Sense-making narratives of autistic women diagnosed in adulthood: a systematic review of the qualitative research

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Few qualitative studies have explored the lives of autistic women diagnosed in adulthood, despite this knowledge being essential to inform awareness of the intersection of autism and gender. This systematic review was undertaken to synthesise available qualitative evidence on the lived experience of autistic women diagnosed in adulthood. The accounts of 50 women from nine qualitative studies were synthesised using thematic analysis and four super-ordinate themes were identified: wanting to 'fit in'; making sense of past experiences; developing a new 'autistic identity'; and barriers to support. The autistic women spent many years without a diagnosis or autism-specific support, felt misunderstood, and experienced social exclusion. Following their diagnosis, they reframed these experiences into new 'sense-making narratives', used social media to contact other autistic people, and developed neurodiverse-affirming autistic identities. The studies suggested that health and social care professionals were not always able to recognise, refer, diagnose, and support autistic women effectively.

Points of interest

- In childhood, the autistic women who participated in the nine reviewed studies remembered feeling that they were 'weird' or 'alien' and being bullied due to their difficulties with socialising

- These participants imitated their more 'easy-going' friends in social situations to keep up appearances and look as if they were in control

- After their diagnosis, the autistic women felt more able to be themselves, rather than trying to be the 'ideal' person that others expected them to be

- The women who participated in the studies believed that, if they had been diagnosed in childhood, they would have coped better with dangerous situations they had encountered during their lives

- Most of the women in the studies felt proud of their autistic identity and the success they had achieved, despite the number of challenges they had faced

Introduction

The researchers carried out this systematic review to explore what the findings from primary qualitative studies may reveal about the lived experience of autistic women diagnosed in adulthood, drawing on neurodiversity and intersectionality as their theoretical framework. This framework supported a critical interpretation of the experiences of the autistic women from the reviewed studies, that stemmed from an intersection of their gender and autistic identities.

Currently, there is no reliable and definitive diagnostic biomarker for autism, and so diagnosis is based on a set of behaviours which must include difficulties with social interaction and restricted, repetitive behaviours and interests which cause significant issues for an individual (WHO 2018). Without a biomarker, diagnosis is more subjective and open to interpretation by clinicians. Although people with these set of behaviours have been around since the dawn of humanity, new disciplines emerged during the last century, such as child psychiatry, that classified and managed the behaviour of the population according to normative measures (Foucault 1975). The construction of 'autism' placed a boundary within a continuum of behaviours and separated out the traits considered 'normal' and 'abnormal' (Molloy and Vasil 2002; Nadesan 2013).

When the additional autism category of Asperger syndrome was classified in 1992, the number of people diagnosed in Europe and North America increased due to the medicalisation of 'atypical' behaviours in people without a learning disability (Conrad 2007; Wheeler 2011; WHO 1992). This rising prevalence contributed to an increase in autism awareness, the availability of assessment centres and autism services, and diagnostic

switching from other developmental and psychiatric conditions to autism (Russell 2021).

Media interest in neurodiversity, autobiographies of autistic people, and fictional accounts increased the likelihood that a person may consider an autism diagnosis as an explanation of their differences (Hacking 2009; Russell 2021; Russell et al. 2015). This subsequently meant that even more people got diagnosed, creating a 'looping effect' (Hacking 1995). Furthermore, autism was historically regarded as a very rare condition of childhood, mainly occurring in boys, whilst now it is considered to be a lifelong neurodevelopmental divergence occurring in all genders (Brugha et al. 2011).

Autism, without a learning disability or language delay, previously known as Asperger syndrome, was categorised in 1992 (WHO 1992). Consequently, autistic women without an additional learning disability or language delay, who had been at school before the early-1990s, were unlikely to have been diagnosed during their school years. Although autism is now known to be a lifelong condition, with similar prevalence rates in all age groups, it was historically understood to be a condition of childhood (Brugha et al. 2011). As autism was thought to affect predominantly young boys, many autistic women remained undiagnosed for decades without any autism-specific support (Brugha et al. 2016). It may be that women, who decide to seek a diagnosis later in life, are able to understand themselves better and make more sense of their experiences. Exploring the lived experiences of autistic women who were diagnosed in adulthood is essential for conceptualising potential avenues of support, yet their 'voice' has been largely missed, as few qualitative studies have been undertaken in this group (Milton 2014). A roundtable report identified gaps in autism research and specifically highlighted the lack of knowledge about autistic women and the small numbers of women included in research studies (Howlin et al. 2015). Feminist disability studies emphasise the importance of all women's voices being brought to the forefront, especially in research where their experiences have traditionally been dismissed

and misrepresented (Garland-Thomson 2005; Piepmeier, Cantrell, and Maggio 2014; Wendell 1989).

While writing this review, the researchers chose to use identity-first language rather than person-first language, for example the term 'autistic person' instead of 'person with autism', as this is the terminology that most of the autistic community in the UK prefers (Kenny et al. 2016; Sinclair 2013). Person-first language has been generally rejected by this community as autistic people do not wish to be disassociated from their condition, as if it is somehow shameful. The terminology used is important, as it shapes people's assumptions and beliefs. Many self-advocates have re-appropriated identity-first language, once used to evidence 'pathology', in a positive way (Bottema-Beutel et al. 2021; Gernsbacher 2017). The term 'autism' has also been used as a shorthand version for 'autism spectrum condition' without learning disability or language delay, which was the set of behaviours previously categorised as Asperger syndrome (WHO 1992).

This systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO Registration number: CRD42017084079). The PRISMA flowchart and tables describing the reviewed studies and participants can be found at

The positionality of the first author

The first author's interest in autism and neurodiversity started eight years ago, when her son was diagnosed with autism and attention deficit hyperactivity disorder (ADHD). She enrolled on a Post-graduate Certificate in Autism and Asperger syndrome at Sheffield Hallam University and it was during a lecture that it suddenly struck her that her son's apparently 'atypical' behaviour was very similar to her own. She was eventually diagnosed with autism and ADHD at the age of 50 years old. The diagnosis explained many of the difficulties, as well as strengths, she had experienced throughout her life, but particularly in her teenage

years when she dropped out, had mental health and substance abuse issues, and attempted suicide. However, she managed to gain her academic qualifications as a mature student on a part-time, distance-learning basis whilst working full-time. In 2017, she started a part-time Professional Doctorate in Health Research at the University of Hertfordshire, and this review undertaken during this programme. She still works full-time at UK Health Security Agency (formally known as Public Health England) as a senior scientist coordinating a quantitative survey of people living with HIV in the UK called Positive Voices. Since February 2020, she has also been assisting in the production of the daily COVID-19 surveillance figures as part of the public health response to the pandemic.

Positionality, along with reflexivity, are critical examinations conducted by feminist researchers which are used to reveal their position in the complex hierarchies of power within society. Having conducted this review as part of her doctoral studies with insider experience of the phenomena explored, her interpretations of the data and writing have been limited by and situated by the knowledge she has learnt and her experiences of the world (Haraway 1988; Willig 2013). However, this knowledge has helped her to relate to and understand the experiences and emotions that the participants in the articles described (Chown et al. 2017; Fletcher-Watson et al. 2019; Milton 2014; Woods et al. 2018). Feminist research encourages this type of insider research and criticises the way positivist approaches emphasise objectivity and neutrality (Franks 2002; Frost and Holt 2013). She believes, as many feminist scholars do, that maintaining a completely objective stance to a research matter is not possible, or even appropriate (Willig 2013). As qualitative research necessitates a researcher's involvement and so, to yield any worthwhile insight into participants' lived experiences, it cannot be done in a neutral or disengaged manner (Madill, Jordan, and Shirley 2000). She has attempted to use her own experience of acquiring an autism diagnosis in adulthood to enrich

her interpretations, rather than thinking of it as a bias needing to be eliminated or 'bracketed out' (Bertilsdotter Rosqvist et al. 2019; Frost 2016).

As subjectivity is an inevitable part of research, the first author maintained an ongoing process of reflexivity throughout this systematic review. Reflexivity is a critical examination of how one sees the social world and understands the relations between content, context and consequences of knowledge that arise from the research process (May and Perry 2017). 'Reflexivity is not just about the ability to think about our actions – that is called reflection – but an examination of the foundations of frameworks of thought themselves' (3). She considered her motivation and reasons for conducting this review and how these may have affected her interpretation of the findings. She kept a reflexive journal from the beginning of her doctoral programme in which she recorded her thoughts and questions about the research, decisions made, challenges addressed and critical themes that she identified (Finley 2002). Whilst writing, she became more aware of her own assumptions and beliefs, as well as the context that surrounded the studies, and how they related to her research interpretations (Frost 2016). She confesses to having developed a positive autistic identity following her own autism diagnosis and is pleased that there are other autistic women who have experienced similar diagnostic journeys to her own. However, she made sure that the interests and views of the study participants were expressed, thus mitigating the risk of bias associated with the subjectivity in the review (Bertilsdotter Rosqvist et al. 2019).

Theoretical Framework: Neurodiversity and Intersectionality

The researchers' understanding of autism was shaped by the theories of neurodiversity and intersectionality. These perspectives underpinned and informed the process and interpretation of the data in this review.

Neurodiversity

'Neurodiversity' was first described in the literature by Singer (1999) who proposed the concept for intersectional analysis. It was based on biodiversity that describes how ecosystems benefit from having a wide variety of life, for example by making them more resilient and sustainable. The behaviours of neurodivergent individuals, including autistic people and those with other neurodevelopmental conditions such as ADHD and dyslexia, may be more extreme when one considers the distribution of sensory, affectual and cognitive processing within the general population (Murray 2020). Although the minority of the population may diverge strongly from the 'norm', they should still be recognised and respected as a natural expression of human diversity that fills an 'ecological niche' in society (Blume 1997; Singer 1999). Autistic people can bring many complementary and beneficial skills to a community, particularly if it values and promotes diversity by moving beyond essentialist binaries of 'us' and 'them' (Chapman 2020; Runswick-Cole 2014).

The neurodiversity paradigm, in line with the social model of disability, challenges the medical model which links autism to a specific stigmatising 'deficit', laden with negative beliefs about restricted abilities and limited potential (Gillman, Heyman, and Swain 2000; Goffman 1963; Ho 2004). These negative attitudes are a form of psycho-emotional disablement that can significantly impact on the emotional well-being and self-esteem of autistic people (Milton and Moon 2012; Reeve 2004; Watermeyer and Swartz 2008). Humanity is neurologically diverse but propositions about normality still assume an ideal, male, white, neurotypical person - defined as a 'normate' by psychologists within the eugenics movement (Garland-Thomson 2017). Autistic people are stigmatised because they exhibit behaviours that currently deviate from the 'norm', so are treated as 'other' and in need of 'treatment' (Scuro 2017; Wolbring 2008). However, to say that there exists a 'normal' human

with a 'normal' brain is no more valid than there being a 'normal' ethnic group, gender, or class (Crow 2017; Walker 2014).

Proponents of the neurodiversity movement, particularly autistic activists, have reclaimed autism for their own and promote diagnosis in a less pathologised form (Kapp 2020; Thibault 2014). Autistic activism emerged in resistance to the medical model discourse depicting autism as a deficit and argued for autism as an identity that should not be cured or regarded as a tragedy. However, autistic people may require support in order to lead a fulfilling life in a world in which they experience specific and nuanced forms of social oppression (Baker 2006; Castells 2009; Shakespeare 2010). The neurodiversity movement challenges autism research funding that primarily focuses on aetiology, screening, treatment, prevention, and cure. They have shifted attention to research aimed at critically understanding and improving autistic experiences, quality of life and decreasing health care inequalities (Kapp et al. 2013; Raymaker and Nicolaidis 2013; Robertson 2009).

Autism advocates also reject functioning labels associated with autism, as they feel that those given the 'low-functioning' label may be devalued and those given the 'high-functioning' label may not be considered for the support they need (Milton and Moon 2012). Clinicians usually distinguish levels of functioning using standard intelligence tests, however these tests have been shown to underestimate autistic intelligence, so their usage may lower expectations and deny autistic people access to appropriate educational support (Dawson et al. 2007). Furthermore, distinguishing between levels of functioning is misleading as the functioning of a person fluctuates depending on the context, for example their perception of control over and inclusion within their environment, their emotional state, other people's expectations, and what support has been provided (Beardon 2017; den Houting 2019; Murray 2009).

This process of resistance and redefinition has started to reshape the autism landscape into a more progressive and less stigmatising one (Gobbo and Shmulsky 2016). Ultimately, the goal is to reduce discrimination and stigmatisation and create a more compassionate and inclusive world that does not pathologise and dehumanise diverse people (Chapman 2020). The neurodiversity theory has enabled many autistic individuals to regard autism as a cognitive style; not a 'disorder' which must be removed or cured like a disease (Bumiller 2008, 4; Cameron 2014b; Swain and French 2000).

Intersectionality

Within an increasingly complex world, intersectionality theory has developed into a valuable interdisciplinary concept for understanding the shared and the unique complexity of multiple social and cultural identities. Originally conceived as a tool for analysing black women's oppression in America, intersectionality is now widely used in social sciences (Crenshaw 1989; King 1988). In intersectionality theory, when a person is a member of more than one marginalised group, they intersect to create a group with a qualitatively unique experience of oppression that is different to the combination of the original groups. Such a group has its own specific needs and problems, as well as ways of meeting those needs and making their mark, which may differ or conflict with those of the original groups and therefore, their 'distinct voice' needs to be recognised (Begum 1992; Garland-Thomson 2005). Biological and cultural categories such as ethnic group, class, gender identity, sexual orientation, marital status, nationality, disability, age, and religion are considered 'multiple and interlocking' (Bowleg 2012, 1267), allowing people to recognise 'the outcomes of these interactions in terms of power' (Davis 2008, 68).

Historically, disability was often unrecognised in contemporary feminist research; however, this intersection is vital for feminist and general philosophy (Hall 2015). Fine and

Asch (1988) suggested that feminists excluded women that were disabled from studies in the past because of fear that they may bolster stereotypical notions of females as dependent. Deep-seated beliefs of female emancipation, independence, and self-sufficiency were the foundation of feminism, but conflicted with the stereotypical view of disabled women (Mohamed and Shefer 2015; Simpson 2019). In addition, the disabled people's movement historically favoured the representation of disabled males within society (Bê 2014). The barriers associated with female gendered role responsibilities, such as assistance with childcare or looking after elderly relatives in order to enable paid employment, were mostly ignored (Morris 1996; Thomas 1999). When individuals with multiple identities are not even recognised within their identity groups, this is known as 'intersectional invisibility' (Purdie-Vaughns and Eibach 2008). Intersectionality theory seeks to make the less visible or under-recognised, visible and explore the inequalities that result in some individuals being marginalised (Smooth 2013). The union of the theoretical fields of gender and disability has deepened our understanding of gender roles, interdependence, experience of care, lived experience and social justice (Garland-Thomson 2002; Wendell 1989).

Saxe (2017) asserts that an intersectional framework should be used to study the lived experiences of autistic women, who are often disregarded due to the male-biased understanding of the condition that dominates autism discourse. Feminist scholars have described how 'stereotypical autistic traits, and their discursive representations have been culturally coded as masculine rather than feminine' (Davidson 2008b, 660). As men often play the role of autistic characters in literature and in the media, the public seem to find it more difficult to envisage an autistic woman (Murray 2012). Unfortunately, when characteristics of a condition are stereotypical of one gender, there is a risk that clinicians will be biased diagnostically (Hughes 2015).

Neurodiversity and intersectionality provided a valuable framework to explore the experiences, social oppression and psycho-emotional disablement faced by autistic women through the male-biased and ableist discourse around autism (Strand 2017; Thomas 2007).

Method

Search strategy

Throughout the process of identifying the included studies, the researchers followed the guidelines stated in the *PRISMA Statement of Preferred Reporting Items for Systematic Reviews and Meta-analyses* (Moher et al. 2015). Eleven electronic databases were searched for peer-reviewed primary research: Global Health, Scopus, Embase, OVID Medline, PsycINFO, SocINDEX, Cumulative Index to Nursing and Allied Health Literature (CINAHL), the National Autistic Society database, Social Policy and Practice, Allied and Complementary Medicine (AMED) and PubMed. We used the search term: (autis* OR asperger* OR ASD) AND (wom* OR female* OR gender). The publications were limited to English language articles dated between 1st January 1943 and 21st August 2020 (Figure 1). References were managed in EndNote X9.3.3 software and 3,322 publications were identified from the searches. This broad approach was chosen to allow for the identification of papers that might not otherwise have been found (Boland, Cherry, and Dickson 2017). Staying abreast of newly published articles throughout the course of this review provided a further 172 articles. Duplicates were removed, leaving 1,340 articles available for screening.

The titles and abstracts of 1,340 articles were screened by consulting the inclusion and exclusion criteria (Table 1). The third author (A-TJ) independently screened a random selection of 15% of the articles in order to check for consistency. If any disparities were found and were not resolved, arbitration would have been sought from the first author's two doctoral supervisors: SS and SR. During the title and abstract screening process, 1,210

articles were excluded, leaving 130 articles to be assessed for eligibility by reading the full

text of each publication. After SS and SR verified their eligibility, nine articles were

classified as 'accepted'.

Study characteristics

Whilst the subject matter of the nine included articles were broadly about the lived

experiences of autistic adults, their original research topics varied: Bargiela, Steward, and

Mandy (2016) investigated the female autism phenotype, Griffith et al. (2012) support needs,

Hurlbutt and Chalmers (2004) challenges of employment, Kanfiszer, Davies, and Collins

(2017) gender and social relationships, Krieger et al. (2012) perceptions of the workplace,

Leedham et al. (2020) diagnosis in middle to late adulthood, Smith and Sharp (2013) unusual

sensory experiences, Stagg and Belcher (2019) diagnosis in later life and Webster and Garvis

(2017) success and critical life moments (Table 2). The countries of origin were mainly from

the United Kingdom, with the rest from the United States, Switzerland and Australia. In two

of the articles, the ages and age at diagnosis of participants were provided as a range,

however the articles confirmed that they had been diagnosed after the age of 18 years of age

(Stagg and Belcher 2019; Webster and Garvis 2017).

Three studies used narrative analysis as their methodology, two used interpretative

phenomenological analysis (IPA), and the others used framework analysis, thematic analysis,

content analysis and grounded theory. While some researchers argue that primary qualitative

studies should have similar methodologies to be included within a meta-synthesis, others

maintain that combining evidence from different analytical approaches is acceptable (Dixon-

Woods et al., 2005). Out of these different methodologies, IPA seems to be the approach that

is most suitable for primary autism research as it is committed to viewing people as experts

on their own personal world, establishing an 'equality of voice' and promoting the process of

reflexivity (Dowley 2016; Howard, Katsos, and Gibson 2019; MacLeod 2019). It focuses on the specific, unique perspectives of each participant, the meanings behind their interpretations, and how they relate to their historical, cultural and societal context (Creswell and Poth 2016).

Data analysis

Thematic analysis was chosen as the methodology for analysing the findings from the nine primary research articles in this systematic review. Thematic analysis is a well-tested technique that encourages reviewers to have an evidential link between their findings and the results of primary studies, using quotes as examples to describe the themes developed, therefore preserving principles that are fundamental to systematic reviewing (Thomas and Harden 2008). The articles were read and reread until the first author (CK) was very familiar with the studies and notes were made about possible themes and concepts that related to the review question, as recommended by Braun and Clarke (2013). To thematically analyse the qualitative findings, digitised pdf copies of the articles were downloaded into the qualitative data analysis software, NVivo Mac Release 1.3, for coding and categorisation.

Only quotes and analysed results and interpretations that were specifically associated with 50 of the participants, who were women who had been diagnosed in adulthood, were analysed (Table 3). Data associated with other participants from the studies, such as men and women diagnosed in childhood, were not extracted. When a strand of data related to multiple concepts, it was coded multiple times. When similarities and associations across the studies were identified, the coded data were grouped into clusters of related concepts. These clusters were identified inductively, and constantly compared and regrouped into sub-themes. Some of the concepts were refined by moving to and from each of the studies to determine how they might relate together. Super-ordinate themes were then developed, enabling the creation

of a higher-order interpretation of the translations. The creation of the super-ordinate and sub-ordinate themes were considered by SS and SR and were subsequently approved.

Throughout the data analysis process, the codes, categories, and themes were evaluated for accuracy and clarity. Whenever the researchers felt uncertain about their decisions or findings, they were double-checked to make sure interpretations were firmly grounded in the data.

Thematic analysis

Four super-ordinate themes were identified in the analysis, which are described below.

Wanting to 'fit in'

When the women in the studies described their childhood experiences, they remembered thinking that they were 'weird', 'alien' or 'a different type of human' due to the difficulties they had interacting with their friends (Kanfiszer, Davies, and Collins 2017; Leedham et al. 2020; Stagg and Belcher 2019). At school they were bullied and persecuted for being 'odd' and felt lonely and distanced from their peers (Bargiela, Steward, and Mandy 2016; Huws and Jones 2010). Culture determines how one interprets and responds to other people's verbal and non-verbal communication and, in Western European and North American nations (WENA), one can be judged harshly for not giving enough eye contact, not smiling, raising your voice, being too direct and so on. Goffman (1963) argued that individuals are continuously trying to manage the impressions they make during social interactions. Those with the ability to perform well are considered 'normal', while those who exhibit unusual behaviour are considered 'abnormal' and stigmatised as a result (Milton 2013). A woman in Kanfiszer, Davies, and Collins (2017) felt that she had been perceived as deviating from the expectations placed upon her:

… they just ostracised me … what they called 'sent to Coventry' where no one in the dormitory would speak to me (laughs) because I so alienated them …It's my reactions, and the way I interacted with people wasn't appropriate … (664).

Difficulties with social interaction and misunderstandings frequently occur between autistic and non-autistic individuals, described as the 'double empathy problem' (Chown 2014; Milton 2012). This theory challenges the idea that autistic individuals lack empathy for others and proposes that both autistic and non-autistic people can misunderstand the feelings and behaviours of the other; after all, social communication is a two-sided affair (Milton 2017). Growing evidence demonstrates that non-autistic people often find understanding autistic people really difficult, are unable to infer their emotional state, and tend to judge them negatively based on first impression (Heasman and Gillespie 2018; Sasson et al. 2017; Sasson and Morrison 2019). 'Acts of invalidation' may occur in the form of disapproving looks or comments, and this psycho-emotional disablism, as described earlier, can have a cumulative negative impact on a person's self-esteem (Reeve 2014).

The women who participated in the studies were unaware that they were autistic during their childhood and adolescence, so they felt compelled to keep up appearances and look as if they were in control. They observed their more 'easy-going' friends and imitated them in social situations, learning their mannerisms and speech, mimicking small talk, and repressed behaviours that others might think were 'weird'. (Krieger et al. 2012; Willey 2015). They described how they had changed their 'persona' or wore a 'mask' as a survival strategy to cover up their difficulties interacting: '[when I] appear sort of normal, that is because of the years of actual effort that I've put into it' (Leedham et al. 2020, 141). 'Masking', also known as 'camouflaging' or 'passing', is a strategy where a person disguises their underlying authentic self and 'passes' as socially competent by using learnt behaviours to act in a 'socially acceptable' manner (Ginsburg and Pease 1996; Kalei Kanuha 1999). However, autistic women often find this lack of authenticity particularly disturbing and damaging to

their self-esteem (Foucault 1975; Murray 2020). Masking may also involve suppressing their repetitive movements, known as stims (short for self-stimulation), such as hand flapping or twiddling hair, despite the fact that they can be used as coping mechanisms during stressful situations (Kapp et al. 2019; Lingsom 2008).

Butler (2006) argued that being gendered as a woman is, in itself, a kind of improvised performance. In this patriarchal culture, women are often expected to be socially accommodating by being hospitable, communicative, nurturing and biddable, which may motivate some autistic women to emulate this behaviour (Gould and Ashton-Smith 2011). However, a few women in the review found it hard to envisage themselves in traditional gendered roles that others expected them to fulfil, such as a mother or carer (Bargiela, Steward, and Mandy 2016; Kanfiszer, Davies, and Collins 2017). They disregarded these expectations, along with the social construct of gender in general, and adopted more 'personal' gender identities (Butler 2006; Davidson and Tamas 2016). In Kanfiszer, Davies, and Collins (2017), a few women described themselves as 'tomboys' and preferred playing with boys when they were younger:

> Girls are sort of bothered about what they're wearing and what their hair looks like and their nails and who's cute in what band … it's not actually possible for me to be less interested … whereas the guys would be mucking about … something I felt more inclined to be involved with (665).

In some locations, such as in the workplace, women often felt a huge pressure to blend in and consequently there was an even greater need to 'mask' in these situations (Russell 2021). In Bargiela, Steward, and Mandy (2016), participants explained that, although masking helped them to interact, it meant that their struggles went unrecognised and so no adjustments were made for them. 'Switching' between masking in different contexts, such as at home, at work and while socialising, was exhausting and detrimental to their sense of self.

Social events were stressful, and some women in the studies spent a long time ruminating over conversations afterwards. Many avoided socialising altogether for fear of negative evaluation by others: 'I thought maybe I'm a bad person, I've got a horrible personality, there's something about me people don't like, and I didn't understand why' (Stagg and Belcher 2019, 353). Clinicians may find it difficult to differentiate between autistic masking and the social role ordinarily adopted by non-autistic individuals, but can distinguish the former by the overwhelming intellectual effort required, emotional cost and recovery time needed for an autistic individual to perform their persona (Beck et al. 2020; Russell 2021).

Making sense of past experiences

Most women felt their diagnosis had been a positive experience as they finally understood their uniqueness and were able to make sense of their lives (Haney and Cullen 2017; Leedham et al. 2020; Tan 2018). Following their diagnosis, autistic women initially felt a range of emotions, such as anger, disbelief, shock, and joy: 'A relief, because for years and years everything has been put down to anxiety and depression. Everything from the last 30 years made sense, it just all fitted in and it made sense'(Stagg and Belcher 2019, 353). Many felt proud of who they had become and the success they had achieved, despite all the challenges they had faced (Krieger et al. 2012; Webster and Garvis 2017). The diagnosis conceptualised their lifelong challenges as real, not just a quirk of their personality that should be cured; removing some guilt and blame from themselves (Punshon, Skirrow, and Murphy 2009; Stagg and Belcher 2019).

One woman described crying and feeling overwhelmed when she was finally diagnosed, as it explained why she had struggled so much when she was younger (Webster and Garvis 2017) The women seemed to have revised their understanding of their challenges and negative experiences; reattributing struggles and misunderstandings to autism within

their 'sense-making narrative' (Leedham et al. 2020). A sense-making narrative may be revised when a person, who previously had an inadequate way of understanding themselves, gains new insight into their past and feels they understand themselves better (Bury 1982; Kim 2013). Before having acquired this knowledge, the women were forced to concoct incomplete explanations for their developmental history and life experiences (Limburg 2016). Other people had attributed their autistic traits to issues of motivation, poor character, or a flawed upbringing (Bargiela, Steward, and Mandy 2016). Following their diagnosis, the women went through a period of intense research and growing self-awareness (Leedham et al. 2020). Some began to read autobiographies written by autistic women, giving them a greater understanding of themselves (Hacking 2006; Linton 2014; Webster and Garvis 2017). They described their diagnostic journeys in autistic women's groups on social media platforms, which allowed them to compare their experiences with those of others (Davidson 2008a).

Many of the women felt that a diagnosis in childhood would have increased the quality of their lives, helped them to progress in life, and giving them the knowledge to better understand themselves (Webster and Garvis 2017). They believed that, if they had been diagnosed earlier, they would have been better able to sense danger, 'read' other people's intentions, and cope with dangerous situations: 'I think women tend to be diagnosed later in life when they actually push for it themselves… if people had helped me from earlier on, then life would have been a whole lot easier.' (Bargiela, Steward, and Mandy 2016, 3286). Reflecting on their past, during and after their diagnosis, was upsetting for some who had experienced abuse, bullying, rape, and harassment (Kanfiszer, Davies, and Collins 2017; Leedham et al. 2020; Webster and Garvis 2017).

Compensatory strategies such as masking, although used to avoid rejection from their peers, may have resulted in their social interaction difficulties going unnoticed and their support needs being underestimated (Beck et al. 2020). Some women felt they had been

misdiagnosed with other mental health conditions when they were younger (Bargiela, Steward, and Mandy 2016). However, these previous diagnoses may have accurately reflected clinicians' understandings of their difficulties at that time, as autistic girls and women went largely under the radar until relatively recently. Moreover, autistic women often experience concurrent mental health difficulties related to the stress of living in a neurotypical world that expects social competency, especially those diagnosed later in life (Atherton et al. 2021).

For most women, the late diagnosis proved valuable, as did having long-term relationships with close friends and family members, both autistic and non-autistic, who accepted and encouraged them to achieve their goals, without criticising their 'quirky' traits (Kock et al. 2019; Leedham et al. 2020; Webster and Garvis 2017). However, a small number worried that the 'label' may be seen by others as shameful and may limit their future potential (Ho 2004; Leedham et al. 2020). A diagnosis not only allows a person to reflect on themselves differently, but it can also change the way others perceive them and consequently treat them (Becker 2008; Goffman 1963). Unfortunately, when someone constantly hears negative messages about their value and ability, it can become a self-fulfilling prophecy as they internalise these judgements and start to believe them (Jussim et al. 2000; Merton 1948; Reeve 2004). The reaction of a person to being diagnosed with autism may depend on when the diagnosis is given and under what circumstances. Perhaps most women in this review found it a positive experience because they voluntarily sought a diagnosis for themselves in adulthood, rather than 'receiving' the label in childhood, without being well informed (Molloy and Vasil 2002).

Developing a new 'autistic identity'

The growing popularity of social media and the neurodiversity paradigm during the last decade has increased the number of autistic women seeking out like-minded others and

connecting and sharing their experiences; empowering them, increasing their well-being and reducing feelings of alienation (Milton and Sims 2016; Straus 2013; Webster and Garvis 2017). In Bargiela, Steward, and Mandy (2016), several women described the importance of finding new autistic friends online who accepted and understood them, highlighting the importance of informal peer support: 'Something that I really appreciate about having the diagnosis is actually being in this club now where people talk about their experiences and having so many echoes of my own' (3289). Socialising with other autistic women online may have helped them construct a positive 'autistic identity', which otherwise may have proved difficult due to the competing discourse around autism, particularly the powerful medical or 'deficit' model (Bagatell 2007; Bertilsdotter Rosqvist, Brownlow, and O'Dell 2013; Davidson 2008a). However, neurodiversity represents autism as a cognitive style, rather than as a 'discreditable' deficit that should be overcome, and this concept seemed to have encouraged the women to redefine autism as a distinct cultural identity, positively influencing their self-image and encouraging them to disclose to others (Haney and Cullen 2017; Tan 2018; Wright, Spikins, and Pearson 2020).

Many of the women felt more able and free to be themselves, rather than an idealised version of what others expected them to be, and so they were absolved from having to wear a mask, particularly around their autistic friends (Leedham et al. 2020). Developing a positive 'autistic identity' appears to have increase personal and collective self-esteem, offering a protective mechanism for psychological wellbeing (Milton and Sims 2016; Tan 2018). In a society where autistic people have traditionally been devalued, this identity construction involves resisting normalising ideology and feeds back into our understanding of autism via the looping effect, as discussed earlier (Hacking 2006; O'Dell et al. 2016). Hopefully a greater societal appreciation of autism and autistic behavioural traits may reduce the

compulsion for autistic females to mask their authentic selves (Hodge, Rice, and Reidy 2019).

For some women, receiving a diagnosis seems to have encouraged them to set goals based on their unique strengths, assert their opinions, ask for support when needed, and realise their potential (Bargiela, Steward, and Mandy 2016; Leedham et al. 2020; Webster and Garvis 2017). One key strength that was frequently mentioned was the ability to 'hyperfocus' on interests; a result of their enhanced processing using a cognitive strategy called monotropism (Murray 2018; Murray, Lesser, and Lawson 2005). Some autistic individuals tend to intensely focus on a task that they are particularly interested in, to the point where the rest of the world seems to disappear and any other, less interesting, tasks get ignored (Grant and Kara 2021). Working on, or building a career from, activities of specific interest to the women provided a sense of stimulation and fulfilment, despite the challenges the women had faced in the past (Bargiela, Steward, and Mandy 2016; Krieger et al. 2012; O'Neil 2008; Stagg and Belcher 2019).

Although the mental health of a few women continued to fluctuate after they were diagnosed, many seemed to have developed more self-compassion and an increased sense of agency. For example, some women managed to gain the confidence to end unsupportive and abusive relationships and friendships (Webster and Garvis 2017). One woman felt less anxious after her diagnosis: 'I don't get as much anxiety as I used to … because I've got better understanding of – and because I understand it better I'm actually able to deal with it better … so I build strategies around that really' (Leedham et al. 2020, 142). An increase in the women's autonomy was indicated by their decision-making and efforts to improve their quality of life. This illustrated the importance of measures that may increase their sense of agency and awareness that they can succeed.

Developing a positive social identity and contacting others in the autism community has the potential for autistic women to increase their self-esteem and to reduce feelings of isolation and alienation (Cameron 2014a; Cooper, Smith, and Russell 2017). Swain and French (2000) proposed a new model called the affirmation model that embraces positive social identities and respects the diverse ways of being in society; challenging presumptions about the 'tragedy' of disability (Cameron 2014b; Swain and French 2008). By contacting the autism community and sharing their narratives about their lives and diagnostic journey, the women in these studies were reframing their sense-making narrative in a neurodiversity-affirming way (Kapp 2020; Swain and Cameron 1999).

Barriers to support

While seeking a diagnosis in adulthood, the women in the study by Bargiela, Steward, and Mandy (2016) felt that healthcare professionals lacked an understanding of the way autistic traits present in women. Some women had found that General Practitioners (GPs) and psychiatrists had dismissed their concerns: 'When I mentioned the possibility to my psychiatric nurse, she actually laughed at me…I asked my mum, who was a GP at the time…if she thought I was autistic. She said, 'Of course not'' (ibid, 3286). As GPs are more used to identifying autistic features in boys, they may not initially think of autism when they meet a woman with social difficulties in their clinic, but instead think of social anxiety or depression, for which medication can be prescribed (Fletcher-Watson and Happé 2019). Studies have revealed a large gender disparity in autism referral and diagnosis (Dworzynski et al. 2012; Russell, Steer, and Golding 2011). This could either reflect a significant gender bias by clinicians or the fact that females are more motivated and successful at emulating non-autistic behaviour (Hurley 2014).

Another possibility for the gender disparity could be that clinicians have been under the impression that women could not be autistic due to misinterpreting a theory about extreme male brains. The theory was informally suggested by Hans Asperger in 1944, who stated that 'the autistic personality is an extreme variant of male intelligence. In the autistic individual, the male pattern is exaggerated to the extreme.' (Frith 1991, 84). More recently, the Extreme Male Brain (EMB) theory hypothesised that autistic brains were extreme forms of the male brain, as they were better at analysing and systemising which are male traits, but less good at empathising which is a female trait (Baron-Cohen 2002). Further research suggested a relationship between pre-natal exposure to the sex-linked hormone testosterone in amniotic fluid and autistic traits (Baron-Cohen et al. 2015). However, this theory was heavily criticised for failing to distinguish between sex and gender; rather it subsumed one into the other (Butler 2006). The theory relies on a binary model of brains which suggests that differences in social skills between males and females are biologically determined, but fails to account for cultural expectations and learnt behaviour (Jack 2011).

An autism diagnosis may function as a key to unlocking legal and financial support that would otherwise not be accessible, including welfare benefits, reasonable adjustments in the workplace, protections, rights, services, social groups, information and educational support (Booth 2016). There was an expectation amongst the women in the review that some post-diagnostic social care support would be available, but unfortunately, their attempts to access it were unsuccessful (Griffith et al. 2012). Women felt that this was due to a lack of specific adult autism services: '… I don't fit mental health. I don't fit learning disability. I just fall through the gaps between departments, whether it's in the health service or social services. I just don't fit anywhere' (ibid, 540).

In workplace environments, assessments should be carried out and recommendations made for reasonable adjustments, for example to lessen specific sensory stimuli that may be a

hindrance to an autistic individual's work performance and wellbeing (Booth 2016).

However, the women had come across a general lack of autism awareness by their employers who did not understand or appreciate the kind of difficulties autistic people may experience in the workplace or what accommodations may be required (Griffith et al. 2012; Hurlbutt and Chalmers 2004). In fact, many felt that their difficulties in socially interacting with co-workers had led to their dismissal from a post in the past. A few of the women were so disheartened that they stopped looking for work altogether:

> It's interacting … they come up to you and start asking you questions about your problems, see, I may make a comment, I may do something inappropriate and it builds up and then the employer … usually it leads to a reason for dismissal (Griffith et al. 2012, 539).

One woman revealed that, due to some previous bad experiences, she had become reluctant to disclose her diagnosis to potential employers. She felt that many employers were reluctant to employ autistic members of staff (Hurlbutt and Chalmers 2004). Autistic individuals must choose carefully whether or not to disclose their diagnosis in particular contexts, as disclosure can have potential ramifications such as social exclusion (Lingsom 2008). Fear of invalidation by others also negatively affected the confidence of some women to disclose their diagnosis to family and friends (Baines 2012; Leedham et al. 2020; MacLeod, Lewis, and Robertson 2013). However, even while trying hard to appear socially competent and pass as 'normal', the women may sometimes fail to maintain their performance and, because of their unusual behaviour, others may assume that they were being deliberately offensive (Goffman 1963; Portway and Johnson 2005). Stigmatisation can therefore result from the application of a diagnostic label or from the autistic behaviour itself. Perhaps if the concept of neurodiversity was more widely accepted within our culture, autistic

people may feel more comfortable disclosing to others, and social support may be offered more readily (Sasson and Morrison 2019).

Limitations

Only the main issues described by participating autistic women were highlighted, so unfortunately other potentially important nuances contained within their personal stories may have been missed (Finfgeld-Connett 2010). The criteria for inclusion in the review were women who had been diagnosed in adulthood, so undiagnosed and self-diagnosed autistic women, autistic individuals with other gender identities and individuals diagnosed in childhood were not represented (Brugha et al. 2011). The countries of origin of all nine articles were from the minority world, traditionally known as 'developed countries'. Data on the women's ethnicity group were only included in one study, in which all the participating women were White British (Smith and Sharp 2013). It is possible that minority ethnic groups may have been under-represented in this review. Demographic information about the participants from the nine studies were limited and not consistent in all of the studies, which meant that we could not apply the full framework of intersectionality to any other aspects of the women's identity, such as ethnicity or class, that may have empowered or disadvantaged them (Kim 2012). A recommendation for future research would be to study the impact of an autism diagnosis on autistic women's intimate relationships, such as with their partners, children or parents (Kock et al. 2019).

Conclusions

Receiving the diagnostic label of autism proved to be a positive 'turning-point' for many of the women who participated in the nine studies reviewed. The identity of 'autism' provided the women with an explanatory framework which allowed them to rewrite their biography and make sense of their experiences. The women's sense-making narratives were affirming

and recognised autism as an intrinsic part of them. These narratives may be viewed as an act of resistance to the metanarrative of autism that have been historically rooted in medicalised approaches to autism (Loftis 2021). In its place, the autistic women in the studies used the paradigm of neurodiversity to interpret and construct a new autistic identity which accepted and valued all types of human diversity and challenged the dominant ideology of the deficit-based medical model. The women expressed the importance of communicating with other autistic individuals following a diagnosis, especially other autistic women. It provided opportunities for mutual recognition and demonstrated how diversity is something to be celebrated and embraced. The women developed a positive identity by virtue of being autistic and proudly described their autistic strengths that made them unique.

However, the studies did suggest that health and social care professionals were not always able to recognise, refer, and support autistic women and were unaware of autistic women's specific challenges. By focusing on the intersection of autism and gender, the review revealed practices of stigma and marginalisation that had affected the women's psycho-emotional disablement. The autistic women were routinely disabled by societal, attitudinal, and structural barriers and experienced frequent discrimination, disadvantage, and social exclusion in employment and within the broader society. Following their diagnosis, the women used their new positive autistic identity to overcome some of these barriers, to facilitate social interaction with other autistic people, and to access and obtain better outcomes for themselves. Further exploration of the lived experiences of autistic women is essential for conceptualising potential approaches to support, particularly as their 'voices' have been largely missing in qualitative studies (Howlin et al. 2015; Milton 2014). Approaches could include the following:

- At the point of diagnosis, information should be given on autistic female social groups, helplines, local voluntary groups, autobiographical books on autism, useful websites, blogs and social media groups

- Counselling support should be made available for women following a late autism diagnosis, since the identification may be traumatic for some

- Support service staff should help to develop an empowering and positive autistic identity for women, for example by providing first-hand accounts from autistic individuals and introducing the concept of neurodiversity

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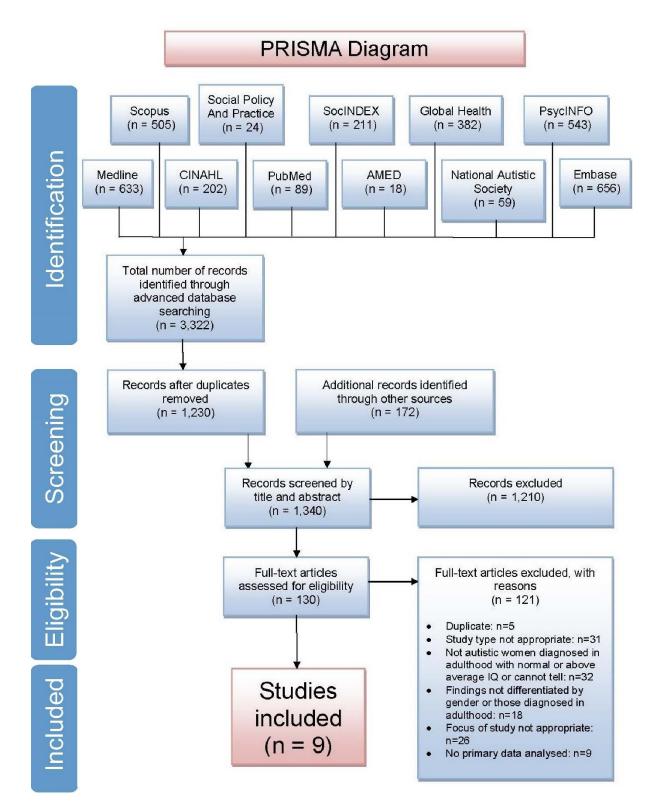
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Figure 1 PRISMA diagram for the systematic review

PRISMA Diagram

Identification

Scopus (n = 505)

Social Policy And Practice (n = 24)

SocINDEX (n = 211)

Global Health (n = 382)

PsycINFO (n = 543)

Medline (n = 633)

CINAHL (n = 202)

PubMed (n = 89)

AMED (n = 18)

National Autistic Society (n = 59)

Embase (n = 656)

Total number of records identified through advanced database searching (n = 3,322)

Screening

Records after duplicates removed (n = 1,230)

Additional records identified through other sources (n = 172)

Records screened by title and abstract (n = 1,340)

Records excluded (n = 1,210)

Eligibility

Full-text articles assessed for eligibility (n = 130)

Full-text articles excluded, with reasons (n = 121)

- Duplicate: n=5
- Study type not appropriate: n=31
- Not autistic women diagnosed in adulthood with normal or above average IQ or cannot tell: n=32
- Findings not differentiated by gender or those diagnosed in adulthood: n=18
- Focus of study not appropriate: n=26
- No primary data analysed: n=9

Included

Studies included (n = 9)

Table 1   Inclusion and exclusion criteria

	INCLUSION	EXCLUSION
Period of publication	• Between 1st January 1943 and 21st August 2020	
Study design/ type	• Qualitative studies • Mixed method studies	• Publication types without original data, e.g. expert opinions, clinical reports, letters, editorials, comments, reviews, books, book chapters, book reviews, blogs and social media posts, news items, or articles not describing studies on the lived experience of adult women diagnosed with ASD without ID or AS aged >18 years. • Quantitative studies (e.g. randomised controlled trials, comparative, case-control, observational, and cross-sectional studies) • Conference abstracts and dissertations
Study population	• Women with a diagnosis of ASD without ID or AS aged >18 years	• Girls or adolescents aged ≤18 years • Women not formally diagnosed in adulthood
Subject matter/focus	• Lived experience of women aged >18 years before being diagnosis with ASD without ID or AS, of the diagnostic process itself and/or life post-diagnosis	• Proposed cause(s), medications, interventions, therapies or 'cures' • Evaluation of methods or diagnostic/ screening tools • Lab-based, animal, genetic, biochemical, neurological or molecular studies • Accounts given by parents or carers • Studies not using primary data • Comparison studies with non-autistic controls or between genders • Studies where one cannot differentiate findings by gender and age group of participants

Table 2 Characteristics of the primary research articles included (n=9)

Author(s)	Title of article	Country	Methodology	Brief description of research design/conceptual framework	No. participants in article	Women diagnosed in adulthood	Number of themes	Number of subthemes	Themes
Bargiela, Steward and Mandy (2016)	The experiences of late-diagnosed women with autism spectrum conditions: an investigation of the female autism phenotype	UK	Framework analysis	This study investigated the female autism phenotype and its impact upon the under-recognition of autism in girls and women in clinical practice. Framework analysis was used to yield hypotheses about this phenotype, to generate new ideas and deepen understanding of key concepts such as camouflaging, and to promote the development of measures to capture both female and male manifestations of autism.	14 (all women but two diagnosed in childhood and two did not contribute in findings)	10	4	19	**You're not autistic:** Labelled with non-autistic diagnosis; Unhelpful professional sterotypes of autism; Quiet at school; so went unnoticed - 'I should have burnt more cars' ; Misunderstood, unsupported or blamed by teachers; The costs of a late diagnosis. **Pretending to be 'normal':** 'Wearing a mask'; Learning social behaviours from TV, books and magazines; Social mimicry; The costs of masking. **Passive to assertive**: Please, appease, avoid conflict; Entrapment in abusive relationships or risky situations; Victim of sexual abuse; Learning to be assertive. **Forging an identity as a women with ASD:** Societal pressures - what is expected of young women; Friendships - uncertainty and intensity; Hard to be friends with neurotypical girls; Easier to be friends with boys; Friendships and support online; Interests define identity and self-confidence.
Griffith et al. (2012)	'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood	UK	IPA	The research explored what autistic people aged 35 years and over thought of their previous and current support. The researchers used IPA to get an 'insider's perspective' and to explore how the participants made sense of their world.	11 (seven men, of whom only six diagnosed, one women	3	3	0	**Some days I do stuggle' - living with AS; 'They don't expect you to have problems with things' - employment issues; 'I just fall through the gaps between' - experiences with mainstream support.**
Hurlbutt and Chalmers (2004)	Employment and adults with Asperger syndrome	US	Content analysis	This paper was the earliest publication of the nine papers used in the review. Its purpose was to provide information about the participant's employment issues and recommendations for preparing autistic people for successful job experiences. Unfortunately, the paper did not discuss the research design or methodology used in the study.	6 (three men and one did not contribute to findings)	2	3	0	**Adults wit AS experience frequent unemployment and underemployment situations; Several factors affect employability, including social skills, communication and sensory issues; Recommendations for aiding success in the workplace.**
Kanfiszer, Davies and Collins (2017)	I was just so different': The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships	UK	Multi-stage narrative analysis	This study used narrative analysis to reveal the life stories of autistic women and to extend existing conceptualisations of autistic experience to include socially and culturally located factors. Its purpose was to enable the marginalised voices of autistic women to be heard and to understand the various multifaceted aspects of their experiences.	7 (although three had ID)	4	2	5	**Gender identity**: 'I was just so different'; 'I think there's some sort of gender identity thing'; 'I never had any mothering instincts'. **Social relationships**: 'When I try, the conversation just goes dead'; 'People don't want to know me'.
Krieger et al (2012)	Becoming a member of the work force: perceptions of adults with Asperger Syndrome	Switzerland	Narrative analysis	The purpose of this study was to gain in-depth knowledge about how autistic individuals assign meaning to contextual and influential factors that occurred throughout their childhood and adolescence and how these factors may have enabled or hindered their participation as adults in competitive employment. The temporal-biographical aspects of the study meant that a hermeneutic, narrative approach was used in the research design, based on Paul Ricoeur's theory of interpretation.	6 (four men)	2	4	9	**Social context - To feel socially secure and be familiar with social environments**: Mom left me alone without accusations; Through her I met other children in the neighbourhood. **Cultural context - To achieve cultural competence**: Teachers are for learning and not for relationships; I am open for new ideas but in the end I must experience them as my own; This is not my world but I know the rules of the game; I like my job but I need enough to do to not feel bored. **Physical context - To be protected or offended**: Working behind a window in the post office protected me. **Temporal context - Receiving and disclosing a diagnosis**: It became clear - my strange needs are legitimate; There is a subtle black and white thinking in Swiss society.
Leedham et al. (2020)	'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood	UK	IPA	This study used IPA in order to focus on the subjective accounts of specific lived experiences of autistic women, including their response to and interpretation of these experiences. The data was analysed via an in-depth iterative process where the researchers engaged in a 'double hermeneutic' process, making sense of how individuals make sense of their world.	11	11	4	10	**A hidden condition**: Pretending to be 'normal' and fitting in; Mental health and mislabelling. **The process of acceptance**: Initial reactions and search for understanding; Reliving life through a new lens; Grief and reflections on the past. **Post diagnostic impact of others**: Initial reaction of others; Stereotyped assumptions. **A new identity on the autism spectrum**: Negotiating relationships, connections and community; Changing wellbeing and views of the self; The meaning of diagnosis.
Smith and Sharp (2013)	Fascination and isolation: a grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome	UK	Grounded theory	Using a modified Grounded Theory methodology, the study aimed to generate a model describing the nature of the relationship between unusual sensory experiences and their effects on the person's internal experience, social life and daily functioning. Semi-structured interviews were conducted with Instant Messaging software. A model was generated revealing how unusual sensory experiences affect the lives of autistic people and describing the coping strategies utilised.	9 (six men)	3	9	18	**Heightened senses. Sensory stress**: Fear/anger; Attach/escape; Avoidance. **Moderating factors**: Single versus many inputs; Low intensity versus high intensity; Order versus chaos; Calm versus stressed. **The stress avalanche. Coping strategies**: Blocking out other inputs; Dampeners; Creating order; Calming strategies. **Other people**: Source of sensory stress; Negative interactions with others; Positive interactions with others. **Isolation. Self-acceptance. Fascination**: Pleasurable/calming; Skills/abilities; Long-term pursuits; Distracting.
Stagg and Belcher (2019)	Living with autism without knowing: receiving a diagnosis in later life	UK	Thematic analysis	Interviews were conducted using the free-associative narrative interview technique, where the interviewee was able to guide the direction of the interview, thus allowing the focus and agenda of the interview to change depending on their own experience. Therefore the autistic participants had the freedom to take the interview in the direction they wished. The resulting transcripts were analysed using thematic analysis.	9 (four men and one did not contribute to findings)	4	5	0	**Early signs of ASC:** Behavioural manifestations of ASD; Education; Experiences in youth. **Awareness of being different:** Disability; Positive aspects of having ASC; Being different; Ways of seeing the world; Fitting in; Recognising or failure to recognise ASD; Family concerns; Relationship problems; **Receiving a diagnosis:** Revelation; Negatives of diagnosis; Relief; Stress. **The usefulness of a diagnosis:** Emotion; The future; Advantages of a late diagnosis; Happiness; Creativity; Confidence; Self awareness; Working life; Work colleagues. **Support and coping:** Getting older; Modern technology; Social media; Specific ASD help from the authorities; Health care; Support; Government departments.
Webster and Garvis (2017)	The importance of critical life moments: An explorative study of successful women with autism spectrum disorder	Australia	Narrative-themed analysis	This study explored the women's experience from a social constructionist perspective, emphasising the social processes by which they developed their social reality, and knowledge about that reality, in an ongoing way during interaction with others. The findings captured the emotional nature of the lived experiences of the autistic women involved as they reflected on being successful.	11	11	4	0	**Agents of change. Belief of others in their capability. Changed identity after diagnosis. Mentor to others.**

Table 3 Participants from the nine included articles (n=50)

Article	Country	Participant's pseudonym	Age Range (From)	Age Range (To)	Age at Diagnosis (From)	Age at Diagnosis (To)
Bargiela, Steward and Mandy, 2016	UK	P01	23	26	19	22
		P03	27	30	27	30
		P05	22	26	22	25
		P06	27	30	23	26
		P07	19	22	19	22
		P08	22	26	19	22
		P09	27	30	19	22
		P10	27	30	23	26
		P11	27	30	27	30
		P14	27	30	23	26
Griffith et al., 2012	UK	Brooke	45	45	35	35
		Rebecca	54	54	45	45
		Sheila	57	57	49	49
Hurlbutt and Chalmers, 2004	US	Daina	56	56	52	52
		Rosalind	43	43	38	38
Kanfiszer, Davies and Collins, 2017	UK	Danielle	20	59	20	59
		Emma	20	59	20	59
		Fay	20	59	20	59
		Gemma	20	59	20	59
Krieger et al., 2012	Switzerland	Celestine	30	30	28	28
		Hannah	34	34	32	32
Leedham et al, 2020	UK	Alice	43	64	40	62
		Celia	43	64	40	62
		Elizabeth	43	64	40	62
		Hannah	43	64	40	62
		Kate	43	64	40	62
		Lily	43	64	40	62
		Marie	43	64	40	62
		Merrell	43	64	40	62
		Mia	43	64	40	62
		Olivia	43	64	40	62
		Ruby	43	64	40	62
Smith and Sharp, 2013	UK	Lucy	49	49	47	47
		Rebecca	25	25	23	23
		Ruth	30	30	29	29
Stagg and Belcher, 2019	UK	Brenda	52	54	unknown	unknown
		Debra	52	54	unknown	unknown
		Linda	52	54	unknown	unknown
		Mary	52	54	unknown	unknown
Webster and Garvis, 2017	Australia	Janelle	28	55	unknown	unknown
		Judy	28	55	unknown	unknown
		Julie	28	55	unknown	unknown
		Mary	28	55	unknown	unknown
		Michelle	28	55	unknown	unknown
		Morgan	28	55	unknown	unknown
		Patty	28	55	unknown	unknown
		Peggy	28	55	unknown	unknown
		Robin	28	55	unknown	unknown
		Susan	28	55	unknown	unknown
		Terry	28	55	unknown	unknown