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A qualitative exploration of the experiences of self-diagnosed autistic women and gender-diverse individuals who are not pursuing an autism diagnosis

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Abstract

A growing number of adults are choosing to self-identify as autistic without obtaining a formal diagnosis; yet, research into this population remains scarce. Women and gender non-conforming autistics are particularly underresearched, with women facing additional barriers to diagnosis. This study examined the lived experiences of self-diagnosed autistic women and gender-diverse adults and explored how autistic identity is constructed outside of formal diagnosis in this population. Participants ($n = 6$) between the ages of 18 and 69 took part in semi-structured one-to-one online interviews with an autistic researcher to discuss their experiences of being self-diagnosed. Interview transcripts were analysed using interpretive phenomenological analysis. Three superordinate themes were found: (1) autistic self-discovery, (2) living without a diagnosis and (3) self-doubt and self-diagnosis. The findings suggest that many of the experiences of self-diagnosed autistic women and gender-diverse adults are similar to those who are diagnosed but with unique challenges and benefits. This study offers a new perspective on self-diagnosis as an empowering way of attaining a positive autistic identity outside of the deficit paradigm embedded within the diagnostic pathway.

Lay Abstract

As awareness of neurodiversity continues to grow, more adults are seeking autism assessments. This rise in demand is placing pressures on diagnostic services resulting in long waiting lists and high private costs. Many autistic adults are choosing to self-diagnose as an alternative to a lengthy and expensive diagnostic process which pathologizes their experiences. Research into this population remains very scarce, and little is known about how and why autistic adults choose to self-diagnose. Autistic women are especially underdiagnosed and underresearched, with gender-diverse autistics rarely included. This study explored how autistic women and gender-diverse adults acquire and shape their autistic identity outside of formal diagnosis and what effect this has had on their lives. An autistic researcher recruited six self-diagnosed autistic adults through social media and conducted online one-to-one video interviews with them. Three main themes were found: (1) autistic self-discovery, (2) living without a diagnosis, and (3) self-doubt and self-diagnosis. The findings offer new insights into the lives of self-diagnosed autistic women and gender-diverse adults and how their experiences are often similar to those who are diagnosed but with unique challenges and benefits. This study offers a new perspective on self-diagnosis as an empowering way of gaining a positive autistic identity outside of the diagnostic model which views autism as a disorder rather than a difference. This may help self-diagnosed autistics feel more able to disclose their identity to others, access more support and experience less invalidation, stigma and self-doubt.

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Background

Defining autism

Our collective understanding of autism and what it means to be autistic has undergone a seismic shift in recent years, as autistic voices are increasingly shaping the direction of research (Roche et al., 2021) and paving the way for change in a narrative previously dominated by non-autistic 'experts' (Leadbitter et al., 2021; Rosqvist et al., 2015). The dominant framework currently used to describe autism, however, is still rooted in the medical model under which autism is defined as a neurodevelopmental disorder (American Psychiatric Association, 2013). Under this model, disability is viewed as a deficit of biological origin representing a pathological deviation from normative social standards, which is undesirable and must be prevented or cured (Haegele & Hodge, 2016; Shyman, 2016).

The social model of disability challenges this notion, proposing that disability results from the presence of systemic environmental and social barriers, placing the onus on society adapting to accommodate disability rather than disabled individuals adapting to accommodate society (Goering, 2015). The neurodiversity paradigm has developed from this model, framing autism as a 'normal and healthy manifestation of biodiversity' (Chapman, 2021). Proponents of this paradigm oppose the medical model for its deficit-focused diagnostic criteria which does not consider any strengths or benefits of being autistic (Pellicano & den Houting, 2022). This pathologizing view of autism has led to social stigma, which has had a negative impact on autistic well-being (Turnock et al., 2022) and identity (Botha et al., 2022). A neurodiversity movement has formed in response to this, rejecting the concept of normative standards for human development against which autistics are judged, and instead viewing neurodiversity through an intersectional lens, arguing that autistic identity development is not just an individualistic experience but a part of a wider and diverse autistic collective identity and culture (Botha & Gillespie-Lynch, 2022). This strengths-based autistic identity focusing on self-acceptance is being increasingly adopted by the autistic community, and this has been associated with positive well-being and self-esteem (K. Cooper et al., 2017; R. Cooper et al., 2021).

Self-diagnosis

Empowered by the neurodiversity movement, autistic people are reclaiming language and are actively defining what it means to be autistic for themselves (Kenny et al., 2016). As a result, many autistic adults are eschewing the pursuit of a formal diagnosis altogether in favour of constructing their own autistic identities with the help of their support networks and neurodivergent communities rather than from healthcare professionals (Overton et al., 2023). This kind of self-determination has been viewed as a legitimate expression of an autistic identity shaped through a social rather than a medical lens (Morrison, 2019; Price, 2022). However, very limited research exists focusing on the experiences of self-identifying autistic adults. A recent scoping review found that self-identification had a positive and beneficial influence on self-understanding and self-acceptance in autistic adults following years of feeling different from others around them (Lewis, 2016; Overton et al., 2023). Parsloe (2015) found that adults who self-identified as autistic before seeking a diagnosis had a more positive view of autism than those who were given a clinical diagnosis. He suggested that this may be due to self-identifying adults actively choosing their identity rather than having it foisted on them, proposing that the process of self-identification may enable individuals to develop a more positive autistic identity. Sarrett's (2016) study of an online autistic community found that autistic self-experts gained their autistic social identity and community membership through self-knowledge and self-awareness rather than through external validation of a formal diagnosis, rejecting the medical model in the process. Self-experts are autistic individuals that place great importance on their own knowledge, experiences and their own embodied subjectivities, including neurodifferences in relation to autism. While for some, a formal diagnosis was perceived as unnecessary and without benefit, for others multiple barriers were identified to seeking a diagnosis, such as lack of trust in healthcare professionals and fear of not being believed (Lewis, 2016), with these barriers frequently reported as a key reason for self-diagnosis (Lewis, 2017). Self-diagnosed autistic women in particular expressed concern that they would be disbelieved by health professionals as they felt they did not have a 'classic' presentation of autism (Lewis, 2016).

Gender

Women are diagnosed with autism far less frequently than men, with an estimated gender ratio of 3:1 (Loomes et al., 2017). This has led to widespread assumptions that autism is more prevalent in men due to genetic factors (Zhang et al., 2020) or as a result of autism defined by an 'extreme male brain' (Baron-Cohen, 2002). However, a more compelling explanation for this gender disparity is that autistic women are widely underrecognized and overlooked for autism assessments, with evidence demonstrating that women face a greater delay in referrals are less likely to be correctly diagnosed and are diagnosed later in life (Fusar-Poli et al., 2022). It is now increasingly understood that the diagnostic tools for autism are not as adequate at detecting autistic women largely due to these measures developed from predominantly male samples (Estrin

et al., 2021). Clinician bias against diagnosing autistic women and girls has also been identified as a barrier for formal diagnosis (Estrin et al., 2021). As a result, autistic women are 'under-recognised, under-researched and under-served' (Chester, 2019), with under- and misdiagnosis leading to lack of timely access to support, missed opportunity for developing self-understanding and a negative impact on well-being (Dell'Osso & Carpita, 2023; Leedham et al., 2020; Oredipe et al., 2023). 'Camouflaging' has been proposed as an explanation for why many autistic women go undetected through life, with women adapting to the neurotypical social demands of their environment by learning to 'mask' their outwards autistic traits and adopting social mimicry in order to fit in (Bargiela et al., 2016; Hull et al., 2020). Camouflaging has been associated with autism-related stigma (Perry et al., 2022) and negative impacts on well-being, emotional regulation and self-esteem (Tubio-Fungueirino et al., 2021). Overall, autistic women face additional difficulties experiencing gendered bias in both healthcare and social settings, as well the psychological price of performing 'normality' to meet neurotypical standards (Yau et al., 2023; Zener, 2019). It is therefore highly probable that a great proportion of self-diagnosed adults are women; yet, there is no study exclusively investigating their lived experience.

There is also an emerging critique of the gender essentialising effects in expressing autism, with camouflaging designated as a 'feminine' autistic trait which excludes gender non-conforming autistic individuals and men, who are just as likely to experience it (McQuaid et al., 2022; Moore et al., 2022). Transgender and gender-diverse individuals are more likely to be autistic than cisgender populations (Warrier et al., 2020) and, as minoritized groups, share many of the same experiences as autistic women (Bruce et al., 2023). Both women and non-binary autistic individuals are under researched, yet share the same priorities in wanting to see more research focusing on better representation of their experiences and on improving the diagnostic process (Putnam et al., 2023). Therefore, it is vital that the experiences of self-diagnosed women and gender-diverse autistic adults are explored together to move toward closing the gap in the research.

This study examines the lived experiences of self-identifying autistic women and gender-diverse adults, and explores how autistic identity is constructed outside of formal diagnosis in this population.

Methodology

Participant recruitment

Autistic women and gender-diverse individuals, identifying as autistic and who did not have or seek a diagnosis, were selected to take part in the study. The participants were only recruited in the United Kingdom. To be included in the study, participants had to be aged 18 or over, identifying as autistic and identifying as either female or outside the gender binary. Participants were recruited through opportunity sampling on social media websites Facebook, Twitter and Reddit. Where recruitment took place in autism support groups, permission was obtained from group moderators. Social media was chosen for recruitment as it is a vital platform for autistic community and culture building (Hassrick et al., 2021). The first author disclosed their autistic identity during recruitment to facilitate trust and understanding with participants as there are documented tensions between autistics and neurotypical autism researchers (Guberman, 2023). The first author was able to use identity disclosure to give reassurance that the aims of the research will benefit the autistic community, reflecting their research priority demands (Roche et al., 2021). Interviews were conducted online over Microsoft Teams to promote accessibility and ensure that participants from anywhere in the United Kingdom could take part. All interviews were 60 min long, and a denaturalized transcription convention was used in transcribing the data where grammar was corrected to increase readability in order to facilitate coding for emergent themes (Oliver et al., 2005).

One-to-one interviewing was the chosen data collection method as the preferred method of studying individual experience (Howard et al., 2019). The interviews were semi-structured for a more participant-led approach, yielding more in-depth exploration of meaning making and richer data. An interview schedule was developed to explore broad subjects such as healthcare experiences, public perceptions of autism and what it was like to self-identify as autistic, to generate more follow-up questions where more detailed data could emerge for analysis. The interview was conducted by the first author, and the data were transcribed manually by the first author.

Overall, six participants took part in the study with an age range of 18–69, identifying as female ($n = 4$), non-binary ($n = 1$) and genderfluid/genderqueer ($n = 1$). See Table 1 for more detailed demographic data.

Table 1. Participant demographics.

Participant Pseudonym	Age	Gender identity
Harper	18	Genderfluid/genderqueer
Riley	18	Non-binary
Willow	29	Female
Sophia	34	Female
Emily	40	Female
June	69	Female

The researcher

The researcher and first author shares key characteristics with the participants, being a self-diagnosed autistic who was assigned female at birth and identifies as non-binary. This enabled the researcher to make potentially more accurate interpretations of the participants' experiences, as also supported by the double empathy theory by D. E. M. Milton (2012) and strengthening data analysis in the process. The researcher occupying the role of stakeholder also meets one of the core demands of the autistic community for more studies to be led by autistic researchers (Chown et al., 2017).

Data analysis method

Interpretive phenomenological analysis (IPA) (Smith et al., 2009) was used to analyse the data. The first author performed the analysis. IPA was chosen as an effective method for delivering insight into lived experience by placing the participant, rather than the researcher, as the expert of their own sense making, equalising the power balance between both parties. IPA is a particularly effective qualitative approach to autistic research as its focus on insider perspective and use of semi-structured interviews amplifies autistic voices, facilitates autistic agency in direction and pacing and encourages rapport between participant and researcher (Howard et al., 2019).

The analysis method began with a coding stage where meaning units were noted under transcribed text. Several readings refined the coding until overarching themes began to emerge. Meaning units were clustered together into smaller groups which became the subordinate themes, such as 'masking to get by' and 'making my own accommodations', and eventually categorized into larger superordinate themes, such as 'living without a diagnosis'. Finally, all themes were pulled together to provide an overarching narrative to answer the research question.

Analysis and discussion

Three superordinate themes were found (see Table 2):

First theme: Autistic self-discovery

The first superordinate theme of autistic self-discovery described how acquiring an autistic identity transformed participants' understanding of themselves in a positive way, which enabled them to re-conceptualise autism outside of the deficit paradigm.

Subtheme I: Understanding myself better. Participants discussed how they became aware of being autistic from early to late adulthood. Most participants came to realise they had autistic family members, diagnosed or undiagnosed, and identified with their traits, which contributed to their self-identification. Two participants reported their child receiving a formal autism diagnosis as the catalyst in their own journey to self-diagnosis:

> I can read her like a book. I understand it. It's intuitive to me in a way that my husband or those around us don't necessarily understand straight away. So I was like, "she's just like me" and so through reading this literature and reviews it all became clear. (Emily)

Participants described discovering about their autistic identity through online content detailing autistic traits which they found themselves relating to, conducting their own research using books and online communities, undertaking tests and even working with other autistic people. All participants experienced feeling different from others around them – not fitting in at school, being bullied or struggling to make friends – which ultimately led many to consider whether they may be autistic: 'I'm not like everybody else. But that's always been the complaint – "why can't you be normal?"' (June). For Harper, being fundamentally misunderstood and othered by their peers prompted them to explore an autistic identity: 'That kind of thing was when I first started being like "people don't like me and I don't know why". The people like, they're observing me and seeing something that I'm not' (Harper).

Coming to the realization that they may be autistic enabled participants to understand themselves in new ways, reframing many of their struggles to gain novel insights and self-acceptance. Riley described their self-diagnosis as resulting from a 'pulling together of my previous life experiences', which led to things finally making sense for them. For Sophia, self-diagnosis meant 'all this explains why I was like this … why I did this as a child, as a teenager'. For most participants, these new insights helped them gain greater self-awareness of their needs and empowered them to self-advocate, while learning strategies and skills to manage their unique challenges: 'I've become a lot more confident and strong and there's a power in that knowledge and in understanding my limitations and my needs, which I didn't have before' (Willow).

These findings are supported by Lewis' (2016) study which also identified greater self-understanding in self-diagnosed participants. Feeling different, being misunderstood and experiencing social difficulties have also been frequently reported by autistic women (Milner et al., 2019; Yau et al., 2023). Self-identification has been associated with a positive influence on self-understanding in autistic adults who often reported relief in finally findings answers to explain their experiences (Overton et al., 2023). The same benefits appear to be experienced for those who also received a formal diagnosis in adulthood (Ghanouni & Seaker, 2023), suggesting that the impact of

Table 2. Superordinate and subordinate themes.

Superordinate theme	Subordinate theme	Supporting quotes
Autistic self-discovery	Understanding myself better	"It all makes sense now" (Riley) "I think being able to reflect on things has helped me a lot" (Sophia) "I've actually been able to learn more about myself and why I am the way I am" (Willow)
	Defining autism for ourselves	"we connect so deeply and we see things so differently" (Willow) "I definitely don't think how other people do, which I've always tried to make as a positive" (Emily) "it's just kind of me, and I wouldn't want someone to take away that because then I would be different and that's just depressing" (Harper)
Living without a diagnosis	Masking to get by	"Masking is just not being yourself in public" (Sophia) "changing my behaviour and how I present myself to just try to fit in" (Emily) "it's hard for me to determine what is masking for too long and what appears as a result of masking instead of what is just my normal personality" (Riley)
	Making my own accommodations	"I've managed to change my life to suit me." (Sophia) "I was lucky to have jobs where I had quite a lot of control over what I did and when I did it, and so that suited me fine" (June) "I've carved out my own life" (Emily)
	Confronting gendered bias	"autistic women definitely get an even shorter end of the stick, and our stick isn't as long to begin with because we burn out faster."(Willow) "the expectations on girls from a very, very young age is..."you're going to be better at making friends, you're going to be better at social interactions"...and there's an additional expectation to be nurturing so when as an autistic girl, if that's not in your wheelhouse of skills...then you feel like you're extra failing" (Emily) "a lot of GPs aren't trained on trans issues so they'll often just reject trans people because they don't know about them, or they've heard on the news something bad" (Riley)
	Managing trust and disclosure	"I think I trust other autistic people more than I trust anybody else" (June) "Self-diagnosed" is kind of a risky thing to say in general which is a bit sad" (Harper) "I'm friends with a lot of autistic people and if I told them that I thought that I was autistic then there would be a solidarity there" (Riley)
Self-doubt and self-diagnosis	Dealing with self-doubt	"There was a bit of doubt that, is this real or is it just because I know about autism that I'm seeing it in myself, or is this actually how I am and I've just realized?" (Sophia) "this constant back and forth: do I have this? Do I not have this?" (Riley) "no, not like me at all who managed to go to university and get a proper career and that sort of thing. How could I be autistic?" (June)
	Challenging the diagnostic model	"There's a lot of things a diagnosis gives you, but there's also a lot of things that it takes away" (Riley) "don't feel like I need it in my life because I've been able to carve my path to date without a diagnosis" (Emily) "I think that being able to self-diagnose is a privilege. Not everyone has the choice." (Sophia)

both self-identification and diagnosis on autistic identity may be very similar.

Subtheme II: Defining autism for ourselves. All participants described what being autistic meant to them in ways which were both individually and collectively meaningful to them: 'I would not be myself if I wasn't autistic' (Willow). For the participants, autism was not something that could be regarded as separate from themselves: 'It's not like there's me and the autism and like, sometimes the autism kicks in and I do something, like, it's just part of me' (Harper). Autism was also frequently defined in a relational way:

> I suppose it's a thing that if you were on a desert island, it wouldn't mean anything. It has a meaning in relation to other people, I think. It's as much about how you relate to other people as how you manage your own environment. (June)

As June suggested, having the chance to relate to others who are alike and belong to the same group may encourage positive meanings of identity. This is supported by Titchkosky (2003) who suggested that any experience of identity is always given in a relational space where individuals embrace and/or resist societal meanings regarding their selves. She argues, however, that there are many possibilities to describe the relation between identity and the body. While the medical model pushes a medicalised narrative, the participants of this study resisted this narrative and have appreciated positive meanings of being autistic such as thinking and seeing things differently, being able to approach problems from a unique angle, focusing on interests, being curious and more efficient. Other benefits mentioned were being emotive, caring about others and the ability to make deeper connections. Defying prevailing norms was viewed as a particularly valued autistic trait:

> It's a different way of seeing the world. It's just perceiving things in a what I think is a more interesting way, kind of challenging the status quo that's always gone before, or not just assuming that that's how things always have to be. (Sophia)

Challenging the status quo refers to some evidence that autistic individuals are wired differently from neurotypicals. This embraces the thesis of autism as a natural neurocognitive variability which dismantles commonly held views in perception science. For instance, research by Mottron et al. (2006) found that autistic individuals have more enhanced local processing than non-autistic people, which enables them to focus better on smaller details and potentially approach established norms and conventions more critically.

These perspectives are validated in the growing body of research demonstrating autism as a largely positive social identity (R. Cooper et al., 2021) and supported by the overwhelming preference for identity rather than person-first language to reflect the understanding of autism as an intrinsic and inseparable aspect of the self (Kenny et al., 2016). The references to a collective autistic identity can be credited to the gains of the neurodiversity movement which has advanced a wider autistic culture of meaning making and rejection of the deficit paradigm (Botha & Gillespie-Lynch, 2022).

Second theme: Living without a diagnosis

Participants described how living in a neurotypical world without a diagnosis led to many consequences for their well-being.

Subtheme I: Masking to get by. Almost all participants described 'masking' their autistic traits by carefully managing their self-expression around others to fit in. Masking was defined by participants as 'being who you think you have to be in order to pass without being seen as weird or too different' (Sophia) by adjusting speech, body language, eye contact or suppressing stims. Masking appeared to also be a strategy participants relied on to avoid disclosing their self-diagnosis to others. Some participants lamented the toll that masking took on their autistic self-expression: 'I also think that the innocence and a certain level of joy in the autistic experience kind of got socialized out of me growing up' (Willow). Masking appeared to be an effortful lifelong process of learning how to exist in a neurotypical world by observing others who seem to have an innate social knowledge the participants had to 'manually learn … rather than being born with them' (Emily):

> And you do learn to fit in, you do learn to shut up, you do learn to listen, and you do learn to watch what other people are doing so you know what to do yourself, that sort of thing. But some things just don't come instinctively, and it would be nice to be a bit more forgiving of that lack of intuition. But I think over the years, of course it makes you quite a student of other people's behaviour, even if you're not terribly insightful about your own. (June)

Several participants expressed the blurring of boundaries between what they perceived as masking and who they were:

> I think there is a certain level where I don't truly know who I am because there is a certain level of masking in me that's just innate and it's hard to separate where the habits and the masking begins and where the mask comes off. (Willow)

Participants described the masking process involving 'a lot of the preparation. It's a lot of the practicing what you're going to say. It's a lot of the planning for every eventuality, what might go wrong' (Sophia) followed by lengthy recovery

to decompress. Participants described masking as exhausting and draining: 'being sociable is almost like an adrenaline sport' (Emily). Some participants reported having to mask for too long causing them to crash and reach autistic burnout, which was mistaken for depression, as 'there will be a point where you can't keep doing it anymore' (Willow).

These findings are supported by research showing autistic women using masking to hide their autistic traits in public by emulating the behaviours of others through deliberate and conscious observation (Bargiela et al., 2016; Hull et al., 2020). The desire to fit in expressed by some participants is supported by masking as a potential strategy for evading stigma and negative attention (Perry et al., 2022). However, masking by non-binary participants challenges the assumption of this strategy as an inherently female expression, with masking also experienced by other genders (McQuaid et al., 2022; Moore et al., 2022). Participant experience of exhaustion and identity blurring post-masking is also consistent with previous research (Milner et al., 2019; Tubio-Fungueirino et al., 2021).

Subtheme II: Confronting gendered bias. Dealing with stereotypes about autistic women and gendered bias negatively impacted the participants. There is little awareness that autistic women could lead successful independent lives: 'It's not really been mentioned that if you're an autistic woman, you can have a family, you can have a job, you can go about life. It's very much that if you're autistic, you need support' (Sophia).

Furthermore, some participants acknowledged double standards in being an autistic woman compared to being an autistic man in relation to accessing care and support. Willow remarked how autistic men could 'exhibit learned helplessness' to access greater care and support, while autistic women received 'no grace' and were not 'allowed to struggle with anything'. Participants acknowledged that women experienced more masking due to gendered social expectations that autistic men were not subjected to, resulting in less recognition of autism in women: 'the reason that we mask so well, and we fly under the radar is that we are strictly socially managed. Whereas it's like boys can be boys or the disabilities are an excuse' (Willow).

Gendered social pressures of motherhood were also mentioned when Emily described unique challenges faced by autistic women dealing with sensory overwhelm:

> as a neurodiverse woman who is a mother, it's an added level of hell because it's yet another sphere in which I'm failing or being made to feel like in society that I don't fit in, that I'm weird because I'm weird for not loving it or I'm weird for finding it very difficult. (Emily)

Positives of self-diagnosis were also cited by Emily who described relief after reading about similar experiences of other autistic mothers: 'that's probably been one of the more positive aspects of being a self-identifying autistic, of going "I shouldn't give myself a hard time for feeling like this is utterly overwhelming"'. For trans non-binary participant Riley, gendered bias was framed in the context of negative prejudice from general practitioners and 'a lot of people that don't like trans people', which they perceived as creating barriers to them accessing gender-affirming healthcare.

Nearly all participants lamented a lack of representation of autistic female and gender-diverse experience in society, remarking that better representation would help educate and inform the public. Experiences of gendered bias are supported by research showing autistic women are under more intense social pressures to perform neurotypicality at the expense of their well-being and self-image (Yau et al., 2023). Less research is available on how autistic women and non-binary adults perceive themselves as treated differently compared with autistic men. However, autistic women report experiencing more vulnerabilities and mistreatment (Zener, 2019).

Subtheme III: Making my own accommodations. All participants had gone through their lives without any formal support or accommodations due to not having a clinical diagnosis, with many choosing not to disclose their self-diagnosis at work and in educational settings, fearing discrimination from lack of legal protection. Some reported growing up without formal support as detrimental, while others expressed discomfort with having a disability label applied to them:

> in the past it was a term applied only to people who were quite seriously disabled who couldn't manage life without a lot of help, so to apply it to somebody like me, who's managed to sail through life fairly unscathed, seems a bit outrageous really. (June)

Most participants found ways to accommodate their own needs by seeking flexible workplace environments which allowed them to have more control over interacting with the public, organising their time, socialising with colleagues and their physical attendance. Most participants felt empowered in doing so through self-awareness of their autistic traits and self-diagnosis to advocate for their needs and use positive coping strategies to manage them:

> I feel that I know myself, I know what I need, and I know when difficult things happen, how to cope, and I've built up all those tools over time to cope through a lot of kind of trial and error. I've had a lot of difficult times, but I've managed to kind of overcome that. (Sophia)

The use of functioning labels to categorize autistics by their perceived ability to adapt to neurotypical societal demands was also challenged: 'people use "high-functioning" as a way to deny support the same way that they use "low-functioning" to deny agency' (Willow). However,

participants also acknowledged that being able to make their own accommodations is a privilege not always available to other autistic adults.

There is yet little research on the experiences of self-diagnosed adults making their own accommodations. Many diagnosed autistic adults choose not to request accommodations at work due to fears of discrimination as a result of disclosure (Lindsay et al., 2021) and thus making one's own accommodations may be a strategy to avoid being pathologized for being different. Many autistic adults may also not feel they are entitled to or require accommodations as they do not describe themselves as having a disability (Kenny et al., 2016). This desire not to be medicalised to access support may also contribute to participants wishing to remain self-diagnosed.

Subtheme IV: Managing trust and disclosure. All participants described exercising great care with whom they disclosed their self-diagnosis, preferring to keep it within a small circle of trusted friends. Participants felt largely unable to disclose their self-diagnosis to non-autistic individuals due to fear of being misunderstood, disbelieved, discriminated against or being subjected to negative bias and stereotypes: '*So, generally I would never disclose my self-diagnosis to a non-autistic person because then I have this massive well of doubt that they won't understand what that means, and I'm terrified of being treated differently for it*' (Riley).

Most participants reported a lack of support and validation from their family with their self-diagnosis, with some unable to even broach the subject due to concerns that their identity would be dismissed:

> And as for self-diagnosis, they'd say, 'yeah, well, you know, doesn't mean anything. Doesn't mean anything'. It would only count if it had got a sort of doctor's signature on it, otherwise it would just be me making stuff up again. (June)

Participants expressed trusting other autistics and neurodivergent people with their disclosure the most, receiving their primary support, solidarity and validation for their self-diagnosis from autistic communities both online and in person:

> I probably only say specifically I'm self-diagnosed with autism with other people who are autistic or self-diagnosed with autism because it's more of a safe space, I feel. I don't want someone to judge me thinking I'm making it up. (Harper)

Participants reported feeling best understood by their autistic peers with whom they were able to be their most authentic selves. This suggests that participants were most likely still masking when in the company of non-autistic individuals, even after self-diagnosis. Conversely, most participants expressed lack of trust with disclosure to healthcare professionals, with several reporting being invalidated when attempting to seek a formal diagnosis. Participants felt these experiences were due to professionals not understanding how autistic women and gender non-conforming adults presented and feeling that they were not being listened to or taken seriously.

Fears around disclosure to non-autistics are supported by research demonstrating similar concerns around being disbelieved and enduring negative bias (Botha et al., 2022). Autistic adults have also reported experiencing better mutual understanding, belonging, ease and personal authenticity in their interactions with other autistics (Crompton et al., 2020). Participant experience of gendered clinician bias is equally evidenced in research, with women and gender nonconforming autistic adults reporting lack of knowledge and understanding from professionals resulting in them being invalidated (Bruce et al., 2023; Estrin et al., 2021).

Third theme: Self-doubt and self-diagnosis

The third theme describes participants dealing with self-doubt about their autistic identity in the absence of a formal diagnosis. It further explores what a diagnosis represents to them and why it should be a choice rather than a requirement to be acknowledged as autistic.

Subtheme I: Dealing with self-doubt. All participants expressed some form of doubt in accepting their self-diagnosis. Riley described 'this cycle of "I don't know and I can't know without a diagnosis"' and Emily talked about second-guessing herself 'So, am I just seeing things that aren't there about myself?' Participants expressed concerns that self-diagnosing with autism would be perceived as 'trying for special treatment' (Riley), 'doing it for attention' (Willow), 'claim for yourself something that you're not entitled to' (June), or even invading disability spaces they didn't feel they could belong to. Several participants mentioned potentially 'gaslighting' themselves, with Harper fearing 'What if I'm not autistic enough?' Self-doubt was also linked to perceptions of how well participants thought they functioned in a neurotypical world:

> but being able to function makes you doubt, well, am I even autistic in the first place? Because if I can cope, surely I'm fine? But then that's like, oh if I say I'm fine, does that mean that if you're autistic, you're not fine? So, it's that kind of internalized ableism again. (Sophia)

These findings may indicate internalising negative public perceptions and stereotypes of autism with poor representation of autistic successes (Botha et al., 2022). Many of these doubts also seem to be linked to a general fear of autistic self-diagnosed adults in not being believed (Lewis, 2016), with Harper remarking 'I think it's a very real fear, just in general about mental health, anything –

what if I'm making it up?' This fear is especially prevalent for autistic women and gender minoritized groups who often feel their healthcare concerns are not understood by professionals (Bruce et al., 2023; Estrin et al., 2021).

Subtheme II: Challenging the diagnostic model. Participants described a variety of experiences of contemplating a formal diagnosis at some point in their lives. Some decided not to proceed due to the pathologizing nature of the process, some felt a diagnosis was too inaccessible, and others did not see the inherent need or value or obtaining one at all. All participants described various barriers to getting a diagnosis such as long waiting lists, age, high costs of private assessments, fear of not being believed, reliance on general practitioners as gatekeepers to referrals, and a concern that a diagnosis would mean being treated differently by others. Several participants also described negative and invalidating experiences with healthcare professionals and questioned their authority on matters of identity: 'they may know in general, but they don't know you. You know yourself the best, how you feel inside' (Sophia). One participant, Willow, described being denied a diagnosis after her assessment, believing it to be due to her ability to mask well and gendered bias from professionals, all despite her experience of being singled out for being different from a young age: 'doctors behave like it's impossible to figure out an autistic woman, but the kids on the playground can peg you straight away'.

Overall, participants agreed that a formal diagnosis had both pros and cons: 'There's a lot of things a diagnosis gives you, but there's also a lot of things that it takes away' (Riley). It was argued that some did not get a choice if they were diagnosed at an early age, which took away their ability to decide for themselves: 'No one should force a diagnosis on someone' (Harper). Ultimately, it was felt that 'being self-diagnosed is the privilege of being able to hide that you're autistic at times, and not everyone is lucky enough to be able to do that' (Sophia).

All participants agreed that although diagnosis was the only way to access formal support and accommodations, this should instead be provided based on individual needs rather than a medicalised label: 'it's not like once you get a diagnosis, suddenly you're allowed to start catering to their needs' (Harper). Some participants described the false promise of help that a diagnosis represented:

> I think a lot of people that are desperate for a diagnosis, they don't want the diagnosis, they want the solutions, they want the help, they want their life to be easier, and just getting a label won't make that happen. (Sophia)

Participants criticised the deficit-based approach to the diagnostic process which characterised autism as undesirable and promoted a negative self-image:

the idea inherently, that to get a diagnosis of autism you have to be suffering is awful and demonizes autism. In a way it's like, this has to be bad and will only be bad for it to be classed as autism. Awful. (Riley)

Participants questioned the purpose and necessity of diagnoses altogether: 'diagnoses related to identity shouldn't exist' (Riley). Most admitted to not wanting a diagnosis as they had managed their life without it and did not see any immediate benefits. However, they described the value of a formal diagnosis in providing legal protection, external validation and recognition of their struggles, with some hoping that it would have a positive impact on self-image: 'it would make me feel better about myself…make me a bit kinder to myself… for anyone like me who is sort of full of self-doubt and quite self-blaming, maybe a diagnosis would help them' (June).

All participants wanted self-diagnosis to be recognised and validated: 'I think it's a shame that self-diagnosis isn't really respected' (Emily). The decision to self-diagnose was described as not one taken lightly: 'It's a decision that no one rushes into, they spend months or years thinking about it and thinking it through before they voice it to anyone' (Riley).

Self-diagnosed adults questioning the need for diagnosis was also explored in Lewis' (2016) study with many of the same reported barriers to diagnosis (Lewis, 2017). The importance of choice in pursuing a diagnosis was also noted by Parsloe (2015) who suggested self-diagnosed adults had a more positive view of their identity as a result. Participants appearing to value self-knowledge over clinician expertise were supported by Sarrett (2016), with Gillespie-Lynch et al. (2017) arguing that autistic adults should be considered as autism experts alongside professionals. Participant critiques of the deficit paradigm and negative conceptualising of autism reflects criticism of the diagnostic process for focusing on negatives and never any positives to being autistic (Crane et al., 2018; Morrison, 2019). In some ways, a formal diagnosis may itself be a barrier to self-determination.

Further discussion

The findings showed the unique challenges of self-diagnosed autistic women and gender-diverse individuals in juggling public misconceptions about autism together with pressures to mask, facing gender bias and the fear of not being truly believed without a diagnosis. However, the findings also showed self-diagnosis as having its own strengths with participants able to construct a more positive autistic identity, attain deeper self-awareness and self-knowledge to gain greater independence, self-advocacy and self-management.

Many of the experiences of self-diagnosed participants, such as masking and negative bias, appear to be shared by late-diagnosed women. Self-diagnosis did not appear

to mitigate the negative effects of masking on the well-being of our participants, though all reported finding more authentic self-expression and acceptance among autistic peers. This is in line with research showing late-diagnosed autistic women also finding online autistic communities helpful and supportive (Haney & Cullen, 2017; Leedham et al., 2020). However, a recent study involving both formally and self-diagnosed autistic adults suggested that higher autistic community connectedness did not moderate the negative relationship between masking and well-being (Cage et al., 2022). This highlights the shared burden of both formally and self-diagnosed autistics in facing societal prejudices which cannot always be escaped through seeking refuge in neurodivergent communities. Rather than framing masking as an individualised problem for autistics to overcome for themselves, more demands could be made of neurotypical society to create more acceptance and thus safety for autistic traits to be more freely expressed. Arguably, this may only be achieved once autism is no longer medicalised as a disorder.

There are nonetheless benefits to formal diagnosis for adults such as increased self-understanding and self-acceptance (Lilley et al., 2022) which are also the benefits of self-diagnosis shared by our participants. However, formal diagnosis confers legal protections and the right to claim workplace accommodations which self-diagnosis currently does not (Davies et al., 2022). Our participants described having to quietly make their own accommodations at work and in their own lives as a result while also noting the 'privilege' of being able to do so. This may refer to socioeconomic privilege, which could enable choices not available to all. One study found that children of higher educated mothers were twice as likely to be diagnosed with autism, creating barriers for life chances and career advancement for those from less advantaged households (Kelly et al., 2019). Lower socioeconomic status may similarly hinder self-identification and limit opportunities for self-tailored accommodations without formal support. However, as expressed strongly by all our participants, formal diagnosis should not gate keep access to accommodations and support for those who need it. Relying on official diagnosis runs the risk of surrendering the right to define who gets to be autistic and what autism is over to clinicians and professions who are predominately not autistic themselves (Fletcher-Watson, 2023).

One of the strengths of the current study is that the main researcher (and first author) is autistic, and that IPA was used to analyse the data. Using IPA in this study, especially the reflexivity required in IPA, enabled the researcher to consider the impact of their own preconceptions on their interpretation of participants' words, thereby reducing the inherent misunderstandings that often occur between autistics and neurotypical people in what is known as the 'double empathy problem' (D. E. M. Milton, 2012). According to this theory, rather than autistics lacking in empathy, it is non-autistics who may struggle to understand the autistic lived experience and this may ultimately translate into an inaccurate representation of autistic meaning making in research (D. Milton et al., 2022). With autistic-led research this problem is bypassed, and more accurate interpretation is thus made possible.

Limitations of this study consisted of a small participant cohort. Future research should utilise a larger sample size to focus exclusively on the experiences of self-diagnosed gender-diverse and transgender autistic adults as this population is currently underresearched. Autistic identity formation outside of gendered phenotype expectations of autism should be explored as well as any additional challenges in accessing gender-affirming healthcare and diagnosis for queer autistics. It is equally important that autistic stakeholders are closely involved in any further research. An additional limitation emerged from using semi-structured interviews as our data collection method was that participants had to be comfortable with verbal expression, which excluded participants who had alternative non-verbal communication preferences. Future mixed-methods studies can explore more systematically and inclusively how experiences may differ between formal and self-diagnosed autistics.

There is a current emergent debate around the validity of self-diagnosis and whether autism should remain as a medicalised label. For the participants, self-diagnosis appeared to develop because of the barriers to clinical diagnosis but later became a deliberate position in relation to a journey through societal normativity toward an appreciation of their own unique identity. Self-diagnosis has a cathartic power to restructure their determination to claim their right to be their own essential self, liberated from the deficit paradigm which frames autism as a disorder in need of intervention. Our study emphasizes the importance of recognising self-diagnosis as a legitimate path to autistic self-discovery in order to improve access to accommodations and support which autistics, especially women and gender-diverse adults, are currently lacking.

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