagement with autistic community groups has been shown to improve self-reported QoL scores (Hesselmark et al., 2014; Garcia-Villamisar et al., 2010). This may be particularly important for autistic women, given the greater perceived pressure to assimilate to social norms in non-autistic groups and greater fatigue associated with this (Cage et al., 2018). Feeling supported was also strongly associated with feelings of acceptance. Families who were perceived to accept and support the autism diagnosis contributed to feelings of better QoL. This phenomenon reflects findings in the wider literature, where positive correlations are found between parental acceptance of chronic childhood conditions, and the child's self-reported QoL (Sairanen et al., 2022). It might also indicate the need for acceptance training aimed at families in line with an autism-affirming stance (Kapp, 2020), to improve QoL for autistic people, through acceptance and affirmation of autistic traits.

Main theme three pointed to autonomy as a key factor for good QoL. Autonomy is a key predictor of QoL for a number of marginalised groups (Brown & Brown, 2009; van Leeuwen et al., 2019). In the current study, autistic women reported high awareness of their needs, interests, and values and self-accommodation of these was associated with good QoL. Autistic women in particular have been shown to develop a distinct and authentic self-identity, transcending autistic and female stereotypes (Mo et al., 2022). Therefore, this theme emphasises the benefit of living authentically aligned to one's views, desires, and needs. However, the ability to enact necessary adaptations to meet the individual's needs was varied, and was often aligned with their financial independence and/or confidence to self-advocate with service providers. Like women more generally, QoL was associated with financial security (Menendez-Espina et al., 2020) but there was great variation between the individuals' capacity to achieve this. Graham-Holmes et al. (2020) found that lower QoL scores for autistic women (compared to men) were in part driven by reduced feelings of self-efficacy, meaning this area might reflect a particular disadvantage for many autistic women. Like autistic men (Webster & Garvis, 2020) there was some satisfaction in raising to challenges and being able to navigate the non-autistic world. However, while the women in this study often noted fatigue and emotional effort associated with self-advocacy, this was not a feature reported by autistic men in the earlier work. It is not clear if this is due to under reporting of emotional burden on the part of the men, or higher rates of internalised emotional impact for the autistic women. Either interpretation might be supported by the literature

(Boyd et al., 2015; Rice et al., 2018). Participants in the current study noted that their ability to partially ‘fit in’ may improve their chances of autonomy, and this may be a particular advantage for them (Sedgewick et al., 2019). However, as previously noted, fitting in can in itself incur personal/emotional costs (Cage et al., 2018). The implications in either case are that autistic individuals should have access to pro-active support to mitigate the negative effects of ‘coping’ in a non-autistic world. Success in autonomy typically entailed feeling able to balance and manage the demands of the non-autistic world by creating a life that allowed space for existing authentically. However, not all participants felt able to achieve this. Supporting individuals to live authentically would be an important step towards improving QoL and reducing the disparity of experience between individuals. Living authentically also represents a priority not well identified in current QoL measures.

Main theme four shows participants defining inclusion as a key factor for good QoL and highlights the importance of the person-environment fit in achieving this. Employment (and/or meaningful occupation) are well-recognised factors contributing to QoL for both autistic individuals (Mason et al., 2018) and other marginalised groups (van Leeuwen et al., 2019). However, the relationship between reasonable adjustments and QoL are less well characterised in the literature. Notably, reasonable adjustments on the part of the employer was not a strongly reported theme identified by autistic men as contributing to personal success (Webster & Garvis, 2020). However, findings in the current study indicate that autistic women value accommodations (which they equated with feeling ‘included’ by others) and this was aligned with better QoL. This reflects previous work which found that accommodations, alongside employer support and understanding, aided autistic people’s functioning and performance at work (Khalifa et al., 2019) and that supportive environments aid self-efficacy and self-defined success for autistic women (Webster & Garvis, 2017). In this way, ‘goodness-of-fit’ between the autistic woman and her environment may underpin QoL and highlights the need for adaptations to non-autistic spaces to encourage inclusion.

The current study has implications for interpreting QoL responses when using existing measures with autistic women. Although main themes from this qualitative investigation are covered to some extent in published measures, the current study suggests that certain facets require more emphasis for this group. For example, in the WHOQOL-BREF (WHOQOL Group, 1998), ‘autonomy’ is mainly explored in relation to the physical environment, while participants in this study also associated success in this domain with opportunities to choose how they spent their time. Equally, the concept of ‘social support’ appears inadequately captured by current QoL measures. Specifically, there is little acknowledgement of the effort required to establish effective support networks, for example, seeking relationships within the autistic community or educating family and friends on neurodiversity. While many themes are resonant for all autistic individuals, this study identified some areas where QoL priorities appeared particular to the autistic women interviewed, for example, improving sense of self through empathic and altruistic pursuits. Additionally, using ‘fitting-in’ strategies to achieve success in employment and access to health services was representative of autistic women’s experience, as was the elevated reporting of emotional implications from doing so. Finally, ‘accommodations’ are deemed an important factor for autistic women, but are not prioritised as a central theme in current QoL measures.

Limitations

This study was conducted in response to the need for research exploring the experiences of autistic women, given the historic focus on autistic men (Gould, 2017). The inclusion criteria was ultimately constrained to offer a focus on the experiences of autistic women, who had experienced self-reported ‘good quality of life’, which in itself is likely to contributed to a sample bias. Participants were notably white, adult but not elderly, many were in employment and most were highly literate. These factors are likely to have an intersecting relationship with QoL and limits our interpretation of findings to the wider population. The purpose of this research was to expose factors identified by the autistic community as contributing to better QoL. Clearly, further exploration is required with diverse populations in order to highlight views and experiences of other autistic groups.

Additionally, this study focused on women AFAB, a decision made in acknowledgment of the likely differences in life experiences between these and gender-minoritised individuals (Lai & Szatmari, 2020; Cooper et al., 2022). It was felt that experiences of autistic individuals who are also gender-diverse would be better explored in a distinct piece of research. While lack of sample diversity is therefore a limitation for the current study, we do offer a deep and rich exploration of a tightly constrained group, who remain under-represented in the literature.

Relatedly, the small sample size and qualitative methods employed in this research mean that relationships between QoL and individual characteristics, such as age, age of diagnosis, etc. could not be quantitatively established. Wherever participants have identified a perceived relationship, we have highlighted this in the narrative. This will offer important perspectives, which could inform future quantitative research in this area.

Clinical implications

Findings from this study could be used to develop new measures of QoL, which reflect autistic conceptualisation of what QoL means to them. Additionally, several key themes in this study have direct implications for working with autistic women in clinical services. Firstly, early diagnosis is important for access to services, the autistic community and developing a positive sense of self. Secondly, early post-diagnostic support should focus on autism-acceptance, with family, friends and professionals as well as with the individual themselves, and should include facilitating autistic peer networks (Crane et al., 2021). Dedicated services should take into account sex/gender differences highlighted in this work, but would benefit from supporting the individual to manage their environment, enact self-accommodating measures, and nurture their sense of autonomy. Employers and health care providers should be encouraged to listen and respond to self-advocating autistic women, to improve feelings of accommodation and inclusion and bolster a positive sense of self-efficacy. Finally, pro-active engagement with autistic women, offered by specialist and knowledgeable service providers, could reduce the burden of self-advocacy on the individual and improve QoL across the group.

Highlights

Autistic women described good quality of life across four themes. Accurate diagnosis was critical:

1. *Positive sense of self,* entailed self-awareness & alignment of personal strengths to pursuits
2. Acceptance within the autistic community was integral to *Feeling supported*
3. *Autonomy* meant the capacity to create one's ideal sensory environment & pursue special interests
4. *Inclusion* involved self-advocacy plus being understood by friends, family & professionals

References

Allely, C. S. (2019). Understanding and recognising the female phenotype of autism spectrum disorder and the “camouflage” hypothesis: a systematic PRISMA review. *Advances in Autism*, *5*(1), 14-37.

Armstrong, T. (2015). The Myth of the Normal Brain: Embracing Neurodiversity. *AMA Journal of Ethics, 17*(4), 348-352. DOI: 10.1001/journalofethics.2015.17.4.msocl-1504

Austin, A., & Goodman, R. (2017). The Impact of Social Connectedness and Internalized Transphobic Stigma on Self-Esteem Among Transgender and Gender Non-Conforming Adults. *Journal of Homosexuality, 64*(6), 825-841. DOI: 1080/00918369.2016.1236587

Ayres, M., Parr, J.R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism, 22*(7), 774-783. DOI: 10.1177/1362361317714988

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of autism and developmental disorders*, *46*, 3281-3294.

Bearman, M. (2019). Focus on Methodology: Eliciting rich data: A practical approach to writing semi-structured interview schedules. *Focus on Health Professional Education, 20*(3), 1-11. DOI: 10.11157/fohpe.v20i3.387

Black, L., Humphrey, N., & Marquez, J. (2023). The influence of minority stress-related experiences on mental wellbeing for trans/gender-diverse and cisgender youth: a comparative longitudinal analysis. *Royal Society Open Science*, 10(7), 221230

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and psychotherapy research*, 21(1), 37-47.

Brown, H.M., Stahmer, A.C., Dwyer, P., & Rivera, S. (2021). Changing the story: How diagnosticians can support a neurodiversity perspective from the start. *Autism, 25*(5), 1171-1174. DOI: 10.1177/13623613211001012

Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of policy and practice in intellectual disabilities*, 6(1), 11-18.

Boyd, A., Van de Velde, S., Vilagut, G., De Graaf, R., Florescu, S., Alonso, J., ... & EU-WMH Investigators. (2015). Gender differences in mental disorders and suicidality in Europe:

results from a large cross-sectional population-based study. *Journal of affective disorders*, 173, 245-254.

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of autism and developmental disorders*, *48*, 473-484.

Cooper, K., Mandy, W., Butler, C., & Russel, A. (2022). The lived experience of gender dysphoria in autistic adults: An interpretative phenomenological analysis. *Autism, 26*(4), 963-974. DOI: 10.1177/13623613211039113

Connell, J., Brazier, J., O'Cathain, A., Lloyd-Jones, M., & Paisley, S. (2012). Quality of life of people with mental health problems: a synthesis of qualitative research. *Health and quality of life outcome*s, 10(1), 1-16.

Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E.L. (2021). Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *Journal of Autism and Developmental Disorders, 51*, 892-905. DOI: 10.1007/s10803-020-04486-4

Crompton, C. J., Hallett, S., McAuliffe, C., Stanfield, A. C., & Fletcher-Watson, S. (2022). "A Group of Fellow Travellers Who Understand": Interviews With Autistic People About Post-diagnostic Peer Support in Adulthood. *Frontiers in psychology*, *13*, 831628.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J.R., & Pellicano, E. (2018). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943-953. DOI; 10.1177/1362361318786721

Garcia-Villamisar, D., & Dattilo, J. (2011). Social and clinical effects of a leisure program on adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 5(1), 246-253.

Graham-Holmes, L., Zampella, C. J., Clements, C., McCleery, J. P., Maddox, B. B., Parish-Morris, J., ... & Miller, J. S. (2020). A Lifespan Approach to Patient-Reported outcomes and quality of life for people on the Autism Spectrum. *Autism Research*, 13(6), 970-987.

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism, 21*(6), 703-705. DOI: 10.1177/1362361317706174

Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., ... & Szatmari, P. (2015). Sex and gender differences in autism spectrum disorder: summarizing evidence gaps and identifying emerging areas of priority. *Molecular autism*, 6(1), 1-5.

Harmsen, I.E. (2019). Empathy in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 49*, 3939-3955. DOI: 10.1007/s10803-019-04087-w

Head, A. M., McGillivray, J. A., & Stokes, M. A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular autism*, *5*(1), 1-9.

Hesselmark, E., Plenty, S., & Bejerot, S. (2014). Group cognitive behavioural therapy and group recreational activity for adults with autism spectrum disorders: A preliminary randomized controlled trial. *Autism*, 18(6), 672-683.

Hong, J., Bishop-Fitzpatrick, L., Smith, L.E., Greenberg, J.S., & Mailick, M.R. (2016). Factors Associated with Subjective Quality of Life of Adults with Autism Spectrum Disorder: Self-Report Versus Maternal Reports. *Journal of Autism and Developmental Disorders, 46*(1), 1368-1378. DOI: 10.1007/s10803-015-2678-0

Hull, L., Lai, M.C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K.V., & Mandy, W. (2019). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism, 24*(2), 352-363. DOI: 10.1177/1362361319864804

Hull, L., Mandy, W., & Petrides, K.V. (2017). Behavioural and cognitive sex/gender differences in autism spectrum condition and typical developing males and females. *Autism, 21*(6), 706-727. DOI: 10.1177/1362361316669087

Hull, L., Petrides, K.V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.C., & Mandy, W. (2017). “Putting on My Best Normal”: Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders, 47*(1), 2519-2534. DOI: 10.1007/s10803-017-3166-5

Hull, L., Petrides, K.V., & Mandy, W. (2020). The Female Autism Phenotype and Camouflaging: a Narrative Review. *Review Journal of Autism and Developmental Disorders, 7,* 306-317. DOI: 10.1007/s40489-020-00197-9

Moderator: Jones, D.R., *Co-moderator:* Nicolaidis, C., *Participants:* Ellwood, L.J., Garcia, A., Johnson, K.R., Lopez, K., & Waisman, T.C. (2020). An Expert Discussion on Structural Racism in Autism Research and Practice. *Autism in Adulthood, 2*(4), 273-281. DOI: 10.1089/aut.2020.29015.drj

Kamio, Y., Inada, N., & Koyama, T. (2013). A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism, 17*(1), 15-26. DOI: 10.1177/1362361312436848

Kanfiszer, L., Davies, F., & Collins, S. (2017). ‘I was just so different’: The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships. *Autism*, 21(6), 661-669.

Kapp, S.K. (2020). *Autistic Community and the Neurodiversity Movement: Stories from the Frontline.* London: Palgrave Macmillan. DOI: 10.1007/978-981-13-8437-0

Kapp, S.K., Gillespie-Lynch, K., Sherman, L.E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology, 49*(1), 59-71. DOI: 10.1037/a0028353

Khalifa, G., Sharif, Z., Sultan, M. & Di Rezze, B. (2019). Workplace accommodations for adults with autism spectrum disorder: a scoping review. *Disability and Rehabilitation, 42*(9), 1316-1331. DOI: 10.1080/09638288.2018.1527952

Kim, S.Y. (2019). The experiences of adults with autism spectrum disorder: Self-determination and quality of life. *Research in Autism Spectrum Disorders, 60*(1), 1-15. DOI: 10.1016/j.rasd.2018.12.002

Krzeminska, A., & Hawse, S., (2020). Mainstreaming Neurodiversity for an Inclusive and Sustainable Future Workforce: Autism-Spectrum Employees. In Wood, L., Tan, L., Breyer, Y., & Hawse, S., *Industry and Higher Education* (pp. 229-261). Springer, Singapore. DOI: 10.1007/978-981-15-0874-5_11

Kreiser, N.L., & White, S.W. (2014). ASD in Females: Are We Overstating the Gender Differences in Diagnosis? *Clinical Child and Family Psychology Review, 17*(1), 67-84. DOI: 10.1007/s10567-013-0148-9

Kuhlthau, K., Orlich, F., Hall, T. A., Sikora, D., Kovacs, E. A., Delahaye, J., & Clemons, T. E. (2010). Health-related quality of life in children with autism spectrum disorders: Results from the autism treatment network. *Journal of autism and developmental disorders*, 40, 721-729.

Lai, M.C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-based support for autistic people across the lifespan: maximising potential, minimising barriers, and optimising the person-environment fit. *The Lancet Neurology, 19*(5), 434-451. DOI: 10.1016/S1474-4422(20)30034-X

Lai, M.C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry, 2*(11), 1013-1027. DOI: 10.1016/S2215-0366(15)00277-1

Lai, M.C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry, 6*(10), 819-829. DOI: 10.1016/S2215-0366(19)30289-5

Lai, M.C., Lombardo, M.V., Pasco, G., Ruigrok, A.N.V., Wheelwright, S.J., Sadek, S.A., Chakrabarti, B., MRC AIMS Consortium, & Baron-Cohen, S. (2011). A Behavioral Comparison of Male and Female Adults with High Functioning Autism Spectrum Conditions. *PLoS One, 6*(6), e20835. DOI: 10.1371/journal.pone.0020835

Lai, M.C., & Szatmari, P. (2020). Sex and gender impacts on the behavioural presentation and recognition of autism. *Current Opinion in Psychiatry, 33*(2), 117-123. DOI: 10.1097/YCO.0000000000000575

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*(1), 135-146.

Loomes, R., Hull, L., & Mandy, W.P. (2017). What is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child and Adolescent Psychiatry, 56*(6), 466-474. DOI: 10.1016/j.jaac.2017.03.013

Lombardo, M. V., Lai, M. C., & Baron-Cohen, S. (2019). Big data approaches to decomposing heterogeneity across the autism spectrum. *Molecular psychiatry*, 24(10), 1435-1450.

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J.R. (2018). Predictors of Quality of Life for Autistic Adults. *Autism Research, 11*(8), 1138-1147. DOI: 10.1002/aur.1965

McConachie, H., Mason, D., Parr, J.R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the Validity of a Quality of Life Measure for Autistic People. *Journal of Autism and Developmental Disorders, 48*(1), 1596-1611. DOI: 10.1007/s10803-017-3402-z

Menendez-Espina, S., Llosa, J.A., Agullo-Tomas, E., Rodriguez-Suarez, J., Saiz-Villar, R., Lasheras-Diez, H.F., Witte, H.D., & Boada-Grau, J. (2020). The influence of gender inequality in the development of job insecurity: differences between women and men. *Frontiers Public Health*, 8, 526162. https://doi.org/10.3389/fpubh.2020.526162

Milton, D.E. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society, 27*(6), 883-887. DOI: 10.1080/09687599.2012.710008

Milton, D.E. (2017). *A Mismatch of Salience: Explorations of the Nature of Autism from Theory to Practice.* Pavillion Press, Hove.

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology, 39*(1), 1-18. DIO; 10.1111/bjdp.12350

Mo, S., Viligoen, N., & Sharma, S. (2022). The impact of socio-cultural values on autistic women: An interpretative phenomenological analysis. *Autism,* 26(4), 1-12. DOI: 10.1177/13623613211037896

Nicholas, D.B., Mitchell, W., Dudley, C., Clarke, M., & Zulla, R. (2018). An Ecosystem Approach to Employment and Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 48*(1), 264-275. DOI: 10.1007/s10803-017-3351-6

Nicolaidis, C. (2012). What Can Physicians Learn from the Neurodiversity Movement? *AMA Journal of Ethics, 14*(6), 503-510. DOI: 10.1001/virtualmentor.2012.14.6.oped1-1206

Nicolaidis, C., Raymaker, D., Kapp, S.K., Baggs, A., Ashkenazy, E. McDonald, K., Weiner, M., Maslak, J., Hunter, M. & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism, 23*(8), 2007-2019. DOI: 10.1177/1361319830523

NIHR (2015). Going The Extra Mile. [online] https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf [accessed: 11.04.2023]

Orfila, F., Ferrer, M., Lamarca, R., Tebe, C., Domingo-Salvany, A., & Alonso, J. (2006). Gender differences in health-related quality of life among the elderly: the role of objective functional capacity and chronic conditions. *Social science & medicine*, 63(9), 2367-2380.

Peterson, C. (2008). What is positive psychology, and what is it not? *Psychology Today.* [online] https://www.psychologytoday.com/us/blog/the-good-life/200805/what-is-positive-psychology-and-what-is-it-not [accessed: 11.04.2023]

Rice, S. M., Telford, N. R., Rickwood, D. J., & Parker, A. G. (2018). Young men's access to community-based mental health care: qualitative analysis of barriers and facilitators. *Journal of mental health*, 27(1), 59-65.

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., Forsyth, K., McCartney, D. & Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, *20*(5), 628-634.

Sairanen, E., Lappalainen, R., Lappalainen, P., & Hiltunen, A. (2022). Effects of an online acceptance and commitment therapy intervention on children's quality of life. *Journal of Child and Family Studies*, 31(4), 1079-1093.

Saxe, A. (2017). The theory of intersectionality: a new lens for understanding the barriers faced by autistic women. *Canadian Journal of Disability Studies*, 6(4), 153-178. https://doi.org/10.15353/cjds.v6i4.386

Scott, M., Milbourn, B., Flakmer, M., Black, M., Bolte, S., Halladay, A., Lerner, M., Lounds Taylor, J. & Girdler, S. (2019). Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism, 23*(4), 869-901. DOI: 10.1177/1362361318787789

Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender Differences in the Social Motivation and Friendship Experiences of Autistic and Non-autistic Adolescents.

Journal of Autism and Developmental Disorders, 46, 1297-1306. DOI: 10.1007/s10803-015-2669-1

Sedgewick, F., Hill, V., & Pellicano, E. (2019). 'It's different for girls': Gender differences in the friendships and conflict of autistic and neurotypical adolescents. *Autism*, *23*(5), 1119-1132.

Strauss, P., Cook, A., Watson, V., Winter, S., Whitehouse, A., Albrecht, N., ... & Lin, A. (2021). Mental health difficulties among trans and gender diverse young people with an autism spectrum disorder (ASD): Findings from Trans Pathways. *Journal of Psychiatric Research*, 137, 360-367.

Sturrock, A., Marden, A., Adams, C., & Freed, J. (2019a). Observational and Reported Measures of Language and Pragmatics in Young People with Autism: A Comparison of Respondent Data and Gender Profiles. *Journal of Autism and Developmental Disorders, 50*(3), 812-830. DOI: 10.1007/s10803-019-04288-3

Sturrock, A., Yau, N., Freed, J., & Adams, C. (2019b). Speaking the Same Language? A Preliminary Investigation, Comparing the Language and Communication Skills of Females and Males with High-Functioning Autism. *Journal of Autism and Developmental Disorders, 50*(5), 1639-1656. DOI: 10.1007/s10803-019-03920-6

Totsika, V., Felce, D., Kerr, M., & Hastings, R. P. (2010). Behavior problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of autism and developmental disorders*, 40, 1171-1178.

Van Heijst, B. F., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, 19(2), 158-167.

Van Leeuwen, K. M., Van Loon, M. S., Van Nes, F. A., Bosmans, J. E., De Vet, H. C., Ket, J. C., ... & Ostelo, R. W. (2019). What does quality of life mean to older adults? A thematic synthesis. *PloS one*, 14(3), e0213263.

Warrier, V., Greenberg, D.M., Weir, E., Buckingham, C., Smith, P., Lai, M.C., Allison, C. & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature Communications, 11*(1), 3959. DOI: 10.1038/s41467-020-17794-1

Washington, A., & Randall, J. (2022). "We're not taken seriously": describing the experiences of perceived discrimination in medical settings for black women. *Journal of Racial and Ethnic Health Disparities*, 10, 883-891. https://doi.org/10.1007/s40615-022-01276-9

Webster, A.A., & Garvis, S. (2017). The importance of critical life moments: An explorative study of successful women with autism spectrum disorder. *Autism, 21*(6), 670-677. DOI: 10.1177/1362361316677719

Webster, A.A., & Garvis, S. (2020). What does success mean for autistic men? A narrative exploration of self-determination. *Autism & Developmental Language Impairments, 5*(1), 1-13. DOI: 10.1177/2396941520945522

WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*(3), 551-558. DOI: 10.1017/S0033291798006667

Williams, Z.J., & Gotham, K.O. (2021). Assessing general and autism-relevant quality of life in autistic adults: A psychometric investigation using item response theory. *Autism Research, 14*(8), 1633-1644. DOI: 10.1002/aur.2519

Table 1

Table 1: Participant characteristics shown at group level		
Characteristics	Sample	M(*SD*)
Age when interviewed (range in years)	22-64	41.9(*14.75*)
Age at autism diagnosis (range in years)	13-62	37.9(*16.65*)
Number of years since diagnosis (range in years)	0-10	4(*3.53*)
Ethnicity n (%):		
- White British	7(70)	
- White Irish	2(20)	
- Other White	1(10)	
Occupation/employment status n (%):		
- In employment	5(50)	
- Student	2(20)	
- Housewife	1(10)	
- Unemployed	2(20)	
Additional confirmed neurodevelopmental and/or mental health diagnoses n (%):		
- Depression	4(40)	
- Anxiety	3(30)	
- Attention Deficit Hyperactive Disorder	1(10)	
- Anorexia	1(10)	
- Post-Traumatic Stress Disorder	1(10)	
Suspected additional neurodevelopmental and/or mental health conditions – undiagnosed n (%):		
- Attention Deficit Hyperactive Disorder	5(50)	
- Anxiety	2(20)	
- Dyspraxia	2(20)	
- Dyscalculia	1(10)	
Highest level of education n (%):		
- GCSE/equivalent	2(20)	
- A Level/equivalent	2(20)	
- Undergraduate degree/equivalent	1(10)	
- Postgraduate qualification	5(50)	

Table 2

Table 2: Main and Subordinate Themes from 10 autistic women answering interview questions on achieving self-reported good quality of life

5. Positive sense of self	6. Feeling supported	7. Autonomy	8. Inclusion
e. Self-understanding	f. Autistic community	e. Creating the ideal environment	e. Non-autistic understanding of autistic experience
f. Mental health	g. Family	f. Physical health	f. Communicating needs
g. Sense of purpose	h. Understanding from professionals	g. Self-accommodations	g. Accommodations
h. Personal strengths	i. Romantic relationships	h. Special interests	h. Accessibility of services
	j. Friendships		

Figure 1: Positive Sense of Self: Main Theme, Subordinate Themes, and Codes

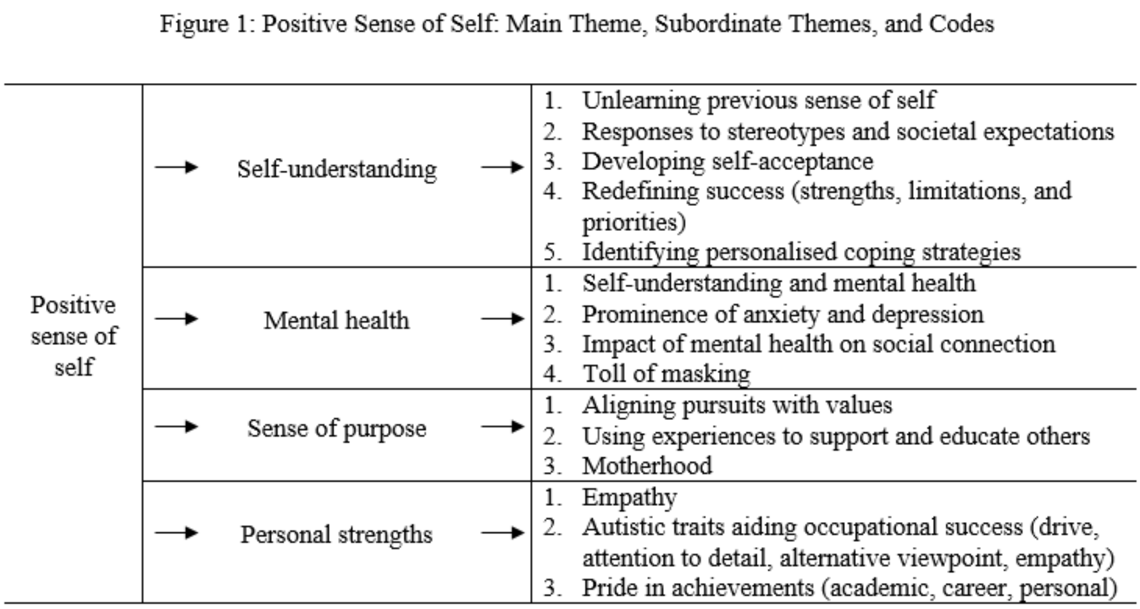


Figure 1: Positive Sense of Self: Main Theme, Subordinate Themes, and Codes

Positive sense of self	→	Self-understanding	→	1. Unlearning previous sense of self 2. Responses to stereotypes and societal expectations 3. Developing self-acceptance 4. Redefining success (strengths, limitations, and priorities) 5. Identifying personalised coping strategies
	→	Mental health	→	1. Self-understanding and mental health 2. Prominence of anxiety and depression 3. Impact of mental health on social connection 4. Toll of masking
	→	Sense of purpose	→	1. Aligning pursuits with values 2. Using experiences to support and educate others 3. Motherhood
	→	Personal strengths	→	1. Empathy 2. Autistic traits aiding occupational success (drive, attention to detail, alternative viewpoint, empathy) 3. Pride in achievements (academic, career, personal)

Figure 2: Feeling Supported: Main Theme, Subordinate Themes, and Codes

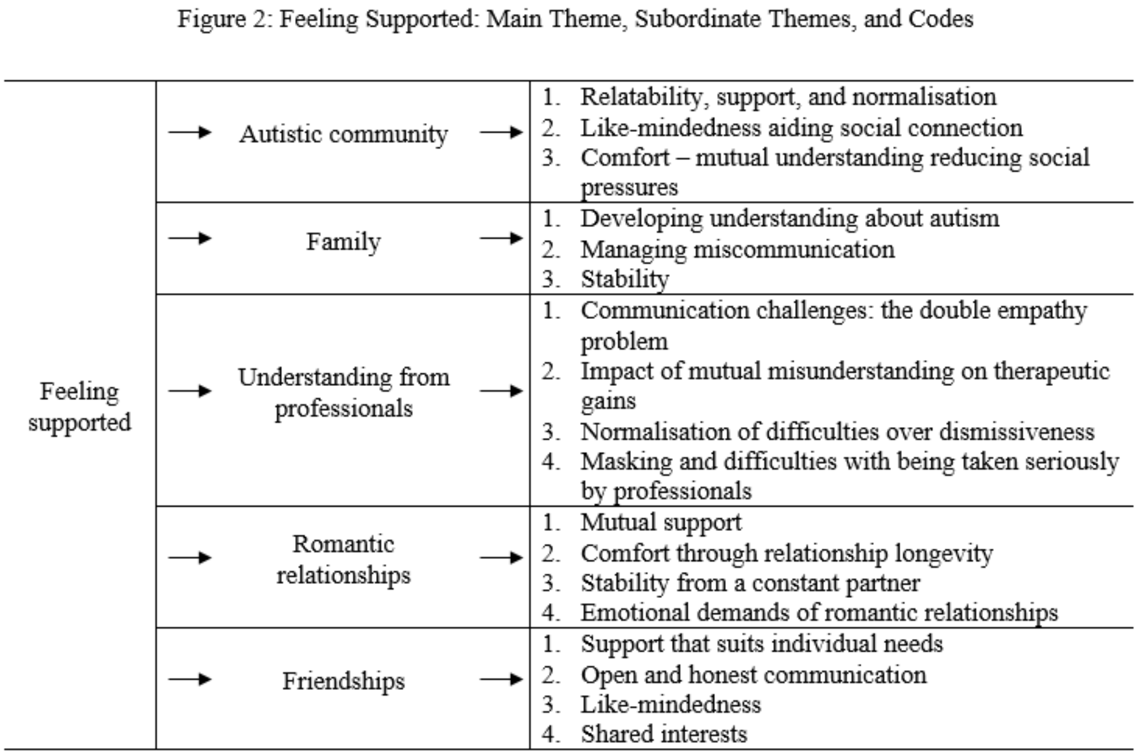


Figure 2: Feeling Supported: Main Theme, Subordinate Themes, and Codes

Feeling supported	→ Autistic community →	1. Relatability, support, and normalisation 2. Like-mindedness aiding social connection 3. Comfort – mutual understanding reducing social pressures
	→ Family →	1. Developing understanding about autism 2. Managing miscommunication 3. Stability
	→ Understanding from professionals →	1. Communication challenges: the double empathy problem 2. Impact of mutual misunderstanding on therapeutic gains 3. Normalisation of difficulties over dismissiveness 4. Masking and difficulties with being taken seriously by professionals
	→ Romantic relationships →	1. Mutual support 2. Comfort through relationship longevity 3. Stability from a constant partner 4. Emotional demands of romantic relationships
	→ Friendships →	1. Support that suits individual needs 2. Open and honest communication 3. Like-mindedness 4. Shared interests

Figure 3: Autonomy: Main Theme, Subordinate Themes, and Codes

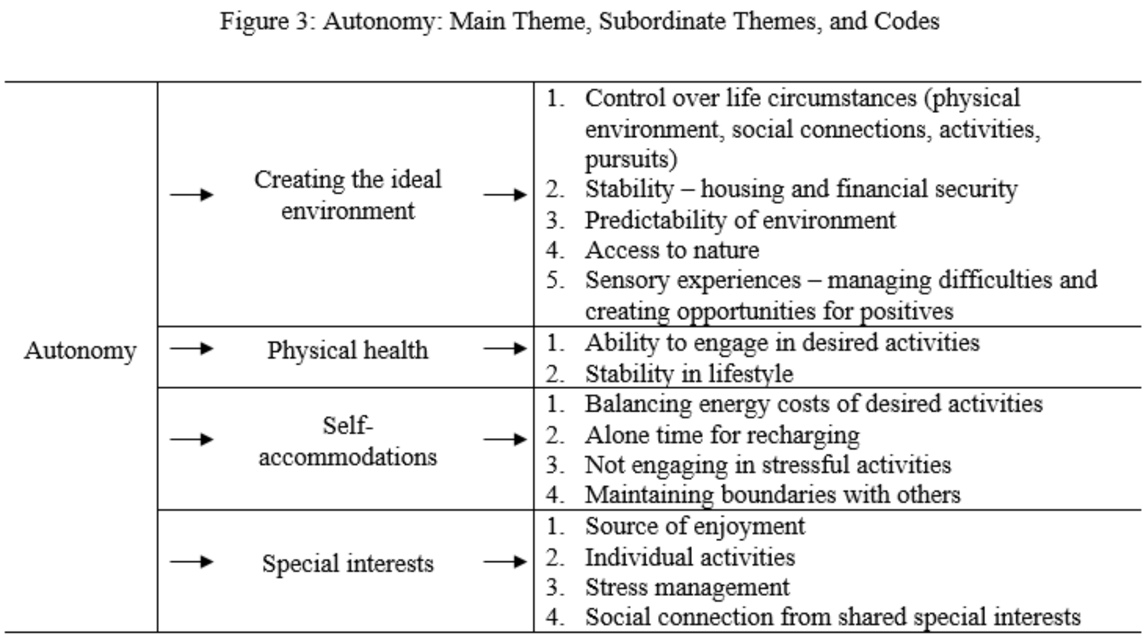


Figure 3: Autonomy: Main Theme, Subordinate Themes, and Codes

Autonomy	→	Creating the ideal environment	→	1. Control over life circumstances (physical environment, social connections, activities, pursuits) 2. Stability – housing and financial security 3. Predictability of environment 4. Access to nature 5. Sensory experiences – managing difficulties and creating opportunities for positives
	→	Physical health	→	1. Ability to engage in desired activities 2. Stability in lifestyle
	→	Self-accommodations	→	1. Balancing energy costs of desired activities 2. Alone time for recharging 3. Not engaging in stressful activities 4. Maintaining boundaries with others
	→	Special interests	→	1. Source of enjoyment 2. Individual activities 3. Stress management 4. Social connection from shared special interests

Figure 4: Inclusivity: Main Theme, Subordinate Themes, and Codes

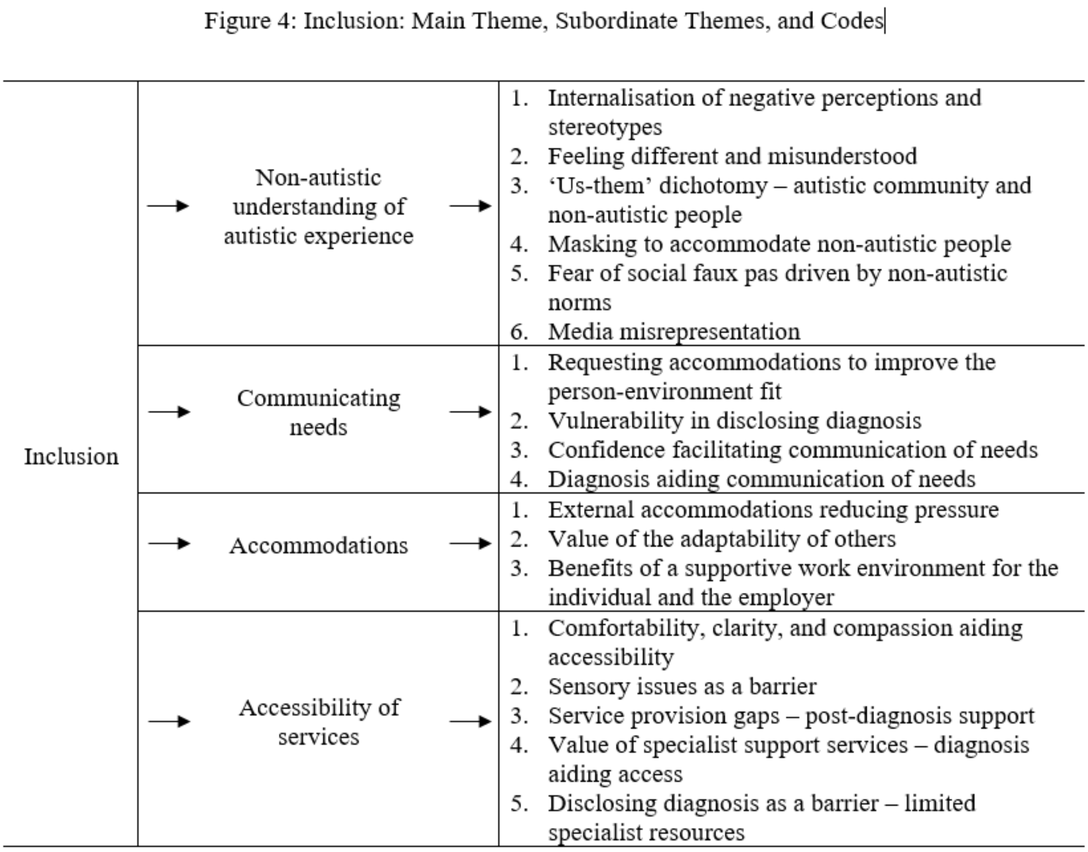


Figure 4: Inclusion: Main Theme, Subordinate Themes, and Codes

Inclusion	→	Non-autistic understanding of autistic experience	→	1. Internalisation of negative perceptions and stereotypes 2. Feeling different and misunderstood 3. 'Us-them' dichotomy – autistic community and non-autistic people 4. Masking to accommodate non-autistic people 5. Fear of social faux pas driven by non-autistic norms 6. Media misrepresentation
	→	Communicating needs	→	1. Requesting accommodations to improve the person-environment fit 2. Vulnerability in disclosing diagnosis 3. Confidence facilitating communication of needs 4. Diagnosis aiding communication of needs
	→	Accommodations	→	1. External accommodations reducing pressure 2. Value of the adaptability of others 3. Benefits of a supportive work environment for the individual and the employer
	→	Accessibility of services	→	1. Comfortability, clarity, and compassion aiding accessibility 2. Sensory issues as a barrier 3. Service provision gaps – post-diagnosis support 4. Value of specialist support services – diagnosis aiding access 5. Disclosing diagnosis as a barrier – limited specialist resources