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The experience of seeking, receiving, and reflecting upon a diagnosis of autism in the UK: A meta-synthesis of qualitative studies conducted with autistic individuals

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ABSTRACT

Background: The autism diagnosis process can profoundly impact an individual's life. The purpose of this review is to systematically identify, appraise and synthesise qualitative research concerning individuals' experiences of seeking, receiving and reflecting upon a diagnosis of autism in the UK. The purpose is to improve understanding of how this process is experienced and identify potential areas for improvement.

Method: Six databases were systematically searched for qualitative studies exploring autistic individuals' experiences of the autistic diagnostic process in the UK. Nineteen studies met inclusion criteria and were analysed using Thematic Synthesis.

Results: Three super-ordinate themes were identified; 'Negotiating self-identity' making sense of the autism diagnosis, including navigating a distressing assessment process, conflicting emotions towards diagnosis, neurodiversity, self-reflection and self-kindness. 'Feeling Misunderstood' in society and the impact on well-being, including social challenges and mental health misdiagnosis. 'Support Post-Diagnosis' including increased understanding, connection and validation. Overall, limited understanding from professionals was found to create barriers to assessment and acquisition of appropriate support.

Conclusions: Adjustment to an autism diagnosis is a dynamic process accompanied by a range of emotional responses. In many cases the diagnosis facilitated self-understanding and self-kindness, contrasting with self-criticism pre-diagnosis. It is recommended that clinicians attempt to recognise strengths and support individuals during the typically deficit-focused autism assessment process. Findings demonstrate the need for further autism training for both specialist and non-specialist professionals and the benefits of peer support around the diagnostic process. This review also highlights wider societal misconceptions of autism, intolerance of difference and the subsequent mental health impacts on autistic individuals.

1. Introduction

Autism is a lifelong neurodevelopmental condition that affects how individuals perceive the world, including social

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communication, social interaction, behaviour, and interests (American Psychiatric Association, 2013). A recent systematic review indicated that autism prevalence rates vary internationally due to complex interactions between community awareness, socio-demographic factors and service capacity (Zeidan et al., 2022) and the autism diagnostic process varies substantially between countries (Zaroff and Uhm, 2012). Since there is such variation in practice and experience between countries, it is therefore important to investigate and understand country-specific issues in order to provide the insight necessary to design appropriate diagnostic services. This review focuses on autistic people's experiences of diagnostic services in the UK which could contribute to improving clinical practice and links to the priority stated in the UK National Autism Strategy (2021–2026) to tackle health and care inequalities for autistic people. Qualitative methods are growing in popularity in autism research (MacLeod, 2019) and this can provide in-depth understandings of lived experiences. This meta-synthesis aims to identify themes evident in the literature about autistic individuals' experiences of the autism diagnostic process in the UK, to provide theoretical and, in particular, clinical and practical insights into this experience.

Existing research about autistic adults' experiences of the diagnostic process is mixed; Jones et al. (2014) report a UK-based survey of 128 autistic adults which found that 40% were dissatisfied with the diagnostic process, while 47% were satisfied. This survey also highlighted particular dissatisfaction with post-diagnostic support. Crane et al. (2018) explored experiences of the UK diagnostic process from different perspectives, including parents of autistic children, professionals involved in the autism assessment process and autistic adults. All three groups reported that the diagnostic process needed to be more accessible and person-centred. Receiving an autism diagnosis in adulthood has been reported as enabling development of self-acceptance and self-understanding (Arnold et al., 2020). Similarly, Punshon et al. (2009) found that an autism diagnosis was linked to feelings of relief and provided answers to questions participants had about themselves. It is important to explore research on the experience of the diagnostic process more thoroughly, from autistic individuals' perspectives. This review utilises a meta-synthesis approach to identify commonalities in the diagnostic experience, including seeking, receiving and reflecting upon an autism diagnosis. This will enable development of understanding and provide a platform from which improvements can be built. Most research exploring the diagnostic experience has been conducted with adult participants (Punshon et al., 2009). However, there are a few studies exploring children or adolescents' perspectives (e.g., Sagers et al., 2011). Including evidence from children and adult participants may reveal differences in experience related to the age of diagnosis. In addition, research suggests that the experience of autism differs between females and males (Gould, 2017; Lai & Baron-Cohen, 2015). Research also suggests that autism diagnosis and autistic traits are common in the transgender population (De Vries et al., 2010). Synthesising research without restrictions on gender categories may reveal more detail about the gender differences in the diagnostic experience. Understanding gender differences and lifespan issues have been identified as priority areas for research by autistic adults (Pellicano et al., 2014).

A narrative review of autism diagnosis in the UK for adults and children, was published in 2018; this focused exclusively on clinical guidance documents, rather than individuals' lived experiences (Hayes et al., 2018). Similarly, existing reviews on adult autism diagnosis have tended to focus on evaluating screening measures and diagnostic tools (Baghdadli et al., 2017; Falkmer et al., 2013; Hirota et al., 2018). A recent scoping review exploring the experience of autism diagnosis in adulthood presented qualitative and quantitative research findings. The review highlighted the emotional impact of diagnosis in adulthood, limited provision of formal support and inconsistencies in access and processes (Huang et al., 2020). The scoping review included studies from 13 countries using various methodologies. Prevalence statistics for autism diagnosis vary between countries, some of this variation is explained by age at diagnosis and diagnostic methods (Parner et al., 2011). Given the differences in autism diagnosis between countries, this meta-synthesis exclusively investigates autistic individuals' experiences of the diagnostic process in the UK. This encompasses the process of seeking a diagnosis, to the diagnostic procedure itself, to reflecting on the diagnostic process as a whole. Unlike Huang et al. (2020), the current review includes samples with autistic children, adolescents, and adults to consider potential differences in experiences of the diagnostic process. The current review adopts a thematic synthesis approach (Thomas & Harden, 2008). The review research question was "What are autistic individuals' experiences of the diagnostic process for autism in the UK?". The review aims to provide clinicians and policy makers with insight into experiences of the diagnostic process and provide an evidence base from which clinical practice can be improved.

2. Method

The protocol for this systematic review was registered on the prospective register PROSPERO (reference: CRD42020204383). The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Moher et al., 2009) were utilised, excluding items not applicable for qualitative research (items 13, 20, 21).

Table 1
Key elements of research question identified with SPICE tool.

Criteria	Description
Setting	United Kingdom
Perspective	Autistic individuals (all ages)
Intervention/ Interest	Experiences of the diagnostic process
Comparison (if relevant)	-
Evaluation	Attitudes, feelings, experiences captured in themes.

2.1. Search strategy

The SPICE (Setting, Perspective, Intervention/ Interest, Comparison, Evaluation) mnemonic was utilised to develop the review question and search strategy (see Table 1). The SPICE framework for defining the scope of systematic reviews is especially useful for qualitative questions (Booth, 2004).

The databases Web of Science, PsycINFO, PsycARTICLES, Medline (all via OvidSP), Scopus, CINAHL (via EBSCO) were systematically searched in October 2020. No restrictions were made on date limits during the searches to obtain all relevant articles from this area of research. Searches were limited to English only texts due to no translation ability. Authors were contacted for two of the studies as it was not possible to locate the full text; there was no response within two weeks to one of these requests.

Search terms were combined with Boolean operators: (Autis* Spectrum OR Autis* OR Asperger* OR Pervasive Developmental Disorder) AND (Lived experience* OR Qualitative) OR (lived experience* OR Qualitative method) AND (diagnosis). Names of specific qualitative methods were included in the search terms e.g., Big Q research, to ensure rigor of the systematic searches (Dixon-Woods et al., 2001; Shaw, 2012). Additional qualitative search terms were also included in the searches, including interpretative phenomenolog*, template, content, narrative, discourse, grounded theory, thematic.

2.2. Study selection

Initially, two researchers independently screened all the identified articles by title and abstract, with irrelevant studies excluded using the exclusion criteria. Duplicates were removed and then the remaining studies were read in full; studies that did not meet the inclusion criteria were removed. Studies were included if they had been peer-reviewed, were of qualitative design, and provided data on autistic individuals' experiences of the diagnostic process for autism in the UK. Studies were excluded if clinically diagnosed autistic participants' data could not be extracted from other participants including self-identified autistic individuals, parents, carers. Studies were excluded if it was not clear that the sample resided in the UK e.g., data collected from international autism websites. The study selection process was agreed at each stage by all authors. Scopus was utilised to complete forward tracking citations and backward reference checking was also completed on the included studies.

2.3. Data extraction

Data relevant to the review research question were extracted from the included studies. Extracted data included: author, year, reported sample characteristics (gender, time since diagnosis, age, presence of co-occurring mental health diagnosis, autism/ Asperger's diagnosis), recruitment, data collection and methodology, key findings and themes. All studies were required to be UK based; the country was included if specified.

2.4. Quality appraisal

The quality of the studies was assessed using the Critical Appraisal Skills Programme qualitative research checklist (Critical Appraisal Skills Programme, CASP, 2018) by the lead author. Thomas and Harden (2008) and many qualitative reviewers do not exclude studies based on quality appraisal (Hannes & Macaitis, 2012; Gallacher et al., 2013). Therefore, all articles following appraisal and critique are included in the thematic synthesis. A random selection of 3 studies were independently appraised by a second reviewer. There were discrepancies on 6 out of 30 CASP checklist questions. The discrepancies were resolved via discussions between the two reviewers.

2.5. Data synthesis

Data from the included studies were reviewed and narratively synthesised using the Thematic Synthesis (Thomas & Harden, 2008). Using the Thomas and Harden (2008) stages to thematic synthesis the process involved extracting verbatim text from the 'findings' or 'results' sections of each included study and transferring into a spreadsheet to perform 'line by line' coding of the text. The extracted text included the participant quotes, the authors' descriptions and interpretations of the findings. Including the authors' interpretations in the synthesis follows the stages suggested by Thomas and Harden (2008) and qualitative literature generally (Toye et al., 2014). Codes were created to identify the content and meanings within each line for each of the included studies. A collection of themes were developed through this inductive process for each study. The complete collection of themes was then compared across the studies to create descriptive themes and grouped in a hierarchical structure. The final stage of the thematic synthesis process was interpreting the themes further to produce a list of super-ordinate and sub-themes relating to autistic individuals' experiences of the diagnostic process for autism in the UK. The development of the themes and coding were discussed at every stage of the synthesis process with co-authors, and any discrepancies were resolved via discussions.

3. Results

3.1. Summary of included studies

Forward and backward reference checking produced an additional three studies. Forward tracking citations were completed using

Scopus and an additional original article was identified. On full-text review none of these articles met the review inclusion criteria.

Fig. 1 shows the PRISMA diagram detailing the screening and identification process for the inclusion of papers for the review. Overall, 19 studies met the inclusion criteria, including data from 486 autistic participants.

Table 2 presents the summary of the included studies characteristics. The studies range in publication dates from 2008 to 2021. This time includes the Diagnostic Statistical Manual of Mental Disorders DSM-5 (2013) and International Classification of Diseases (ICD-11, 2020) changes to the autism diagnostic criteria. There may have been inconsistencies in clinical practice adapting to this revision. Authors considered this change in the diagnostic process during the interpretation of findings.

Thirteen studies specified which UK country they were conducted, England (N = 11), Wales (N = 2) and no authors specified Scotland or Northern Ireland. Most studies (N = 16) collected data via interviews. From the studies that reported age, participants ranged in age from 9 to 59 years. Data regarding gender were available for 166 of the participants: 63 males, 103 females. Powell and Acker (2016) reported 59% of the sample was male but did not confirm the remaining participants gender identities. Most studies employed interpretative phenomenological analysis (n = 8) or thematic analysis (n = 7). Other approaches included framework analysis, open-ended exploration of lived experience account, and multi-stage narrative analysis.

3.2. Quality appraisal results

Quality appraisal using the CASP checklist indicated that most studies achieved an overall moderate to good standard, see Table 3. Most studies also provided valuable recommendations for clinical practice and clear rationales for their chosen methods. All studies were included in the synthesis regardless of quality. Most studies did not meet the CASP criteria relating to relationship consideration and reflexivity (n = 8 did not meet; n = 6 unsure), limiting the transparency of the findings. Most authors provided a description of the epistemological standpoint of the study (e.g., Gaffney, 2020). When the epistemological standpoint was not reported, it was

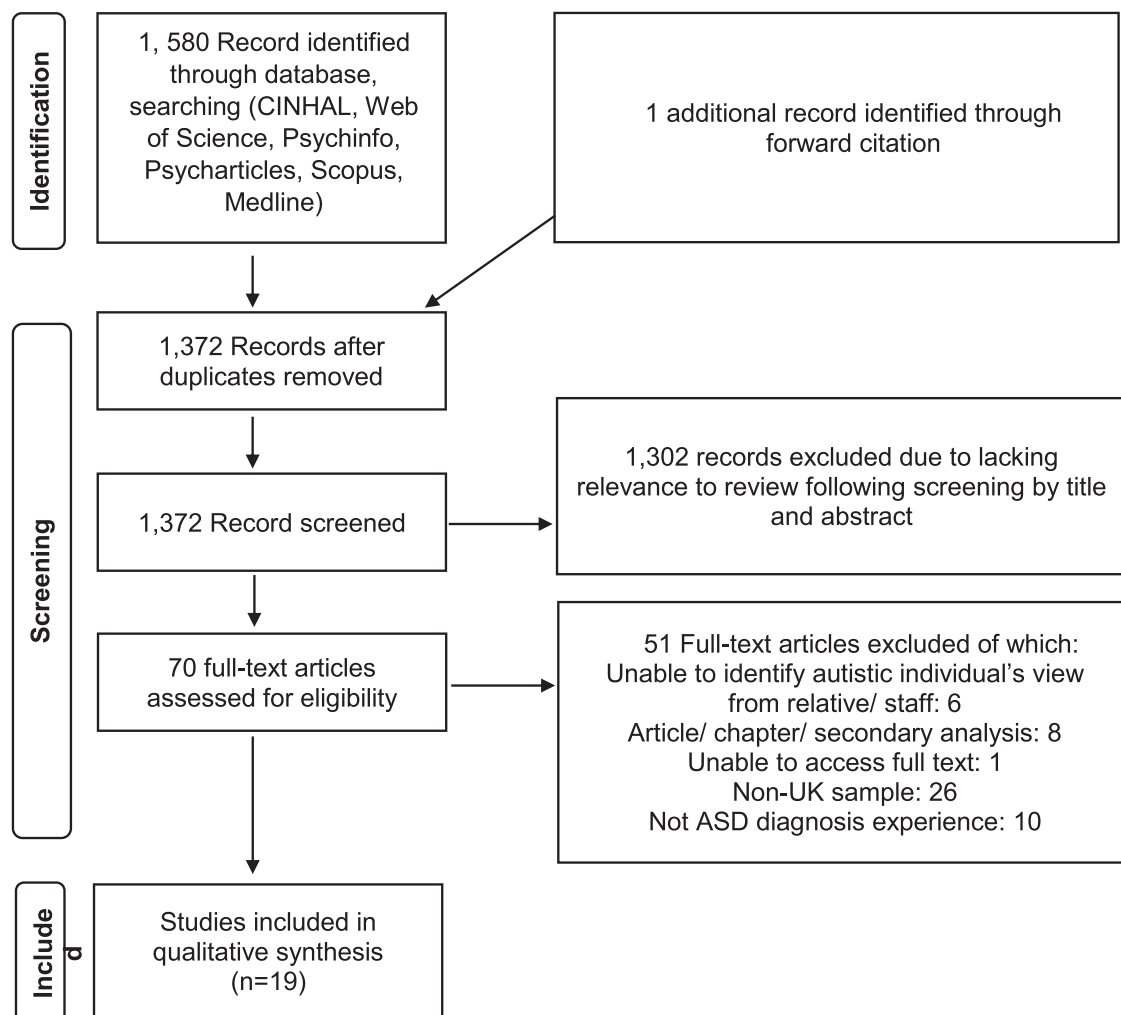


Fig. 1. PRISMA Diagram showing search strategy.

Table 2
Summary of study characteristics.

Authors (Year)	Country	Participant characteristics	Recruitment	Data collection & Methodology	Key findings, themes
Bargiela et al. (2016)	U.K.	N = 14 autistic women	Via existing contacts in the research team, adverts on social media.	Semi-structured interview. Framework analysis.	Conflicts between ASC and a traditional feminine identity. Experiences of sexual abuse. Training to improve recognition of autism in women.
Ruiz Calzada et al. (2012)	U.K.	N = 10 families, including 9 young people. Ages 9–16 years. 9 males. 6 diagnosed Asperger's, 3 high functioning Autistic Disorder	Specialist assessment clinic for high-functioning pervasive developmental disorder.	Semi-structured interviews 'Framework' approach	Advantages of diagnoses. Disadvantages of diagnoses. Improvement of post-diagnostic services.
Crane et al. (2018)	England	N = 30, 10 parents, 10 professionals. 10 autistic adults (9 Asperger syndrome), 6 women, 4 men. Age range 29–59 years. 9 participants diagnosed in adulthood.	Online survey	Semi- structured interview. Thematic analysis	Themes: the process of understanding and accepting autism, multiple barriers to satisfaction with the diagnostic process, inadequate post-diagnostic support provision.
Gaffney (2020)	England	N = 6 autistic females, aged from 14 to 20 years old. Two participants were diagnosed in their teens, four participants were diagnosed under 11 years old.	Posters displayed in learning support departments in secondary schools.	Semi structured interviews. Interpretative phenomenological analysis	Some participants were unsure about the meaning of autism. Suggested that young people find autism diagnosis useful, but some reported the diagnosis can be harmful to personal identity.
Hickey et al. (2018)	England	N = 13, aged over 50 years. 10 male, 3 female	NHS adult autism diagnostic service, autism support and social groups in London.	Semi-structured interviews Thematic analysis	Themes: difference, life review and longing for connection. Highlight the need for improving access to diagnosis and reducing isolation.
Huws and Jones (2008)	Wales	N = 9, 3 female, 6 males. Ages ranged from 16 to 21 years.	Specialist college for autism.	Semi structured interviews. Interpretative phenomenological analysis	The effects of the diagnosis or disclosure of diagnosis from the perspective of the person with autism be given greater consideration.
Jones et al. (2013)	Wales	N = 9, 3 female, 6 males. Ages ranged from 16 to 21 years.	Specialist college for autism.	Semi structured interviews. Interpretative phenomenological analysis Secondary analysis by 'expert author'.	Complexity of interpersonal relationships, a desire to 'fit in' to a wider group, a feeling of being regarded as 'different'. Expert author helped avoid a 'diagnostic overshadowing' interpretation of the findings.
Jordan et al. (2021)	England	N = 8, 7 males, 1 female, aged between 19 and 51 years old. Co-occurring depression/ low mood.	Online advertisements in two university disability services and health and wellbeing department.	Semi structured interviews. Interpretative phenomenological analysis	Autism has made me the person I am', 'I can't function in the world' and 'It's like trying to do accounts on the futures market': Making sense of emotions. Findings highlight a need for specialist mental health provision for autistic adults.
Kanfiszer et al. (2017)	U.K.	N = 7 autistic women diagnosed in adulthood. Three participants had an intellectual disability. Co-occurring mental health diagnoses. Aged between 20 and 59 years old.	Community mental health services, an inpatient service, community support group.	Semi structured interviews. Multi-stage narrative analysis.	Gender identity and social relationships. Participants drew upon notions of 'normalcy' in how they internalized a representation of the self. Nonconformity with cultural expectations of feminine results in questions around gender identity.
Kock et al. (2019)	England	N = 8 autistic women diagnosed in adulthood. Aged between 20 and 40 years old.	Two specialist ASD diagnostic clinics and an advertisement in the National Autistic Society newsletter.	Semi structured interviews. Interpretative phenomenological analysis	Themes: "Response to the diagnosis and receiving more information about Autism"; "Factors influencing dating behaviour"; "Sex and sexual experiences"; "Experience of intimate relationships as a person with Autism
Leedham et al. (2020)	England	N = 11 autistic women who received their diagnosis ages 40 years or older.	NHS adult autism diagnostic service	Semi structured interviews. Interpretative phenomenological analysis	Themes: a hidden condition; the process of acceptance; the impact of others post-diagnosis. Change in identity enabled greater acceptance and self-understanding, but painful to adjust at later stage of life.
MacLeod et al. (2018)	U.K.	N = 16, 10 males, 6 females.	Via student support departments at five higher education institutions.	Semi structured interviews. Interpretative	The autism diagnosis was perceived both as an aid to self-understanding and a cause of additional barriers. Recommendations for a more inclusive

(continued on next page)

Table 2 (continued)

Authors (Year)	Country	Participant characteristics	Recruitment	Data collection & Methodology	Key findings, themes
Markham, 2018	England	N = 1 autistic woman	Review and commentary on the author's lived experience of ASD diagnosis as a patient in a secure, forensic hospital.	phenomenological analysis Open-ended exploration of lived experience account/ case study.	higher education curriculum and environment. Encourage practitioners to be inclusive of patient perspective when completing diagnostic assessment. Future research into the assessment of females for ASD in secure, forensic hospitals.
Milner et al. (2019)	U.K.	N = 22, 18 autistic females and 4 mothers of autistic females. 16 autistic females had a clinical diagnosis of autism, 2 were self-diagnosed. Ages ranged from 11 to 55 years.	Adverts on social media, word of mouth, through contacts at a secondary school and through a tertiary referral autism diagnostic clinic.	Group and individual discussions. Thematic analysis	Themes: fitting in the with the norm; potential obstacles for autistic women and girls; negative aspects of autism; the perspective of others; and positive aspects of having autism. Clinical implications: improved awareness, diagnosis and support for autistic women and girls.
Miles et al. (2019)	England	N = 8 autistic females aged 12–17 years old.	Contact with Special Educational Needs Coordinators in secondary and middle schools.	Semi structured interviews. Thematic analysis.	Themes: perceived peer acceptance; friendship and social competence. Autistic adolescent females are socially motivated to form friendships.
Price et al. (2017)	England	N = 10, 3 trainee medics doctors with Asperger syndrome.	Professional support unit for trainee doctors.	Semi-structured interviews. Thematic analysis.	Themes: the diagnosis as a double-edged sword, developing insight into problem, and the effect of disclosing the diagnosis. Highlighted misunderstanding of AS, and how fear of exposing weaknesses may prevent trainees seeking support.
Powell and Acker (2016)	England	N = 74 Average age 36.08 years, 59% male participants.	Adult Asperger syndrome diagnostic clinic	Opened ended questions on feedback form. Thematic content analysis.	Diagnosis provided an alternative explanation for social and emotional difficulties. Externalizing blame from self to autism.
Punshon et al. (2009)	England	N = 10, 7 male, 3 female. Age from 22 to 45 years. Age at Asperger's diagnosis ranged from 21 to 44 years.	Local service for adults with Asperger syndrome.	Semi structured interviews. Interpretative phenomenological analysis	Themes: negative life experiences; experiences of services; beliefs about symptoms of AS; identity formation; effects of diagnosis on beliefs; effect of societal views of AS. Highlighted the importance of the societal view of AS. Recommendations for post diagnostic support.
Stagg and Belcher (2019)	U.K.	N = 9, 5 female, 4 male, aged between 52 and 54 years old. Majority received their diagnosis within two years of the study.	Online autism forums and messages posted on a blog run by the second author.	Free-associative narrative interview. Thematic analysis.	Diagnosis was described as a positive. Recommendations for identifying older adults with undiagnosed autism.

challenging to accurately evaluate the underpinning theory of the study.

3.3. Thematic synthesis

There were 57 codes in the 'bank of codes' and 9 descriptive themes. Analysis of the data revealed three super-ordinate themes: 'Negotiating self-identity' making sense of the autism diagnosis; 'Feeling Misunderstood' in society and the impact on well-being; and 'Support Post-Diagnosis' including increased connection and understanding.

The identified themes summarise the findings across the included studies. The themes do not provide an exhaustive list of participants' experiences. Participants' quotes are provided to illustrate the themes and '...' represents when quotes have been edited. Table 4.

3.4. Negotiating self-identity

This super-ordinate theme describes participants' dissatisfaction with the assessment process, how they make sense of their autism diagnosis in relation to their identity, and the range of emotional experiences involved.

3.5. Distressing assessment process

Participants reported various challenges during the assessment process, including barriers to assessment and the critical, deficit focus to assessments. Participants often recalled the emotional impact of feeling analysed and examined, with professionals commonly described as unsupportive. Gender differences were also discussed, some participants suggested autistic women face increased barriers

Table 3
Quality appraisal results.

Authors (year)	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship and reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research
Bargiela et al. (2016)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Ruiz Calzada et al. (2012)	?	✓	✓	✓	✓	x	✓	✓	?	✓
Crane et al. (2018)	✓	✓	✓	✓	✓	x	✓	?	✓	✓
Gaffney (2020)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Hickey et al. (2018)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Huws and Jones (2008)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jones et al. (2013)	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
Jordan et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Kanfiszer et al. (2017)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Kock et al. (2019)	✓	✓	✓	✓	✓	?	✓	?	✓	✓
Leedham et al. (2020)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
MacLeod et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Markham (2018)	✓	✓	?	?	x	x	x	x	?	?
Milner et al. (2019)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Miles et al. (2019)	✓	✓	✓	✓	✓	x	?	?	✓	✓
Price et al. (2017)	✓	✓	?	✓	✓	x	✓	?	✓	✓
Powell and Acker (2016)	✓	✓	?	✓	?	x	?	✓	✓	✓
Punshon et al. (2009)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Stagg and Belcher (2019)	✓	✓	✓	?	✓	✓	✓	✓	✓	✓

Note ✓=yes; x = no; ?= unclear.

Table 4
Super-ordinate and sub-themes.

Super-ordinate themes	Sub-themes
Negotiating self-identity	Distressing assessment process Conflicting emotions towards diagnosis Neurodiversity Self-reflection and self-kindness
Feeling misunderstood	Autism is misunderstood Social challenges Mental health impact and misdiagnosis
Support post-diagnosis	Increased support and understanding Connection and validation

to assessment compared to men.

Stigma was reported as a barrier to seeking an assessment (e.g., Punshon et al., 2009, p. 274). Across the studies most participants reported feeling dissatisfied with the autism assessment (Crane et al., 2018; Bargiela et al., 2016; Milner et al., 2019; Punshon et al., 2009; Leedham et al., 2020). Punshon et al.'s (2009) study title, *“the not guilty verdict”* implies a power imbalance between participants and the assessing professionals, suggesting a pressure for participants to justify themselves during their assessment process. One participant compared their experience of receiving a medical diagnosis and how the support from professionals contrasted to their autism diagnosis experience:

“it was cold, it was calculating... it was just yes or no” (Crane et al., 2018, p.3765). Across the studies the autism assessment process was described as *“harrowing”* (Leedham et al., 2020, p.139) and *“drawn-out”* (Milner et al., 2019, p. 2396) particularly when asked to recall difficult past experiences (e.g., Crane et al., 2018; Milner et al., 2019; Leedham et al., 2020). This highlights how participants commonly felt unsupported by professionals during the assessment process.

A participant in the Crane et al. (2018) study reflected on the age appropriateness of the assessment materials and suggested the assessment process felt patronising at times. Participants also reported the negative focus of the assessments;

“Nobody wants their negative side highlighted all the time” (Crane et al., 2018, p.3766).

It is noteworthy that most of these reflections were from participants diagnosed in adulthood. Arguably, adults would be more acutely aware of the assessment process and potentially sought their diagnosis themselves. The experience of receiving an autism diagnosis in childhood may differ to assessments in adulthood, particularly if children are not fully informed of the process. This review included samples with autistic children and adolescents, but insufficient data was obtained to conclude on differences in the lived experience of receiving an autism diagnosis in childhood and adulthood.

Some studies specifically explored women's experiences of the autism diagnosis process (Bargiela et al., 2016; Gaffney, 2020; Kanfischer et al., 2017; Kock et al., 2019; Leedham et al., 2020; Markham, 2018; Milner et al., 2019; Miles et al., 2019). Similar reports of dissatisfaction and the emotional impact of assessments were reported:

“Negative experiences were reflected by the majority of the women. ‘We headed to the nearest café and cried, cried, cried for a day; [...] it was the most awful, awful experience’” (Milner et al., 2019, p.2396).

Participants also reflected on gender differences in the assessment process and suggested autistic women encounter greater barriers to diagnosis than men, due to the impact of compensatory behaviours:

“That’s the trouble with female ASD is in that time slot of whether they’re going to say yes or no to your diagnosis you could be performing or camouflaging” (Milner et al., 2019, p.2396).

This illustrates the complexity of camouflaging behaviours and how they can inhibit accurate diagnosis. This finding highlights the need for professionals to complete thorough assessments and observe nuances in interactions, especially in adults where camouflaging behaviours are likely to be well-established.

3.6. Conflicting emotions towards diagnosis

Adjustment to an autism diagnosis is a dynamic process accompanied by a range of emotional responses. Participants described how their feelings changed over time as they navigated their new autistic identity. Adult participants often shared reflections on challenges in their past and suggested that receiving their diagnosis earlier in life would have been more beneficial for their sense of self and emotional wellbeing.

Most studies described a range of emotional responses to receiving an autism diagnosis, including sadness towards late diagnosis (Hickey et al., 2018; Powell & Acker, 2016; Leedham et al., 2020; Bargiela et al., 2016; Jordan et al., 2021; Stagg & Belcher, 2019; Punshon et al., 2009) and positive reactions, including relief and validation (Powell & Acker, 2016; Leedham et al., 2020; Crane et al., 2018; Gaffney, 2020; MacLeod et al., 2018; Kock et al., 2019; Jordan et al., 2021; Stagg & Belcher, 2019; Milner et al., 2019; Punshon et al., 2009):

“It really was like a sort of eureka moment ... it was kind of a relief” (Stagg & Belcher, 2019, p.353).

This quote refers to the new insights and reassurance that many participants reported on obtaining their diagnosis. Often the

diagnosis was described as providing answers to questions that participant had about themselves, including feeling different to others. Similarly, some participants described the positive impact the diagnosis had on their sense of self and identity;

"I was happy. I feel validated. liberated." (Powell & Acker, 2016, p.75).

This quote illustrates the importance of the diagnosis, "*validated*" and "*liberated*" have connotations of freedom and truth, alluding to overcoming doubt and the sense of achievement felt in obtaining the diagnosis. These reactions could be in response to overcoming the various barriers to diagnosis and the emotional intensity of the assessment process. Interestingly, participants' responses often related to relief that they were able to explain themselves to others and suggested previous experiences of discrimination:

"Yeah... [since the diagnosis]...I can like say to people if they say something that isn't very nice - give a reason to them for why I am the way I am" (Kock et al., 2019, p.44).

Comparatively, in some studies, positive feelings towards the diagnosis were juxtaposed with feelings of shock: *"I didn't believe it at first, because I didn't think I had that"* (Huws & Jones, 2008, p.102) and a sense of grief, reflecting how the diagnosis is lifelong:

"I am never going to be like one of these 'normal' people. I am stuck being like this now." (Pushon et al., 2009, p.278).

These quotes describe participants feeling different due to their diagnosis and "*at first*" suggests stages of emotional responses to their diagnosis, reflecting the complexity of emotions involved. The literature also highlighted participants' concerns about their diagnosis disclosure:

"Relieved at first but I am now starting to see how difficult it can be having AS, not least the disclosure issue" (Powell & Acker, 2016, p.75).

A participant in Stagg and Belcher (2019) study alluded to regretting seeking his diagnosis:

"if I hadn't bothered finding out what Asperger's was, I would have just been this lonely person who just carried on. I sometimes wonder whether I should have, is it a bad thing to have had, the diagnosis." (Stagg & Belcher, 2019, p.355).

Concerns about diagnosis disclosure are related to judgements from others and how sharing the diagnosis may alter the view people have of the participants, this is also discussed in relation to social challenges.

Participants that received their diagnosis in adulthood often described feelings of "*sadness for their pre-diagnosis self*" (Leedham et al., 2020, p.140).

"...having to, psychologically, on your own, reassess your whole life. And at the age of 53 it's going back a long way". (Hickey et al., 2018, p. 361).

Participants reflected on past difficulties and suggested that their lives would have been improved with earlier diagnosis:

"...if I had known, and if people had helped me from earlier on, then life would've been a whole lot easier." (Bargiela et al., 2016, p. 3286).

Interesting, studies with younger participants more commonly reported feelings of anger or avoidance when asked to reflect on their feelings towards their diagnosis:

"if I had a choice between not existing and having this [diagnosis] I would choose not existing, because I hate it so much." (Gaffney, 2020, p.142).

This suggests despite obtaining the autism diagnosis earlier in life, challenges remain in processing and negotiating self-identity in relation to the diagnosis.

Two studies (Gaffney, 2020; Markham, 2018) described participants who disagreed with their autism diagnosis: *"Melody refuted the validity of her autism diagnosis as she did not see herself as different to peers"* (Gaffney, 2020, p.142).

Two studies (Powell & Acker, 2016; Ruiz Calzada et al., 2012), described participants feeling "*indifferent*" to learning about their diagnosis: *"I'm not that interested [in the meaning of the diagnosis]"* (Ruiz Calzada et al., 2012, p. 235). Interestingly, both samples reported diagnoses of Asperger's syndrome. Arguably, feeling disinterested the diagnosis could be described as avoidant and may reflect the earlier stages of adjusting to the diagnosis. Two studies (Huws & Jones, 2008; Gaffney, 2020;), described some participants actively avoiding information about autism post-diagnosis. Both these samples included younger participants, where other people (e.g. parents) may have instigated their assessments, compared to adult participants who often reported researching autism before seeking their own assessment.

The literature highlights the range of emotional responses participants described in relation to their diagnosis, including validation, relief, grief, and anger, illustrating the individuality of the diagnostic experience.

3.7. Neurodiversity

The literature illustrates the range in individual experience and personal meaning ascribed to the autism diagnosis. Participants reflected on society's expectations, alongside the challenges and unique strengths associated with autism. In the majority of studies (Bargiela et al., 2016; Gaffney, 2020; Kanfischer et al., 2017; Leedham et al., 2020; MacLeod et al., 2018; Hickey et al., 2018; Jones

et al., 2013; Jordan et al., 2021; Stagg & Belcher, 2019; Milner et al., 2019; Pushon et al., 2009), participants described their efforts to meet societal expectations of “normal”:

“...[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, p. 141).

Participants discussed the non-social challenges associated with autism and in some cases the related restrictions society places on these differences e.g., the following quote highlights the impact an autism diagnosis has on an individual’s career options:

“my behaviour’s been quite bad because of autism... like having trouble with spelling and maths... and things like can’t do the job you exactly want to do like because of it.” (Jones et al., 2013, p.103).

Comparatively, in over a quarter of studies, participants celebrated the strengths and unique qualities of autism;

“Ryan also attributed his positive personality traits, such as being ‘honest’ and ‘moralistic’, to being autistic.” (Jordan et al., 2021, p.1688).

This sub-theme illustrates the pressures to conform to “neurotypical” expectations and highlights the challenges of managing these expectations whilst also celebrating the unique strengths associated with autism.

3.8. Self-reflection and self-kindness

The literature suggests the diagnostic process prompted participants’ self-reflection and facilitated greater self-understanding and self-kindness. Across the studies, participants reported that their diagnosis helped make sense of difficult past experiences, especially when the diagnosis was received in adulthood:

“Suddenly the first fifty years of my life made sense” (Hickey et al., 2018, p.361).

In most of the studies, participants described developing greater self-understanding and feeling less critical towards themselves after receiving their autism diagnosis.

“...Now I understand why I’ve felt the way I have a lot of the time and why I’ve been the way I am a lot of the time as well.” (Leedham et al., 2020, p.140).

In a quarter of studies, participants reported researching autism, both pre- and post-diagnosis, to develop their understanding. In some studies, participants criticised traditional theories of autism and highlighted common misconceptions of autistic women:

“Having researched ASD, she spontaneously and firmly, rejected the Extreme Male Brain Theory (e.g. Baron Cohen, 2002). ‘... I definitely don’t have the extreme male brain ... lots of other women I know and myself are living proof that we’re definitely not extreme males ...’ (Kanfisz et al., 2017, p. 665).

3.9. Feeling misunderstood

This super-ordinate theme explores participants’ interpretations of how autism is conceptualised in society, including common misconceptions and considers the subsequent impact on their well-being.

3.9.1. Autism is misunderstood

Across the studies, participants reflected on experiences of feeling misunderstood by others and related this to society’s limited understanding of autism, often underpinned by unhelpful stereotypes.

“I’ll always remember my special needs teacher saying I’m too poor at maths to be autistic.” (Bargiela et al., 2016, p.3286).

The experience of feeling misunderstood negatively impacted participants’ self-esteem, social experiences, and employment opportunities. In some studies, the participants spoke about wanting to improve other people’s understanding of autism by educating others or participating in research.

“I don’t think they know what Asperger’s syndrome is [laughs] but I have told them anyway... She said I was staring at her and I said ‘Sorry, I have got Asperger syndrome’ and she went ‘You must be clever then’. (Pushon et al., 2009, p. 280).

3.9.2. Social challenges

Participants shared examples of social challenges they had endured as part of their assessment process, including unhelpful responses to diagnosis disclosures, feeling different from peers and experiences of victimisation:

“I got bullied because I was different” (Jones et al., 2013, p.139).

Participants also reported dismissive responses from others following their diagnosis disclosure:

“‘You don’t have autism, you’re perfect. There’s nothing wrong with you.’....he thinks I’m his perfect little girl....who’s got nothing wrong with her, so I can’t talk to him about if I’ve had a bad day.” (Leedham et al., 2020, p.141).

This quote illustrates the commonly reported suggestion that autism and the related differences are not celebrated in society, instead considered to be “wrong”. Gender differences were raised by participants in two studies, including “masking”. Participants also suggested the social challenges and expectations were greater for autistic women than autistic men:

“Boys are more content to be themselves... whereas the girls really want to fit in, um, and I think that makes them unhappier...I think it’s harder, much harder as a girl because girl peers are less forgiving of other girls. The girls seem to be very tolerant of the boys with autism and almost mother them” (Milner et al., 2019, p.2394).

3.9.3. Mental health impact and misdiagnosis

Participants described the mental health impact of feeling misunderstood and some participants shared experiences of misdiagnosis and the potential for diagnostic over-shadowing. Participants also expressed frustrations towards the inappropriate mental health diagnoses they received before their autism diagnosis. One participant in Leedham et al. (2020) described the power imbalance in her experiences with mental health professionals:

“I was almost convinced that they wanted to be right and I’d actually buried some deep trauma and I had no memory of it and I started questioning the whole – like everything.” (Leedham et al., 2020, p.139).

Some studies discussed the validation participants felt when their autism diagnosis replaced previous mental health diagnoses:

“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 & Belcher, 2019, p. 353).

This quote highlights the potential for diagnostic overshadowing, where professionals hold a reductionistic view on an individual’s behaviours, in this example, neglecting the possibility the participant could be autistic. Similarly, a participant in MacLeod et al. (2018) reflected on attempting to understand her anxiety, “AS” refers to Asperger’s Syndrome. This quote also presents another example where participants described comparing themselves to societal expectations of “normal”.

“Would somebody classed as normal do the same thing... Is my anxiety AS or is my anxiety what a normal person would have.” (MacLeod et al., 2018, p. 690).

3.10. Support post-diagnosis

This super-ordinate theme explores the helpful responses and supportive outcomes that some participants experienced after receiving their autism diagnosis.

3.10.1. Increased support and understanding

Despite some participants reporting that formal post-diagnostic support is limited, over a quarter of studies suggested that participants found increased support following diagnosis disclosure:

“Several participants experienced tailored and helpful support, with many describing supportive adaptations at work” (Leedham et al., 2020, p.141).

Some participants reported increased support from statutory services post-diagnosis, “It helped me get help from social services” (Powell & Acker, 2016, p.77), and increased understanding from others:

“After getting the diagnosis mom ... explained all of my stresses...I then passed them [exams] which proved it was the environment rather than my learning skills” (MacLeod et al., 2018, p.689).

3.10.2. Connection and validation

Many studies reported that participants found increased understanding from autistic people and joined autism groups to connect and share experiences:

“ We all know that we have got something but it helps us because we are not rude to each other and we understand each other.” (Pushon, et al., 2009, p.277).

A fifth of studies reported on the genetic aspect of autism. Participants suggested that recognising their shared family experiences developed a greater understanding of individual needs. In some case participant’s experiences instigated other family members’ autism assessments:

“The diagnosis process brought into light that my father and grandfather had quite similar developmental histories to me...It was also quite a bonding experience for the male line in my family...later on, my brothers went through a similar process.” (Crane et al., 2018, p.3769).

4. Discussion

This review aimed to identify, appraise, and thematically synthesise the available qualitative literature to provide a detailed

understanding of autistic individuals' experiences of seeking, receiving and reflecting upon an autism diagnosis in the UK. Three super-ordinate themes were identified: '*Negotiating self-identity*', '*Feeling misunderstood*', and '*Support post-diagnosis*'.

The first super-ordinate theme, '*Negotiating self-identity*', describes how the autism diagnostic process impacts individual's sense of self and relationships with others and highlights that this process is not linear. Dissatisfaction with the assessment process was widely reported, including lack of support and a deficit focus (e.g., Milner et al., 2019; Crane et al., 2021). This super-ordinate theme illustrates the diversity in emotions that participants experienced as part of their diagnostic process, including relief (e.g., Stagg & Belcher, 2019; Pushon et al., 2009), anger (e.g., Gaffney, 2020) and indifference (e.g., Powell & Acker, 2016). In many of the studies, participants reported developing self-understanding and self-kindness, compared to previous self-criticism. This finding is central to Leedham et al.'s (2020) research, where several autistic women suggested their diagnosis in adulthood facilitated a transition from self-criticism to self-compassion and also chimes with themes reported by Arnold et al. (2020) from an Australian sample. Interestingly, in the wider literature exploring self-compassion, Howes et al. (2020) reported that autistic traits are negatively correlated with self-compassion in men and women. Future research could explore autistic individuals' perceptions of self-compassion to develop understandings in this area. Reduced self-compassion may be explained by the social challenges commonly encountered by autistic individuals. In the current review, participants often compared themselves to a "normal", this comparison emphasises their feelings of difference. "Feeling different" was a theme identified in a study investigating the experiences of adults seeking an autism diagnosis in Australia (de Brozie et al., 2022). This super-ordinate theme illustrates the process of adjusting to a new identity on the spectrum post diagnosis.

The second super-ordinate theme, '*Feeling Misunderstood*', highlights participants' experiences of the limited understandings of autism and the subsequent impact on well-being. Several participants reported common unhelpful stereotypes of autism; this is consistent previous research where stereotypes consistently presented autistic individuals as "weird" (Trewick et al., 2019), adding to feeling not "normal" (e.g., Hickey et al., 2018). This review found that participants of all ages reported multiple experiences of victimisation (e.g., Pushon et al., 2009; Jones et al., 2013). This is also consistent with previous literature from the UK (Trewick et al., 2019) and Canada (Weiss & Fardella, 2018).

Unsurprisingly, mental health difficulties were discussed within the samples. Adult participants also referred to experiences of misdiagnosis and diagnostic overshadowing, including mental health diagnosis of anxiety and depression which did not fully explain their experiences (e.g., Stagg & Belcher, 2019; Leedham et al., 2020). Similar missed opportunities and varied diagnostic experiences have also been reported in the diagnostic experiences of autistic adults in Australia (de Brozie et al., 2022). This is all consistent with previous research that suggests autistic women's needs are commonly misattributed to different mental health diagnoses (Eaton, 2018), including: depression, eating difficulties, and anxiety (Attwood, 2007; Bargiela et al., 2016). Previous research suggests mental health issues commonly co-occur with autism, with one study reporting that 79% of autistic adults in the Netherlands met diagnostic criteria for a mental health condition, with depression and anxiety as the most common (Lever & Geurts, 2016).

The current review suggests there are gender differences in the experiences of the diagnostic process. Autistic women reported camouflaging in social situations and discussed the potential impact of these behaviours on professionals' decisions to refer for assessment and provide the diagnosis. This is consistent with previous research findings that compensatory behaviours can be a barrier to autism diagnosis, for both men and women (Hull et al., 2017) and the use of these behaviours can negatively impact individuals' mental health (Bargiela et al., 2016). Included in the current review, the participants in Milner et al. (2019) suggested that society was more accepting of autistic males, than autistic females. Acceptance of autistic males may be related to higher diagnosis rates in males, with approximately three times more males diagnosed than females (Loomes et al., 2017), and women commonly reporting barriers to autism assessment (Lewis, 2017). This super-ordinate theme highlighted the social challenges, gender differences and the impact these experiences can have on autistic individuals' mental health.

The third super-ordinate theme, '*Support Post-diagnosis*', presents the beneficial outcomes that some participants experienced as part of the diagnostic process. Shared experiences with others in the autistic community created a sense of connection and validation that participants had not experienced pre-diagnosis (Bargiela et al., 2016). This theme is consistent with previous research, with newly diagnosed participants in the USA describing themselves as finding a new community post-diagnosis (Tan, 2018). Similarly, in the broader autism literature, Crompton et al. (2020) highlighted the benefits of peer support for autistic adults and the need for autistic-led social activities. A fifth of the studies included in this review reported on the genetic aspect of autism; this facilitated understanding of relationship needs (e.g., Kock et al., 2019) and instigated some participant's autism assessments (e.g., Pushon et al., 2009). Most participants described limited post-diagnosis support, which was also reported in an Australian cohort of autistic people diagnosed in adulthood (de Brozie et al., 2022). However, some participants reported increased understanding from friends, family, and employers (e.g., Leedham et al., 2020; MacLeod et al., 2018). This super-ordinate theme illustrates some positive outcomes post-diagnosis.

This review extends previous research findings by providing distinct themes and an in-depth account of the literature investigating autistic individuals' experiences of the diagnostic process in the UK.

5. Clinical implications

This review highlights several clinical implications and suggestions to improve understandings of autism. Participants commonly reported limited understanding from professionals, creating barriers to assessment and appropriate support. Research with autistic women that received their diagnosis in adulthood suggested that their life experiences would have improved if they had received their diagnosis earlier, including the prevention of mental health issues and social challenges (e.g., Bargiela et al., 2016; Leedham et al., 2020). These findings highlight the importance of early identification and support, especially for women. Dissatisfaction with the

assessment process was also reported, consistent with previous research (Jones et al., 2014). These findings illustrate the need to review the current assessment process; involving autistic individuals in service development and evaluation could be a useful starting point. Most participants diagnosed in adulthood described the deficit focus of assessments (e.g., Milner et al., 2019); therefore it is recommended that clinicians recognise personal strengths in the diagnostic process.

This review highlights the need for further training for professionals in primary care, mental health services, schools, and other agencies to better understand autism and signpost to specialist autism services, when required e.g. to refer for diagnostic assessment. It is hoped greater autism awareness will enable access to appropriate support for autistic individuals and reduce the unmet needs of autistic girls and women. Training and support should be co-facilitated with autistic individuals where possible. Some participants' shared suggestions about educating others about autism and their participation in research (Powell & Acker, 2016; MacLeod et al., 2018).

Connection and validation within the autistic community were commonly reported and valued by participants (e.g., Pushon et al., 2009; Bargiela et al., 2016), highlighting the benefits of peer support around the diagnostic process. With this knowledge, professionals should signpost to autism support groups. Caution is recommended to ensure professionals do not assume all autistic individuals will want to access this support.

The review emphasises the range in autistic individuals' experiences of the diagnostic process and the prejudice often reported. Promoting autism awareness in all settings and encouraging inclusion in society may support a move to celebrating difference. Future research could evaluate the efficacy of inclusion/ autism awareness strategies that challenge the 'disability' narrative.

6. Limitations and future research directions

Participants varied in the time since their autism diagnosis, e.g., Hickey et al. (2018) reported an average six years before the study, Stagg and Belcher (2019) reported an average of two years before the study. Comparatively, Gaffney (2020) included participants that received their diagnosis before their 11th birthday. This time variation may have impacted the participants' experience of the diagnostic process. Similarly, the diagnostic process is unlikely to be consistent across service providers. The studies also varied in publication dates from 2007 to 2021, this includes the DSM-5 (2013) change to the diagnostic criteria, and there may have been inconsistencies in practice adapting to this revision.

Most studies were conducted in England ($N = 11$) and no authors specified any recruitment from Scotland or Northern Ireland. Further research in Northern Ireland, Scotland and Wales will provide greater detail about the autistic diagnostic process in the UK. Four studies included participants under 16 years old, this suggests there is limited research exploring children's experiences of the diagnostic process for autism in the UK. Therefore, there was insufficient data to conclude potential differences in the lived experience of receiving an autism diagnosis in childhood or adulthood, further research exploring children's experiences of the diagnostic process for autism is needed. Few studies reported participants' ethnicity; those that did (e.g., Hickey et al., 2018) described the participants as 'white'. Autistic individuals identifying from other ethnic backgrounds may report different experiences of the diagnostic process. Kelly et al. (2019) reported ethnic minority children had lower levels of autism diagnosis in the UK. A report by the National Autistic Society (Slade, 2014) stated that ethnic minority communities face additional challenges to obtaining autism diagnoses and support. The report also highlighted the scarcity of research about ethnic communities' experiences of autism and this presents an important consideration for future research.

Gender differences were considered, and autistic women reported that professionals' limited understanding of autism were barriers to obtaining assessment. There were insufficient data to conclude on the influence of non-binary categories of gender and the diagnostic process experience, further research is needed in this area. Kanfischer et al. (2017) was the only study that reported data from participants with intellectual disabilities. This presents limited developmental diversity across the data and highlights a need for future research to include participants with intellectual disabilities. This is consistent with previous research recommendations to understand how the experiences of autistic individuals vary by age, gender, symptom severity and socio-demographic factors (DePape & Lindsay, 2016).

Attempts were made to contact the authors of two articles as it was unclear whether both articles drew on the same data set (Jones et al., 2013; and Huws & Jones, 2008), no response was received. The decision to include both studies was based on the different themes identified and the 2013 paper using an alternative form of analysis (secondary analysis by 'expert author'). Service user involvement in autism research is important given the 'double empathy problem' (Milton, 2012), describing the possible mutual misunderstandings between neurotypical and autistic people, potentially threatening the authenticity of qualitative data.

7. Conclusions

This is the first meta-synthesis of autistic individuals' experiences of the diagnostic process in the UK. The findings can inform clinicians and policymakers about the factors impacting the diagnosis process in the UK. Factors include barriers to assessment, scarcity of appropriate post-diagnostic support and the impact of a deficit-focused assessment process on individuals' well-being. Findings present the process of adjusting to a new autistic identity as dynamic and accompanied by a range of complex emotional responses. In many cases, the diagnosis facilitated self-understanding and a non-judgemental approach to difficulties, contrasting to the self-criticism often reported pre-diagnosis. Experiences of connection and validation from the autistic community supported participants' well-being. The findings from this review highlight wider societal issues around misconceptions of autism, intolerance of difference and the subsequent impacts on individuals' mental health. Recommendations are suggested to improve autism awareness and ways to address these misunderstandings by employing a participatory approach to research, training, and service development.

Declaration of Competing Interest

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

Data Availability

No data was used for the research described in the article.

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