'You don't look autistic': A qualitative exploration of women's experiences of being the 'autistic other'

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Abstract

There is currently a paucity of literature exploring the experiences of women on the autism spectrum. It is imperative research is conducted to capture the experiences of women on the autism spectrum and ensure appropriate support is provided to this cohort. Drawing upon a social constructionist framework, this qualitative research study sought to understand how psychological and socio-cultural constructions of autism spectrum condition and gender influence the well-being of women on the autism spectrum. Eight participants engaged in a semi-structured interview, with thematic analysis conducted to demonstrate the impact of gender roles and social expectations on the women's identity and autism spectrum condition expression. The research highlighted the changing understandings of autism spectrum condition across a woman's lifespan and the process and impact of resisting hegemonic autism spectrum condition categorisation. The findings demonstrate that social constructions of gender and stereotypical understandings of autism spectrum condition, which prioritise a deficit, medical model, have significant consequences for women's well-being and subjectivity. The women experienced challenging formative years, but with diagnosis and the evolution and acceptance of their identities, they were able to resist negative narratives of autism spectrum condition, embrace their strengths and develop adaptive coping strategies. It is hoped this article generates insights for societal and clinical recognition to better support women on the autism spectrum.

Lay abstract

Most autism spectrum condition research addresses the neurological and biological causes of autism spectrum condition, focusing upon deficits associated with autism spectrum condition and behavioural interventions designed to minimise these deficits. Little is known about the lived experiences of adult women on the autism spectrum and how they navigate social expectations around gender, autism spectrum condition and gendered understandings of autism spectrum condition. The lived experiences of eight women on the AS will be shared here, with attention to how gendered expectations influence women's experiences of autism spectrum condition, their sense of self and well-being. Findings showed these women struggled to reconcile the expectations of others, particularly early in life. The women had difficultly conforming to stereotypical ideals of femininity, yet as they aged, they felt less need to conform, valuing their unique style and behaviours. The women also rejected deficit-oriented descriptions of autism spectrum condition generated by the medical community, preferring to focus on their strengths and unique characteristics. It is hoped this article helps psychologists and the wider community to understand and meet the needs of women on the AS.

In understanding the experiences of women on the autism spectrum (AS), it is important to reflect on the social construction of gender and dominant constructions of autism spectrum condition (ASC). Femininity is traditionally associated with empathy, emotionality, caring, communication, nurturing, sensitivity and compassion (Mayor,

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2015) as opposed to masculinity, traditionally associated with logic, rationality, strength, physical aptitude and stoicism (Mayor, 2015). The internalisation of these gender norms begins in early childhood through 'gendered parenting' and socialisation (Bussey & Bandura, 1999) and may be passively or actively taught. Retribution for gender transgressions may become powerful lessons through which children learn gender-appropriate behaviour (Davidson & Tamas, 2016).

Women on the AS can present as socially awkward or assertive and forthright and may suffer overt and covert social sanctioning, isolation and alienation (Davidson, 2007). The policing of femininity starts at a young age, often through relational bullying and shaming, which acts as a strong motivator for girls on the AS to maintain the appearance of 'normal'. Girls on the AS report 'doing gender' and masking their 'abnormal' behaviours in the relevant literature (Baldwin & Costley, 2015; Bargiela, 2015; Cridland et al., 2014; Helmers, 2018; Kourti & MacLeod, 2018; Ratto et al., 2018). Similarly, women on the AS describe the pressure they feel to play specific traditional feminine roles and mask their more obvious ASC traits (Bargiela et al., 2016; Davidson, 2007) with negative consequences for their identity, mental health and relationships. If women adequately 'perform' gender and pass as neurotypical (NT), they may avoid criticism and 'outing' (Davidson & Tamas, 2016). Pressure to meet gendered expectations can have severe consequences for women on the AS as the desire to please others and conform is prioritised (Bargiela et al., 2016). Without early recognition and the development of interpersonal skills, girls and women on the AS are vulnerable to abuse and exploitation, further justifying the need to explore the experiences of ASC to better understand and support this cohort.

Differential expectations for males and females can add a layer of complexity when combined with preconceived ideas related to ASC presentation. Gendered expectations can influence the way behaviours of undiagnosed young women are perceived and received by their parents, teachers and professionals (Bargiela, 2015; Cheslack-Postava & Jordan-Young, 2012). For example, girls on the AS have reported 'gender normal' obsessions with books, craft, jewellery, music, art and animals (Davidson & Tamas, 2016; Duvekot et al., 2017). They tend to collect information on people rather than objects (Gould, 2017) with restricted interests, such as dolls, being misinterpreted as pretend play (Green et al., 2019; Halladay et al., 2015). These behaviours go some way to explain why the recognition of ASC is more difficult for girls. Parents of girls on the AS, who exhibit social difficulties, may interpret their daughters' behaviours as reflecting gender-appropriate personality characteristics such as shyness, passivity or immaturity (Kreiser & White, 2014) and peers may react to these subtle social difficulties with relational aggression and ostracisation.

At school, girls on the AS may not present with external, problematic behaviours such as hyperactivity, aggression and inattention; behaviours more likely to result in referrals to clinical behavioural intervention services. They may internalise symptomatology (Bargiela et al., 2016; Hull et al., 2017), and these symptoms may be more readily overlooked by teachers, creating missed opportunities for early intervention. Not only do these experiences have long-term consequences for future education and employment opportunities, without a diagnosis, messages of shame may affect the emerging identity of young women on the AS as they internalise negative statements or actions made by others. Accounts from mothers of girls on the AS and late-diagnosed women on the AS indicate they believe they would have benefitted from earlier diagnosis, and had this occurred, some of their difficult life experiences could have been avoided (Hull et al., 2017).

As part of a larger research project, this study sought to understand the impact of social and gender expectations on women's presentation and experience of ASC, their subjectivity and well-being. This study also aimed to examine the validity and meanings attached to the constructions of ASC.

Method

Methodology

This research utilised a qualitative framework, drawing upon a feminist, social constructionist epistemology. Critical epistemologies such as these allow for reflection on dominant cultural narratives and seek to understand how social constructions of reality impact human experience (Burr, 2015). Feminist constructionist research challenges 'taken for granted' assumptions and considers the perspectives of diverse groups who have previously been invisible (Bailey, 2011). These frameworks enabled a critique of the medical model of 'illness' and 'psychopathology', allowing questions to be raised around patriarchal influences on constructions of gender, diagnosis and ASC. Also acknowledged within these epistemological frameworks are the cultural and social norms surrounding the manifestation of 'disorders' across gender lines, and these were important to this study.

Methods

Following ethical approval from the Charles Sturt Human Research Ethics Committee, a purposive sampling technique was employed to recruit a relatively homogeneous sample. The call for participants specified the women should be aged 18 years and over, residing in Australia with a formal diagnosis of ASC and who identified as 'high functioning'. While this term may be problematic in describing the experiences of ASC and is contested within the ASC community, it reflects a colloquial, and possibly a

NT, understanding of ASC that warrants consideration. Given the dominance of such language in positioning individuals' experiences of autism, we sought to interrogate this terminology within this study. Addressing such language also allowed participants to explicate their experiences in relation to this label and highlight the challenges such a label presents. The complexity of this terminology is explored throughout the analysis.

A private Facebook group was created, enabling participants to access information about the study and assist in building rapport between the participants and researcher. Recruitment processes were guided by sensitivity to communication and sensory needs and allowed participants to select the interview's location and format (Haas et al., 2016). No rewards were offered for participation.

After written consent was obtained, one semi-structured interview was conducted with participants. Questions were open-ended, allowing participants the freedom to discuss issues they felt essential to the topic. Interviews were anonymised and transcribed verbatim, and then analysed using thematic analysis (Braun & Clarke, 2006). Guided by Polkinghorne (2005), data collection and analysis was not a direct reflection of participants' experiences, but rather a reflection on the meaning of experiences. Interview data were co-created at the time of the interview between the researcher and participants insofar as the researcher's questions affected the participants recall (Polkinghorne, 2005). During analysis, predetermined ideas around participant responses were confirmed and actively disconfirmed to ensure the participants' descriptions remain the focus of the analysis (Polkinghorne, 2005). This is further discussed within the section pertaining to reflexivity. Due to time constraints, follow-up interviews were not conducted, but participants were invited to review their interview transcripts and provide feedback on the interview sessions that were conducted.

Themes were constructed around participants' experiences of their ASC as distinct from what is stereotypically depicted as 'autism'; their understanding of ASC as a non-static entity that changed across the lifespan; and their reactions to and resistance towards categorisation of ASC experiences; gendered, performance-oriented and diagnostic alike (Burr, 2015).

Participants

Relevant demographics of the sample are displayed in Table 1. Participants reported a formal diagnosis of either Asperger's or autism spectrum disorder (ASD). Five of the participants reported being classified as 'Level One: requiring support' (Volkmar & McPartland, 2014). Ages ranged from 24 to 53 years ($\bar{x} = 39.12$, standard deviation = 9.3).

All but one participant had received a diagnosis within the previous 5 years; however, confirmation of formal diagnosis was not obtained, nor was a self-report screening assessment conducted. The study did not record information about socio-economic status, ethnicity or nationality; however, one participant identified as culturally diverse. Participants were allocated an alias during analysis to ensure anonymity.

Community involvement. The researchers consulted autistic perspectives when designing this research via engagement with community level forums and other publicly available information generated by autistic communities on the communicative, sensory and interpersonal needs of those with autism. This educative engagement informed the study's design and the environment(s) in which future interaction between the researchers and the participants took place. No individuals with an ASC diagnosis were involved directly with the processes surrounding this research.

Reflexivity

As women and feminists, we were positioned as both 'insiders' and 'outsiders' to the research population (Dwyer & Buckle, 2009). As such, we carefully reflected on and analysed participants' responses to ensure our assumptions about the participants' experiences did not dominate the analysis. As women, we have also experienced gendered expectations; however, this insight, while beneficial, can create analytic blind spots.

As members of the NT population, we were positioned as 'outsiders', which presented several challenges. In ASC research, the 'double empathy' problem can occur when people of different dispositional outlooks and personal conceptual understandings attempt to communicate meaning (Chown, 2014; Milton, 2014). An awareness of these complexities ensured recognition of the assumptions made during data interpretation. Interestingly, during the data collection phase, we identified with some ASC characteristics discussed by the women, further highlighting the liminal positioning of neurodivergent and NT populations. This subjective experience highlights the blurred boundaries of ASC and the nuances required when understanding the phenotype of ASC.

Consistent with feminist research practices, power dynamics and the politics of representation were considered (Bailey, 2011). Interview questions and the process of interviewing itself was conducted in a manner designed to democratise the research encounter so far as possible, acknowledging the inevitable power structures that exist despite a research agenda that attempts to engage and empower participants but is nonetheless inevitably limited. During the analysis, in response to our academic privilege as researchers and contributors to the production of knowledge about women and ASC, we were drawn to advocate on behalf of the participants and present the complete organic account of the women's lived experiences.

Table 1. Participant demographics.

Participant pseudonym	Age (at diagnosis)	Reported diagnosis (previous diagnosis)	Marital/familial status	Employment
Charlotte	54 (53)	Asperger's	Single; divorcee with no children	Part-time from home
Sally	41 (38)	Asperger's	Single mother with three children, two of whom are on the spectrum	Part-time work and tertiary study
Jenny	24 (23)	Autism spectrum disorder. Support Level One (anxiety, depression, eating disorder, social anxiety, obsessive-compulsive disorder, attention-deficit hyperactive disorder)	Unknown	Unknown
Sarah	47 (40)	Autism spectrum disorder (bipolar, depression and anxiety)	Unknown	Full-time
Jane	39 (39)	Asperger's or autism spectrum disorder	Married with children	Unknown
Ella	35 (34)	Autism spectrum disorder. Support Level One (post-natal depression, anxiety)	Married with two children. All family members are on the spectrum	Healthcare worker and self-employed
Maisy	31 (28)	Autism spectrum disorder. Support Level One	Married with two children. One child also on the spectrum	Healthcare worker
Piper	44 (39)	Autism spectrum disorder. Support Level One and ADHD	Married with one child who is on the spectrum	Contract office work

ADHD: attention-deficit hyperactivity disorder.

However, epistemological integrity requires critical reflection of both the accounts of participants and the context of our interpretation of participants' lived experiences. These critical reflections must be acknowledged as central to the resulting analysis. It was in this subjective but conscious, critical space that the following themes were developed.

Findings and discussion

This article presents three themes representing participants' experiences of the intersection between socially constructed gender norms, dominant understandings of ASC and sense of self. Core to this thematic analysis was the notion of gender and ASC interacting to create a sense of othering for women on the AS, defined as *the look of ASC*. Inherent to this concept was the influence of gender on experiences of ASC. Participants expressed how misconceptions of ASC, particularly the notion that ASC is experienced by males, impacted their experiences. Themes centred around the socialisation of gendered behaviour, understanding gendered experiences of ASC across the lifespan and resisting categorisation as a woman with ASC.

Theme 1 – Subverting social expectations: constructing the neurodivergent feminine self

This theme explores participant's views of gender differences in ASC and their experience of gender expectations. Of the differences between genders, participants noted how women on the AS engage in more masking behaviours than men and demonstrate superior social skills. Some participants argued that this difference was, in their opinion, biologically or neurologically driven:

> because we [are] women, we interact differently to men, and a lot of our interaction is social anyway. And we, by nature, are more verbal than men, and I think because we kinda [are] cued to look at social interaction, I think we can learn how to socially interact, whereas guys don't get that. And I suppose because of the way their brains are wired. They are much more concrete, much more literal. (Charlotte)

Others highlighted the impact of learning gender norms for female ASC presentations:

> the socialisation of women and men is very different, so there is a lot more pressure on women and girls, right from a young age, were [are] socialised differently, we're expected to be caring and nurturing, and all those things and I think that definitely played into my wanting to be a parent. (Sally)

Several women discussed being held responsible for their behaviours before diagnosis, including Jenny, whose sense of failure was reinforced by teachers who attributed her academic difficulties to a lack of trying. Jenny's parents mislabelled her behaviours and punished her for emotional outbursts. Other participants described emotional abuse from their parents, leading to an internalised sense of self-blame that continued into adulthood.

Jenny's parents' and teachers' frustrations with her behaviour may reflect gendered expectations. A study by Ratto et al. (2018) found girls with ASC were rated by

their parents as having stronger autistic traits and lower life skills than their male counterparts. Such findings highlight differing perceptions of behaviours exhibited and accepted for daughters and sons. Parents may be less accepting and more willing to pathologise externalised (ASC) behaviours from girls.

Piper highlights how gendered expectations resulted in social sanctioning from both her teachers and peers. Consequently, she converted to more appropriate feminine behaviours:

> . . . back in school, I used to have my hand up a lot in class, and so I learnt to not put my hand up so much because I got told it was the reason I was being bullied because I knew too much, [I was told] don't put yourself out there so often, and then, that's when I stopped putting myself out there.

Interestingly, modelling may be relevant to the gendered expression of ASC, as Sally noted when discussing her daughters' diagnostic journey, 'so of [my] girls, I think the older two are definitely on the spectrum, but they're not diagnosed, because, I unconsciously, before I even had a diagnosis, taught them accommodations, all their life'.

The influential role of parenting and modelling is significant, given the heritable nature of ASC. As identified above, an undiagnosed ASC parent may inadvertently model to their ASC child gendered behaviours and coping mechanisms to manage social demands. As children tend to model same gender parents, this has clinical implications and may provide a partial explanation for the lack of early diagnosis in girls.

When reflecting on experiences of socialisation, social sanctioning and society's gendered expectations, most participants expressed disdain regarding stereotypical presentations of femininity and rejected the pressure to conform. As Jane highlights, 'I have never followed other women in trends of clothing, makeup, shoes, accessories. I dress for comfort and practicality and occasionally because an outfit makes me feel nice'. As ASC represents a widely perceived transgression of appropriate femininity, further subversions of femininity may be rendered less confronting. In line with this, participants discussed being comfortable with their self-expression and identity, which stemmed predominantly from their uniqueness and interests. For Charlotte, a diagnosis gave her permission to not engage in gender performance, noting, 'and I suppose that's the good thing about being an Aspie, you don't have to buy into that media image of what's fashionable'. Another interpretation of 'femininity transgressions' in women on the AS would be to argue such transgressions are not the result of a conscious decision to relax self-standards rather than attempt to adhere to unsuccessfully met gender standards, but a simple manifestation of autistic behaviour, as highlighted by Charlotte 'I really struggle wearing dresses, dresses and skirts cause, to be totally honest, I feel buck

naked'. Gender norms were described as performative and effortful, as Sally notes, 'Not always been a big fan of performing femininity, mainly because it's hard and from experience and I wasn't too good at it, and I didn't have the interest'.

While women on the AS may find the performance of femininity particularly challenging, this experience is not necessarily unique to women on the AS. Indeed, Sally highlighted how the expectations she feels as a woman with ASC may not be dissimilar to NT women, stating: 'I don't think there are many women who don't feel that, the need to meet social expectations'. In exploring the experiences of those within 'categories' such as 'ASC' and 'gender', continuity, as well as difference, must be acknowledged, and this was reflected in the findings of this study.

In another potential transgression of femininity, one participant acknowledged their gender and sexual fluidity, while other participants proudly saw themselves as engaging in an alternative performance of feminism. Participants actively created their own identity and definitions of femininity. The extent to which such positions can be considered transgressive of gender norms depends in part on the dominant culture. As society moves away from a gender essentialist narrative and becomes more inclusive of different presentations of femininity, judgements of those who deviate from the norm may lessen. As Burr (2015) comments, 'Our identity is constructed out of the discourses culturally available to us, and which we draw upon in our communications with other people' (p. 122). Disavowing physical presentations of 'femininity' may be considered less radical as neurodiversity and femininity, alike, are re-conceptualised over time and within different contexts.

As varying presentations of gender become more accepted, the negative consequences of gender transgression may reduce. For women on the AS, they may be less vulnerable to fragmented identity formation and poor well-being. As women on the AS experiences are heard and normalised, the assumption that particular interests and systematising skills are an exaggeration of the 'male brain' is again challenged (Baron-Cohen, 2002). In a blistering critique of the concept of the male brain, Ridley (2019) argues that the idea is essentialist and reductionist and as a descriptor or explainer of autism, should be abandoned.

Participants recognised the influence of society's expectations on them as women; however, the expectations of others appeared to have the most impact on their well-being, suggesting a level of meta-representation of stereotypes. Piper discussed how others interpret her assertive nature as aggression and, in response, isolate her, while Jane highlighted the complexity of being authentic and responding to the judgements of others; 'I disregard other opinions on how a woman should appear, but at times I do resent that others might be thinking I don't dress

or apply makeup in a suitable womanly way'. Participants' experiences of gender echo Rudie Simone's (2010) experience in 'Aspergirls', where she remarks, 'Women with ASC can harbour a disinterest in society's expectation of what being female means. Though we may not feel particularly womanly, others will still see us as such and measure our behaviour against non-autistic females' (p. 62).

Not all experiences of gender in relation to ASC were identity-related, with Jane highlighting a much more worrying interpretation of what it means to be a woman and how gender is enacted and performed by women on the AS. Her sentiments reflect a desire to belong and to feel 'normal', overriding personal safety concerns:

> In this age of #metoo, I had the opposite problem through my teens and one which I feel shame for. Because no boy ever tried to hit one me/flirt with me/ask me out, I totally believed that I was ugly, unworthy of a man's interest, not good enough. I like to think this scepticism at least kept me safe from sexual predators, but in truth, no man ever tried. This added to my belief that there was something intrinsically wrong with me.

Social judgements and prioritising the need to belong over personal safety are reported in the literature for ASC adolescents (Bargiela, 2015; Kanfiszer et al., 2017) and are consistent with the findings in this research where several participants had been subject to sexual and emotional abuse. Inconsistent with the literature (Bargiela et al., 2016), participants in this study did not attribute gender role expectations to some of the choices they have made as adults:

> I chose to marry a man and have children because I always wanted to have children. I think I relate to them better. This was my choice. I could also have been happy choosing a female partner, but it would have been more difficult to have children. (Jane)

Several women prided themselves on living an 'alternative' lifestyle such as working in bush regeneration or participating in the 'kink community' where gender normative performance is less restrictive, demonstrating their capacity to proactively engage with inclusive and diverse communities.

Participants experienced difficulties when fulfilling normative gender roles such as motherhood and marriage. Of the four women who experienced relationships with NT men, three women discussed marital problems, resulting in increased stress, anxiety and depressive symptoms. These marriages ended in separation. Of the women who were mothers, all discussed failing to live up to the socially constructed view of motherhood. They described a lack of immediate maternal bond with their baby, difficulty reading their babies' cues and difficulties with NT guides for routines and mothercraft skills, with significant consequences for their well-being:

> so motherhood itself, so people describe it as a natural or something and you have instincts for and for me, it wasn't, nothing about it was instinctual, I felt like I needed a manual to teach me how to be a mum, nothing I read really made sense.

One key finding is when positioned as caretakers and nurturers, a woman's well-being is, at times, determined by the well-being of those around her rather than her own experiences. This is exaggerated for women on the AS who may not be able to adequately articulate their emotional experiences and advocate for their own needs. Gender stereotypes were acknowledged by the women and most discussed previously attempting to fit the social construct of femininity as teenagers and young adults, consistent with research on ASC teenagers (Bagatell, 2003; Bargiela, 2015). As adults, the women were more accepting of their gender performance. They had released the requirement to conform, in relation to both gender expectations and expectations of them as a person with ASC.

Theme 2 – ASC across the lifespan

This theme explores the temporal nature of ASC and the changing presentation of ASC throughout a participant's lifetime. The experience and presentation of ASC appeared to be fluid and reflective of internal and external expectations, as Sally explains here:

> I definitely had a lot of angry outbursts in my late 20s, early 30s. As a mum, I was very angry, and that was a moral failing according to my religion and my husband, and it was only, as that's reduced and I've started to read about it, I'm just like ahhhh . . . okay, anxiety can be expressed as anger as well. I'm moving more into a phase [of ASC] where I will shut down.

Interestingly, participants suggested these temporal changes in ASC experience were not observed in men as noted by Piper, 'A lot of these women grow up, they change, and they grow up. And the guys don't because their ASC holds them in that point and they [partners] can't handle it'. Sally's coping strategies evolved with time, and she had worked to increase her capacity to manage the sensory demands of her workplace, out of necessity as much as desire:

> I remember the first night I went to work, did a three-hour shift. I came home and lay on the couch and immediately fell asleep. Now, I can coach [gymnastics] up to nine hours in a day, and I will be very tired, but you know, I can, I can survive.

Participants spoke of losing friendships during adolescence and early adulthood, separating their identity from

their parents through independent choices and struggling to find their way during early adulthood. These pressures are not unique to the women on the AS, and NT women often experience similar scenarios; however, the way developmental and lifespan milestones are navigated and interpreted may be unique to this population. Jones et al. (2013) highlighted the complexity of separating ASC experiences from the normative experiences of the age and stage of participants' lives. There is a danger that developmentally based phenomena in adolescence may be perceived as typical of ASC pathology rather than typical adolescent experience (Jones et al., 2013). Awareness of the complexity of interpersonal relationships, a desire to 'fit in' to the broader community and a feeling of being regarded as 'different' are frequently reported as general characteristics of adolescence (Jones et al., 2013). When analysing the women's statements, it is imperative to apply a normative developmental lens to not pathologise otherwise 'normal' and age-appropriate behaviours related to identity development and maturation.

Once diagnosed, participants re-evaluated their lives and reframed past experiences with a compassionate lens. Internalised feelings of failure and shame shifted to an external arena, and participants' self-perception and understanding improved. Diagnosis created a framework with which to process a coherent self-narrative and no longer pathologise one's thoughts and behaviours. With a diagnosis, participants were released from others' expectations of them and did not have to try and assimilate into society, with requisite benefits for well-being:

> I've come to accept, especially since getting my diagnosis, I'm not the same as other people and knowing it on a deep level since I was very young, and now understanding why that's the case, I'm pretty happy with the way I am, I'm not everybody's cup of tea, and that's okay. (Sally)

> Yeah, that's actually been the release of getting the diagnosis; I can stop trying so hard.

> I feel more freedom to be me, still putting on the public mask because socially, that's what you have to function, but within myself, I can be a lot more true to myself

> (Charlotte).

> . . . before, I wasn't diagnosed, and I think I just felt awful about myself and like 'why can't I cope with this' and it had a big toll on me mentally, whereas now, it's a lot easier and I sort of know now why things are the way [they are], and it's a lot easier to cope. (Jenny)

Several women continued with psychological support following diagnosis and described having more self-compassion and understanding of their need for support. Such findings suggest the need for ongoing support for ASC women even when the individual presents as 'high functioning'.

Participants described living a more authentic life post-diagnosis, revealing personality characteristics they had previously concealed. They became less protective of themselves and gained the confidence to disclose their diagnosis to certain friends and employees. Diagnosis legitimised participant requests for provisions in the workplace, and participants felt confident to discuss their traits and needs with close friends, reducing the need for constant masking. One participant, Ella, described embracing her 'geek' persona and openly expressing gender fluidity post-diagnosis. The temporality of diagnosis was significant; some participants expressed the notion that an early diagnosis may not have been beneficial. Early diagnosis could have suppressed their growth and development due to the deficit model of ASC, even though an earlier diagnosis might have meant greater support and understanding at certain junctures in their lives, highlighted by Maisy:

> if someone was deemed low functioning, they were not really given [the] opportunity to extend themselves or be who they are. I was non-verbal . . . I would just be labelled as a nonverbal child who didn't have much hope of integrating, who didn't have much hope of learning social skills, and what I mean by 'damage' [of labelling] is all the assumptions that came with the diagnosis.

Participants embraced their ASC traits and unique personalities to live authentically in the community, and such responses to diagnosis are reflected in the literature (Bagatell, 2007; Hickey et al., 2017; Punshon et al., 2009). Positive responses to late diagnosis, in particular, may reflect maturity and an evolution in self-identity and self-acceptance that comes with age. With a late diagnosis, most participants had somewhat successfully navigated the more challenging milestones of life such as moving out of home, completing tertiary education, marriage, children and employment, and therefore did not harbour the trepidation parents of ASC children or ASC adolescents may have about their future. This highlights the importance of visible ASC role models in the community for families and children navigating the ASC diagnosis process.

Theme 3 -- Taking control of the (ASC) narrative: redefining diagnosis and (dys)function

This theme explores the complexity of disability, functioning labels and identity. Participants reported a complicated relationship with the negative, masculine portrayal and medicalisation of ASC. While participants embraced the diagnosis of ASC and discussed the positives of understanding and insight, all rejected the stigma and disability narrative attached to ASC. Interestingly, Piper expressed an ambivalent relationship with formal understandings of

ASC, noting, 'I love and hate the labels in the same breath cause . . . it sort of explains me and it sort of doesn't'.

Two participants placed ASC in the same arena as mental health conditions such as depression or anxiety, suggesting it is only when they are overwhelmed that their ASC traits negatively impact their life. Others positioned ASC in a disability framework but did not perceive themselves as disabled and resisted the deficit model by highlighting their strengths and achievements, such as completing university, gaining employment and starting a family. Language is both critical and contested in ASC spaces, and Ella highlights this tension:

> . . . technically I'm disabled, but when you look at what I've done in my life, and I guess I've done a considerable amount of stuff in my life like we travel every year, we do tonnes of stuff and so I, I don't classify it as a disability, but at the same time I still need help [. . .] so, the word 'disabled' I'm not a huge fan of in general.

Some women were comfortable identifying ASC as a difference of neurology and nothing more. Sarah stated, 'I define myself as an individual with a unique set of qualities and constraints'. What stands out in these responses is the continuum of definitions of ASC from those with the condition. For example, ASC shifts from a manageable mental health condition to a disability to a mere difference in neurology with limitations and strengths, depending on the individual concerned and the life stage of the individual. Moreover, how 'disordered' an individual may be perceived to be depends in part on expectations for that individual, which are inevitably linked to gender, culture, socio-economic status and other social markers.

Several participants had found the diagnostic process challenging and traumatising, creating a sense of distrust in the medical community. Sarah highlights, 'Find a good life coach or mentor, stay away from counsellors who know much less than they think they do'. In a similar vein, Sally highlighted the importance of seeking an expert in the field with supporting credentials:

> when I have a proper job, the first thing I'm going to do is take my girls to someone who is actually an expert in diagnosing girls, just not someone who just tells me they are and takes my hundreds of dollars and then doesn't give me a diagnosis.

Diagnosis may not only signal one's legitimacy; it may also be crucial in determining how one should feel about ASC, as Ella highlights:

> So, when my son was diagnosed, and he's much more severe than any of us, it was very much 'we're sorry this has happened to you', and you know, 'we don't know if he will ever go to mainstream school' and this and that, and 'autism is horrible'.

Guilt, shame and failure may be inferred from diagnostic narratives. As Piper stated, it is not only ASC individuals who are labelled and subjected to stigma but also family members: 'The amount of parents who get told 'you're just a bad mother, you can't connect to your child''. The complex relationship participants experienced with ASC and the construct of disability reflects broader philosophical questions regarding ASC and its existence beyond language and the construct of difference. Participants' difficulties were framed around the expectations of the social context in which they exist (Molloy & Vasil, 2002). As Molloy and Vasil (2002) describes, disability is the product of social discourses and practices, medical discourses, town planning, school assessments and workplace practices. This emphasises the significance of the environment and expectations for the lived experience of women on the AS. Participants' accounts also raised questions as to who is best positioned to diagnose and support ASC individuals, with Maisy highlighting the potential for those most affected by decision-making to be excluded from the decision-making process:

> it's true with any disability sector, to make decisions about how best to support a particular disability, you need people with that disability on the funding committee, on the decision-making committee, and without really consulting with individuals who go through certain experiences every day, you're not going to get anywhere and what is the point? (Maisy)

Embedded in Theme 3 is 'Punishment of function'. Participants demonstrated a complicated relationship with the unofficial label 'high functioning', at times, colloquially equated with 'ASC: Level One; requiring support' (Volkmar & McPartland, 2014). For participants, categorisation did not represent their experiences of ASC, as Sally suggests:

> I like the analogy of a mixing board, a sound mixing board with different functions having each of its own slider and some functions could be way up high whereas others could be way down low at the same time and I think the perception of high functioning, it means that people think that I think that you're only a little bit autistic and that's just not the case.

What constitutes 'functionality' is highly problematic. Piper's reflections on her life-management skills reflect the idiosyncratic experience of functioning:

> I might be high functioning where I can drive a car, get a job, not necessarily keep it, but I can get a job, I can manage a budget, kind of, sort of. I'm not too far in debt. I can follow basic road and criminal laws, and I can understand the world, what they don't see is all the ways I can't.

Participants' functionality resulted in a lack of early identification, which in turn resulted in a lack of support with education and employment and through transitional life periods. Perceptions of functionality negatively affected participants during the diagnosis process, as clinicians and doctors dismissed them due to their presentation

or achievements. Being 'high-functioning' carried certain inevitable drawbacks:

> I had a hell of a time getting diagnosed for the ASC cause I had any number of clinicians go, 'oh, look, you're a parent, and you got married, and you have a job'; hey! Let's not even go down that path cause that's just bullshit; therefore, you can't be autistic, and I'm just like, are you fucking kidding me? I'm like, can you see how long I can keep a job for? (Piper)

> she [general practitioner] dismissed me with 'I think if you finished university, you can't have Asperger's' (Jenny)

Paradoxically, a lack of functioning, such as low maths grades, also eliminated girls from the possibility of ASC (Bargiela, 2015). Labels of 'functionality' were seen as benefitting the NT community and governmental policies, giving the NT community permission to ignore the requirements of ASC individuals and doubt the authenticity of diagnosis when ASC individuals are unable to manage expectations. Labels of functionality create another layer of false persona, adding to the complexity of identity development for women on the AS. Being 'high functioning' is described by Ella as a threat and a way of obliterating her ASC and its significance for her life and identity; 'it's a slap in the face every time someone says, 'oh you're high functioning'. So, 'we're just going to ignore the fact that you have Autism completely', which is what usually happens'.

Despite contentions around labels and the implications for those with ASC, some participants used labels to position themselves away from what they referred to as 'classic autism'. Jane attributed her achievements in life as a demonstration of her functionality, ignoring or dismissing the impact of ASC on her emotional and psychological well-being:

> Several of the women adopted the identity 'Aspie' in response to the deficit model of ASC:

> Whereas Asperger's, we're sort of, we're not to that end of the spectrum, like we're kind of, I suppose, we're in the middle, we're wired differently, we communicate differently, we work differently, but I don't think we're as far as the Autism. (Charlotte)

The term, "high functioning", derives from the previous diagnosis, Asperger's syndrome, and depicts a more strength-based perspective with the hopes of creating a new, more inclusive framework. Interestingly, none of the women considered or reflected upon the removal of Asperger's from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), suggesting, again, a resistance to the medical 'experts' defining their identity and experiences.

Jane and Charlotte used functional categories to support downward comparisons, a technique used to maintain self-esteem, often in the face of a situation or misfortune that is difficult to remedy through instrumental action (Crabtree et al., 2010; Crocker & Major, 1989; Jones et al., 2013):

> I do not identify with the classic autism, and although I realise that to some people, I have an elitist view, I can't help that. It is not intended to be elitist. I simply know that I do not struggle with daily life to the same extent that those with classic or low-functioning autism struggle. I don't have the same neurology as them, any more than I have the same neurology as a neurotypical person. (Jane)

Participants actively constructed their identities, independent of the medical community, self-identifying with the strengths of ASC. While the social model of disability and a social constructionist epistemology seeks to identify the influence of social institutions on experience, it cannot deny the importance of agency in identity development, and this was relevant to participants' experiences of ASC.

The complex experiences of these women highlight the issues surrounding the construct of functionality and what it means to function in society (den Houting, 2019; Tint & Weiss, 2017). The punishment of functionality is not unique to ASC and is often experienced by individuals with mental health issues such as high-functioning anxiety or high-functioning depression. High-functioning depression, for example, describes a person who suffers the symptoms of depression (lethargy, low mood and feeling hopeless) but can complete tasks for school and work with effortful concentration. The constructs of functionality and disability highlight how normative social expectations define what is 'normal' and 'abnormal' behaviour rather than underlying pathology (Jaarsma & Welin, 2012). As Bumiller (2008) highlights, the symptoms of diagnosis are not necessarily the sources of difficulties in functioning, but rather reflect the demands of social expectations. The performance of function inhibits recognition of need and limits access to supports.

Implications

The results of this analysis suggest that women on the AS are subject to the same societal expectations as NT women but may experience and respond differently to these expectations. While gender norms may not be as visceral to this population, judgements from others influence the women's understanding of self, which in turn may influence their identity and well-being. Findings also support social models of disability that suggest difficulties experienced, such

as those seen in ASC, reflect the socio-cultural environment rather than being symptomatic of underlying pathology. The women's experiences and subsequent well-being cannot be accurately understood without understanding the conditions that shaped their experiences (Cosgrove & McHugh, 2000). Thus, researchers and clinicians are required to engage the political, social, cultural, interpersonal and material systems in order to support women on the AS. For these women, their identity reflects the nature of their interactions within society. Consequently, the spectrum of ASC, 'high to low functioning' is experienced within each woman and these experiences are dependent on the outcomes of these interactions. As they age, women appear to have more control over the interactions they value and place less emphasis on the outcomes, particularly once a diagnosis is obtained.

Women on the AS may require extra practical and emotional support during transitional times in their life, such as relationships, motherhood and employment. It is crucial for clinicians to normalise and validate the difficulties this population experiences. Green et al. (2019) discuss the importance of consciousness raising of feminine norms that can lead to well-being and functional difficulties rather than attribute these difficulties to an intrinsic pathology alongside other therapeutic techniques.

The theoretical implications for this study further the debate as to what constitutes a disability, how functionality is medically constructed and the ontological status of ASC. The deficit, pathological status of ASC is challenged when perceived clinical deficiencies are positioned as a response to restrictive socio-cultural demands and not from the 'disorder' itself. This study highlights the impact of narrow essentialist gender norms on the experience of ASC and the negative consequences this has for subjectivity. With expanding definitions of gender-appropriate behaviours, the idea of gender-specific phenotypes of ASC may become redundant. Furthermore, the experience of ASC may be less damaging, and the ontological status of ASC may morph as gender is perceived as a continuous rather than binary construct. Such findings offer support for the movement away from the medical model view of ASC as an entity to be cured and towards an understanding of neurodiversity.

It must be emphasised that the findings and analysis of this study cannot be generalised to all women on the AS. This study provides a snapshot of the unique experiences some women on the AS experience when responding to socio-cultural norms. Participants did not disclose co-morbidity issues; therefore, it should be considered that those individuals with ASC and other conditions are likely to have more complicated experiences regarding their well-being and identity. Other identities such as sexuality and culture were not considered in this analysis, although it is acknowledged these experiences would influence the development of the women's identity. Further to this, women who self-diagnosed as ASC or were under the diagnostic threshold were omitted from the research. These women's experiences are pertinent to understanding the influence of social institutions on women's experiences of ASC. Undiagnosed women do not have the validation of a label and therefore may not experience the assurance and legitimacy attached to gaining access to the ASC community. Future research may expand on the influence of social structures and the experience of ASC for both women and men compared to NT women and men and the impact this has on well-being. Future research may also explore psychology's role in creating and redefining ASC and what role clinicians play in supporting or advocating for the neurodivergent community.

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