



“I Always Knew I Was Different”: Experiences of Receiving a Diagnosis of Autistic Spectrum Disorder in Adulthood—a Meta-Ethnographic Systematic Review

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Abstract

A broadening of diagnostic criteria and increased awareness of autism has led to a large number of individuals whose difficulties remained undetected until adulthood. This systematic review aimed to synthesise empirical evidence of the experience of individuals who received their diagnosis of autism in adulthood. Eight studies met the inclusion criteria. A meta-ethnographic approach was used to synthesise the findings. Analysis revealed two meta-themes: feeling “*like an alien*” and the “*not guilty*” verdict, each with three associated subthemes. The findings indicate the need for timely diagnosis and provision of post-diagnostic support to alleviate the mental health implications of not having a framework to understand one’s experiences and to support the process of adjustment to the diagnosis.

Keywords Autism · Autistic spectrum disorder · Adult · Diagnosis · Experiences · Meta-ethnography · Review

Autism is a neurodevelopmental disorder characterised by impairments in social communication and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association (APA), 2013). Autism is typically diagnosed in childhood, with the average age of autism diagnosis globally being 60.48 months (van’t Hof et al., 2021). More recently there is a trend of seeking a diagnosis in adulthood. This can possibly be explained by increasing public awareness (Hansen et al., 2015; Huang et al., 2020) and impairments becoming more apparent when faced with the challenges of adulthood (Young et al., 2011).

Detection and diagnosis of autism can be delayed due to a number of factors. Some individuals learn to hide autism-related characteristics and use compensatory strategies (known as masking or camouflaging) to make up for social communication difficulties (Hull et al., 2017; Lai et al., 2017), whilst others may have received another related diagnosis with the underlying autism remaining undetected (Mazzone et al., 2012). Research suggests autism is under-diagnosed in

females (Loomes et al., 2017) as a result of greater instances of masking and diagnostic procedures being biased against females (Kirkovski et al., 2013; Lai et al., 2017). Furthermore, it is important to note that there have been substantial changes to diagnostic criteria over the past 40 years (Huang et al., 2020). Advances in brain imaging, genetic and behavioural investigations have influenced the identification and assessment of autism (Murphy et al., 2016).

A broadening of diagnostic criteria and increased awareness of autism led to a large number of individuals whose difficulties remained undetected until adulthood (Huang et al., 2020; Lai & Baron-Cohen, 2015). Assessment of autism in adulthood presents unique challenges as it relies on knowledge of the individual’s developmental history (Huang et al., 2020). However, adults and their families often lack access to childhood medical records or there is inaccurate recall of developmental milestones (Huang et al., 2020; Lai & Baron-Cohen, 2015; Rutherford et al., 2016). Some adults find it challenging to provide self-reports of their difficulties (Bishop & Seltzer, 2012) and autism can present as part of a complex presentation of co-occurring mental health conditions (Howlin et al., 2014; Moss et al., 2015). Additional challenges for adults include a lack of valid and reliable assessment measures, service availability (Wigham et al., 2019) and social barriers such as anxiety, mistrust of healthcare professionals and stigma (Lewis, 2017).

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Autistic people¹ are at risk of emotional, behavioural, social, occupational and economic difficulties (Howlin & Moss, 2012). The timely detection of autism can reduce these risks and lead to improvements in quality of life due to the identification of needs, provision of support, access to services and reduction of stigma and self-criticism (Calzada et al., 2012; Hurlbutt & Chalmers, 2002; Portway & Johnson, 2005; Wong et al., 2015). Diagnosis may also help reduce masking as individuals feel more comfortable not conforming to non-autistic expectations leading to improved quality of life (Bradley et al., 2021).

Research into undiagnosed adults is essential as many individuals who receive a diagnosis of autism in adulthood are being treated for social difficulties, anxiety and mood disorders (Bishop-Fitzpatrick et al., 2018; Geurts & Jansen, 2012) without their core difficulty being recognised. Prior to diagnosis, autistic adults' difficulties are often misunderstood and poorly addressed negatively impacting their wellbeing and functioning (Bargiela et al., 2016; Portway & Johnson, 2005). Therefore, the lack of appropriate diagnosis can compound autism-related difficulties.

Research has largely focused on autism in childhood with research in adulthood comparatively limited; a 2017 review estimated that only 3.5% of published research involved adults (Howlin & Magiati, 2017). Previous reviews focused on the characteristics of autistic adults following childhood diagnosis (Kirby et al., 2016; Magiati et al., 2014); however, have not considered the challenges of receiving a diagnosis in adulthood. Individuals who receive their diagnosis in childhood may differ in their experiences, psychosocial outcomes and autism beliefs from individuals who receive their diagnosis in adulthood as they had not had a framework in which to make sense of their difficult life experiences (Brugha et al., 2011).

Furthermore, reviews also synthesised the literature on the suitability of assessment and diagnostic tools for adults and identified best practise for the assessment (Baghdadli et al., 2017; Falkmer et al., 2013; Hayes et al., 2018). They have not, however, provided an understanding of the individual experiences of assessment and diagnosis. The diagnostic process can often be experienced as challenging and arduous (Crane et al., 2018). Levels of satisfaction with the diagnostic process are mixed for adults who receive a diagnosis of autism in the UK; 40% of respondents were "very/quite" dissatisfied, whilst 47% were "very/quite" satisfied (Jones et al., 2014).

Moreover, Huang et al.'s (2020) scoping review provided an overview of research on the diagnosis of autism in adulthood. Their findings suggested that accessibility of services and processes are inconsistent, formal support services are inadequate and receiving a diagnosis of autism has a significant emotional impact for adults. However, due to the broad nature of the review question, the identified focus of

the empirical research was wide-ranging and did not allow for a detailed discussion of each theme.

Given the ageing population, increasing diagnosis rates (Lyll et al., 2017), limited access to diagnostic services for adults (National Institute for Health and Care Excellence [NICE] 2012) and high costs associated with autism (Horlin et al., 2014), investigating the experience of diagnosis in adulthood is of considerable importance. To empower and advocate for an individual following a diagnosis, clinicians must understand those individuals' unique experiences. This could inform the development of specialised support programmes and thus access to appropriate support.

Therefore, the present review aims to systematically synthesise empirical evidence to address the question: "*What are the experiences of autistic individuals who receive their diagnosis in adulthood?*".

Method

This systematic review was created under the guidance of the "Preferred Reporting Items for Systematic Reviews and Meta-analyses" (PRISMA 2020; Page et al., 2021). The PRISMA checklist was used to facilitate preparation, reporting and gauge completeness and transparency of the review (Page et al., 2021; Online Resource 1). This review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) and a published protocol is available under the registration number CRD42021279148. Ethical approval was granted by Coventry University Ethics Committee.

Systematic Literature Search

Database Search

The systematic literature search was carried out in October 2021 for papers that explored the experience of receiving a diagnosis of autism in adulthood. Studies were identified using electronic databases: Medline, Embase, Web of Science and APA PsycInfo. Additional studies were found using Google Scholar and manual review of reference lists of extracted articles. A database auto-alert was also set up to gather any relevant articles which were published between the time of the search and the end of March 2022.

Search Strategy

A structured search strategy was created using relevant key words determined with the assistance of a specialist librarian. Table 1 presents an overview of the key search terms used. The search strategy followed Boolean logic when searching for key words. The Boolean operators "AND" and "OR" were

Table 1 Key search terms

Main concepts	Synonyms and alternative spellings (2nd wave)	Location
Autism	Autistic Disorder OR Autis* OR Asperger Syndrome OR Asperger* OR Autistic Spectrum Disorder OR Autistic Spectrum Condition OR Autism Spectrum Disorder OR Autism Spectrum Condition OR ASD OR ASC	Title Abstract
Adult	Adult*	Title Abstract
Diagnosis	Diagnos* OR delayed diagnosis	Title Abstract
Experience	Experienc* or perception* or attitude* or view* or feeling*	Title Abstract
Coping	Cope or coping	Title Abstract

used to construct a combination of keywords. The truncation * was used to retrieve different variations of search terms. The detailed search strategy used across the four databases for searches are presented in Online Resource 2.

Identification of Studies

Screening

After duplicates were removed, titles and abstracts were screened for relevance by the first and second author independently. Inter-rater reliability analysis using the Kappa statistic was performed, the overall Kappa coefficient was $\kappa = 0.521$, indicating moderate agreement (Viera & Garrett, 2005). In some instances, there was a disagreement over which articles to retain; however, following a discussion, there was complete agreement across all article titles and abstracts reviewed.

Eligibility

Following the initial screening of the title and abstract, the full-text remaining articles were screened for eligibility

using specified inclusion and exclusion criteria (Table 2). The first and second author independently reviewed the full texts. Inter-rater reliability analysis was conducted, the overall Kappa coefficient was $\kappa = 0.754$, indicating substantial agreement (Viera & Garrett, 2005). There was disagreement over three articles; however, following discussion, there was complete agreement on all full-text articles.

Studies were only included if they used a qualitative design or a mixed-method design where the qualitative findings were reported separately. Only research exploring individuals' experiences of assessment and diagnostic process in adulthood were included. NICE guidance for diagnosing and managing autism considers adults to be individuals aged 18 and over (NICE, 2012). Consequently, studies were only included where participants received their diagnosis aged 18 or over given the process and experience of diagnosis in adulthood is likely to be experienced differently to children. Studies were only included if participants received a diagnosis of autism following assessment, as the experiences of adults who have undergone assessment and not received a diagnosis are likely to differ significantly. Samples were included if participants had a confirmed diagnosis using any classification system. Studies were excluded if the participants self-diagnosed their autism.

Table 2 Inclusion and exclusion criteria

Criteria	Include	Exclude
Research design	All qualitative research designs Mixed designs, where qualitative findings can be extracted	Quantitative methodology Mixed method designs where qualitative findings could not be extracted
Research aim	Exploring how adults experience receiving a diagnosis of autism in adulthood	Exploring how children or adolescents experience receiving a diagnosis of autism Exploring one parent or parents/partner's experiences of their child/partner receiving a diagnosis of autism in adulthood
Sample	Age of diagnosis ≥ 18 years	Age of diagnosis ≤ 17 years Not received a diagnosis of autism
Language	English	Non-English
Time period	Published between 2008 and 2022	Published prior to 2008

Only studies published in English were included to enable interpretation by the authors. Additionally, only articles published between 2008 and 2022 were included as the diagnosis of autism in adulthood is a relatively recent phenomenon. Furthermore, this ensured studies indicated in the scoping review conducted by Huang et al., (2020) were reviewed in addition to any further studies published since their final search in November 2018.

Data Extraction

The first and second author independently extracted the data from each paper to ensure accuracy. The following data points were extracted from each study: author, year, country, research aims, research design, sampling method, sample characteristics, method of data collection, method of data analysis and key findings.

Quality Assessment

To assess the quality of the studies identified, the Critical Appraisal and Skills Programme (CASP) checklist was used (CASP 2018). The CASP does not produce a quality score; however, in line with other researchers (Boeije et al., 2011; Lachal et al., 2017) a three-point scale was applied to each criterion (0 = criterion not met, 1 = criterion partially met, 2 = criterion fully met). The total score for each article was calculated by summing the scores such that articles could receive a total score between zero and 20. The articles were individually assessed against the CASP criteria by the first and second author independently and the mean CASP score was used for the final rating. Inter-rater reliability analysis was performed; the overall Kappa coefficient was $\kappa = 0.749$, indicating substantial agreement (Viera & Garrett, 2005).

Data Analysis

The meta-ethnographic approach outlined by Noblit & Hare, (1988) guided the review process. Meta-ethnography is one of the most widely used and influential methodologies for synthesising qualitative studies in health and social care research (Dixon-Woods et al., 2007; France et al., 2014; Hannes & Macaitis, 2012) and can produce a new interpretation, model or theory which goes beyond the findings of individual studies that are synthesised (Noblit & Hare, 1988). Therefore, meta-ethnography has the potential to generate new evidence on how patients experience their health condition or treatment, thus how this may influence treatment adherence (Campbell et al., 2011) and can help to understand why interventions or services work in certain settings but not in others (Noyes et al., 2018).

To reduce the impact of subjectivity and ensure the trustworthiness of the data, the second author was involved in all

phases of the meta-ethnography. Both authors determined the research question, focus of the synthesis, conducted the literature search and made decisions on inclusion criteria and quality assessment. The first author completed the remaining phases independently; however, the second author coded a section of a transcript by extracting metaphors and themes. The authors then compared transcripts to consolidate the meaning of the codes used. The final phases of data analysis were regularly presented at research meetings to the second author to ensure adherence to the procedure.

Results

In total, 1637 articles were initially identified, of which 378 were duplicates, resulting in 1259 studies considered suitable for further screening. Following the screening of titles and abstracts, 1236 records were excluded. Full texts for the remaining 23 eligible articles were reviewed and a further 17 articles were excluded from the review at this stage. Additionally, studies were identified via other methods including Google Scholar, citation searching and database auto-alerts. A further 12 articles were identified and assessed for eligibility, of which 10 were duplicates, resulting in an additional two studies retained for inclusion. A further screening of studies who have cited Huang et al., (2020) paper and database auto-alerts was completed prior to publication which resulted in an additional study retained for inclusion. This resulted in nine articles being retained for quality assessment (QA) (Fig. 1).

Study Design and Quality

Included studies were from the UK ($n = 6$), USA ($n = 1$), Australia ($n = 1$) and South Africa ($n = 1$). All studies employed a qualitative methodology except for Powell & Acker, (2016) who used a mixed-method approach. Across the studies, the sample size ranged from eight (Atherton et al., 2022) to 77 participants (Lewis, 2016). All studies used a mixed-gender sample except for Leedham et al., (2020) who only included females and Lupindo et al., (2022) who only included males. The mean age of participants ranged from 29.8 years (Atherton et al., 2022) to 60.38 years (Hickey et al., 2018) and the mean age at diagnosis ranged from 34.75 years (Lupindo et al., 2022) to 49.19 years (Lilley et al., 2021).

Studies used a number of different methods to collect data; semi-structured interview ($n = 5$), free-associative narrative technique ($n = 1$), open-ended text questions ($n = 1$), an oral history approach ($n = 1$) and an online open-ended survey ($n = 1$). There was also a range of methods used to analyse the data including thematic analysis ($n = 5$), interpretative phenomenological analysis ($n = 3$) and Collaizzi's

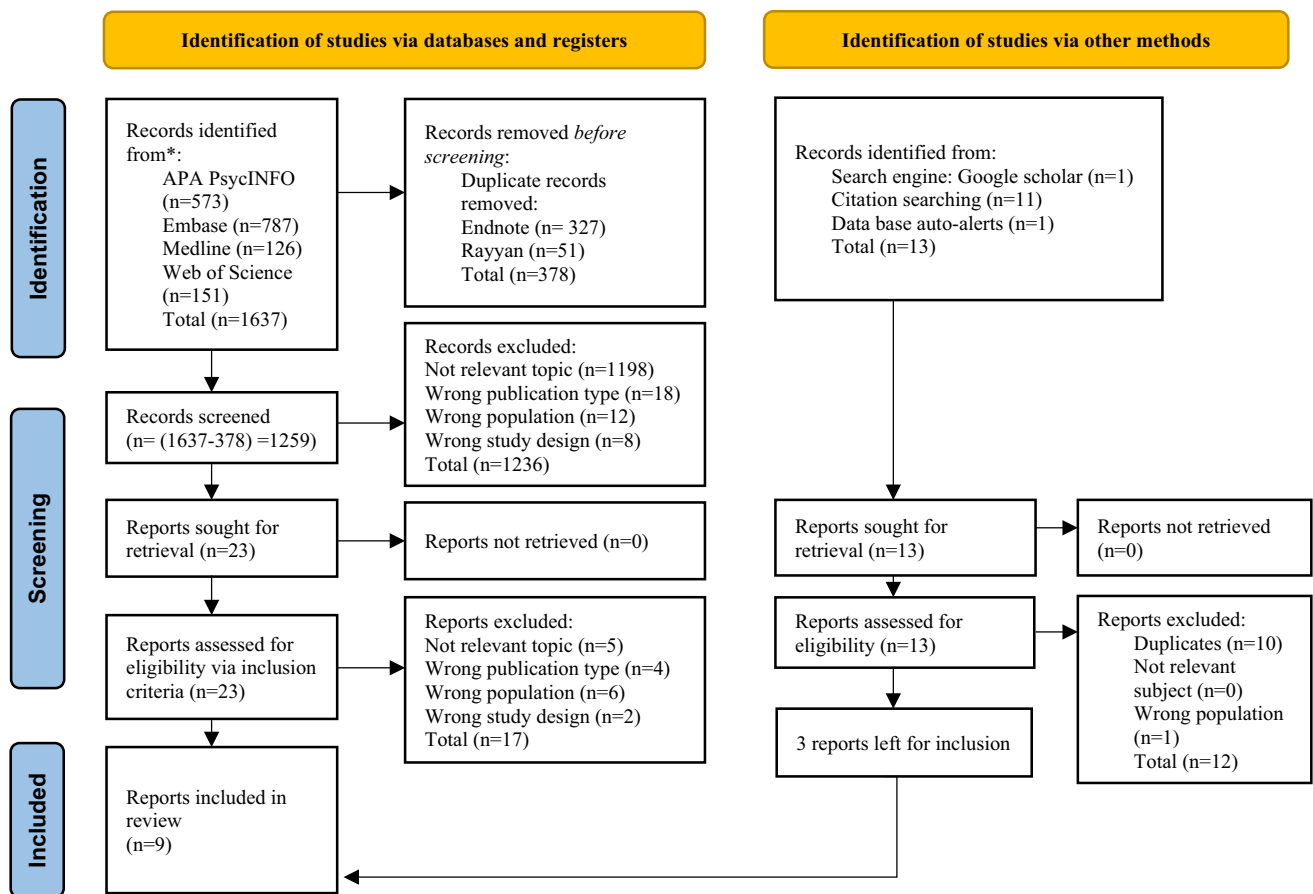


Fig. 1 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources. *Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers). **If automation tools were used, indicate how many records were excluded by a human and how

many were excluded by automation tools. From: page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372: n71. <https://doi.org/10.1136/bmj.n71>. For more information, visit: <http://www.prisma-statement.org/>

descriptive phenomenology method ($n = 1$). Characteristics of the nine studies included in this review are presented in Table 3.

Based on their appraisal using the CASP tool, the studies included in the review were of good quality with all papers scoring between 80 and 95%. QA scores for individual papers are presented in Table 3. Lower-scoring papers often lacked sufficient detail with regard to the relationship between the researcher and participants and ethical issues. Not describing how researchers' subjectivity was managed, reduces the credibility of results. Only the papers by Lupindo et al., (2022) and Stagg & Belcher, (2019) provided a reflexive comment on their positionality. However, other papers did describe some reflexive techniques (Leedham et al., 2020; Lewis, 2016; Lilley et al., 2021; Punshon et al., 2009). Furthermore, all but one paper (Powell & Acker, 2016) evidenced that approval from an ethics committee was

granted; however, the level of detail about ethical procedures varied across articles.

Other limitations highlighted from the CASP related to the data analysis process and the contribution of the study to existing knowledge. The studies by Leedham et al., (2020) and Lewis, (2016) did not include a second researcher as part of the analysis process, therefore, reducing the trustworthiness of the results. Furthermore, the suitability of the data analysis procedure may be questioned for the study by Stagg & Belcher, (2019) which used thematic analysis (TA) when interpretative phenomenological analysis (IPA) may have been more appropriate, therefore, limiting the conclusions drawn from the findings. IPA has a dual focus on the unique characteristics of individual participants making sense of their experience and patterning of meaning across participants whereas TA focuses solely on the patterning of meaning across participants. Therefore, IPA appears to align better with (1) the aim of the study to explore the lived experience of individuals receiving the

Table 3 Characteristics of studies

Author(s)/year/country/QA Inter-rater Reliability (κ)	Research aims*	Research design/sampling method	Sample characteristics**	Method of data collection/method of data analysis	Key findings
Atherton et al (2022)—Study 2 only UK QA = 95% $\kappa = .615$	To explore identity, quality of life, and the impact of a late diagnosis in eight autistic adults To understand the lived experiences of autistic adults with a late diagnosis	Qualitative Convenience sampling—recruited from sample used in study 1 (Atherton et al., 2022)	N = 8 Gender: n = 4 Female, n = 4 Male Age: 24–63 years, (Mean = 29.8 years) Ethnicity: N = 8 White Diagnosis: N = 8 ASC	Individual semi-structured interview (phone/online) IPA	Four themes: 1. Barriers to diagnosis Four subthemes: 1a) <i>Academic and social success</i> 1b) <i>Perceptions and stigma</i> 1c) <i>Gender (for females)</i> 1d) <i>Long, difficult process</i> 2. Negatives of a non-diagnosis Five subthemes: 2a) <i>Feeling like an alien</i> 2b) <i>Not fitting in</i> 2c) <i>Bullying/exclusion</i> 2d) <i>Masking/camouflaging</i> 2e) <i>Mental health strains</i> 3. Benefits of a diagnosis Four subthemes: 3a) <i>Understanding, acceptance</i> 3b) <i>Finding a missing piece</i> 3c) <i>Empowering</i> 3d) <i>Counselling</i> 4. Two sides of a diagnosis Two subthemes: 4a) <i>Challenges as well as benefits</i> 4b) <i>Complacency, labelling</i>
Hickey et al (2018) UK QA = 95% $\kappa = 1$	To explore the lived experience of autism in later adulthood, what autism had meant for individuals' lives and their perceptions regarding the helpfulness (or otherwise) of diagnosis	Qualitative Purposive sampling—recruited from an NHS adult autism diagnostic service and autism support and social groups in London	N = 13 Gender: n = 3 Female, n = 10 Male Age: 51–71 years, (Mean = 60.38 years) Ethnicity: N = 13 White Diagnosis: n = 8 AS, n = 5 HFA	Individual semi-structured interview TA (Braun & Clarke 2006)	Three overarching themes: 1. Difference Two subthemes: 1a) <i>Realisation of difference</i> 1b) <i>Reducing outward difference</i> 2. Life review Three subthemes: 2a) <i>Understanding the past</i> 2b) <i>Externalising autism</i> 2c) <i>Self-acceptance</i> 3. Longing for connection Four subthemes: 3a) <i>Isolation and loneliness</i> 3b) <i>Positive aspects of isolation</i> 3c) <i>Reaching out pre-diagnosis</i> 3d) <i>Reaching out post-diagnosis</i>

Table 3 (continued)

Author(s)/year/country/QA Inter-rater Reliability (κ)	Research aims*	Research design/sampling method	Sample characteristics**	Method of data collection/method of data analysis	Key findings
Leedham et al (2020) UK QA = 95% $\kappa = .615$	To understand the experiences of autistic females who receive a diagnosis in middle to late adulthood	Qualitative Purposive sampling—recruited from a local NHS diagnostic service	N = 11 Gender: N = 11 Female Age: 43–64 years, (Mean = 50.81 years) Diagnosis: n = 5 AS, n = 3 ASD, n = 3 HFA Age at diagnosis: 40–62 years, (Mean = 47 years)	Individual semi-structured interview (in person) IPA	Four emergent themes: 1. A hidden condition Two subthemes: 1a) <i>Pretending to be 'normal and fitting in</i> 1b) <i>Mental health and mislabelling</i> 2. The process of acceptance Three subthemes: 2a) <i>Initial reactions and search for understanding</i> 2b) <i>Relieving life through a new lens</i> 2c) <i>Grief and reflections on the past</i> 3. The impact of others post-diagnosis Two subthemes: 3a) <i>Initial reactions of others</i> 3b) <i>Stereotyped assumptions</i> 4. A new identity on the autism spectrum Three subthemes: 4a) <i>Negotiating relationships, connections and community</i> 4b) <i>Changing wellbeing and views of the self</i> 4c) <i>The meaning of diagnosis</i>
Lewis (2016) USA QA = 95% $\kappa = .615$	To explore the experience of realising a diagnosis of autism in adulthood	Qualitative Purposive sampling—recruited from online message boards, forums and support groups for individuals with autism	N = 77 Gender: n = 32 Female n = 40 Male n = 4 Other Age: 18–65 years, (Mean = 39 years) Ethnicity: n = 64 White, n = 3 Asian, n = 3 Black, n = 2 American Indian, n = 1 Hispanic Diagnosis: n = 24 ASD, n = 1 PDD, n = 1 Unknown Age at diagnosis: 18–60 years, (Mean = 35.3 years)	Online open-ended survey Descriptive phenomenology using Colaizzi's (1978) method	Six themes: 1. I always knew I was different 2. Riding the emotional roller coaster 3. Striving for self-acceptance 4. Strategizing towards a better life 5. Maintaining normalcy 6. Wandering into the future

Table 3 (continued)

Author(s)/year/country/QA Inter-rater Reliability (κ)	Research aims*	Research design/sampling method	Sample characteristics**	Method of data collection/method of data analysis	Key findings
Lilley et al (2021) Australia QA = 95% $\kappa = .615$	To understand the experiences of autistic adults who grew up in an era before autism was well-known To explore how autistic adults thought about the self at different times in their lives and how autism diagnosis has impacted on self-identity	Qualitative Convenience sampling with snowballing methods, including a social media campaign	N = 26 Gender: n = 14 Female, n = 10 Male, n = 1 Non-binary, n = 1 Did not state gender Age: 45–72 years, (Mean = 52.89 years) Ethnicity: n = 25 White, n = 1 White European and Aboriginal Diagnosis: n = 18 ASD, n = 7 AS, n = 1 Autism Age at diagnosis: 39–68 years, (Mean = 49.19 years)	Oral history approach – individual semi-structured interview or written contribution TA (Braun & Clarke, 2006)	Four themes: 1. Being different Three subthemes: 1a) "In my bubble" 1b) "On the outside looking in" 1c) <i>Positively different</i> 2. Exploring identity Three subthemes: 2a) "Playing a role" 2b) "Ticking some boxes" 2c) "Re-inventing myself" 3. The suffering self 3a) <i>Negative self-conceptions</i> 3b) "Trying to survive" <i>trauma</i> 3c) <i>The turmoil inside</i> 4. Being autistic Three subthemes: 4a) <i>Illuminating the past</i> 4b) <i>Being kind to myself</i> 4c) <i>Being "my true self"</i>
Lupindo et al (2022) South Africa QA = 95% $\kappa = .615$	To explore first-hand experiences of ten adult males who were diagnosed with autism during their adulthood	Qualitative Purposive sampling—participants were clients at The Neurodiversity Centre	N = 10 Gender: N = 10 male Age: 28–64 years, (Mean = 36.42 years) Diagnosis: N = 10 ASD Age at diagnosis: 26–64 years (Mean = 34.75 years)	Individual semi-structured interviews TA (Braun & Clarke, 2006)	Three main themes: 1. Failure to diagnose ASD in childhood despite signs and symptoms 2. Ramifications of missed/misdiagnosis in childhood and adulthood on psychological wellbeing 3. The impact of receiving a diagnosis of ASD in adulthood
Powell and Acker (2016) UK QA = 80% $\kappa = .737$	To explore how participants who attended a new clinic felt about their diagnosis of AS and in what ways it affected their lives	Mixed methods Opportunity sampling—recruited from the authors' adult AS diagnostic clinic	N = 74 Gender: 59% Male Age: Mean = 36.08 years, SD = 12.10 years Diagnosis: n = 54 AS, n = 20 Subclinical threshold	Two open-end text questions Thematic Content Analysis (Braun & Clarke, 2006)	Six main themes for emotional reaction to assessment: 1. Relief 2. Positive feelings 3. Mixed feelings 4. Negative feelings 5. No clear feelings 6. Diagnostic disappointment Seven main themes for effect of assessment on life: 1. Understanding and explanation 2. Feel better 3. Support 4. Social interaction 5. Nothing has come of it 6. Lack of clarity 7. Negative effect

Table 3 (continued)

Author(s)/year/country/QA Inter-rater Reliability (κ)	Research aims*	Research design/sampling method	Sample characteristics**	Method of data collection/method of data analysis	Key findings
Punshon et al (2009) UK QA = 95% $\kappa = 1$	To identify: 1) What are the experiences of adults with AS relating to their diagnosis 2) Whether there is adjustment to diagnosis 3) How services might help individuals negotiate the diagnostic process and adjust to their diagnosis	Qualitative Convenience sampling—recruited from local service for adults with AS	N = 10 Gender: n = 3 Female, n = 7 Male Age: 22–45 years, (Median age = 31 years) Diagnosis: N = 10 AS Age at diagnosis: 21–44 years, (Median = 35 years)	Individual semi-structured interview (in person) IPA	Six superordinate themes: 1. Negative life experiences 2. Experiences of services (pre-diagnosis) 3. Beliefs about symptoms of AS 4. Identity formation 5. Effects of diagnosis on beliefs 6. Effects of societal views on AS
Stagg and Belcher (2019) UK QA = 85% $\kappa = .756$	To investigate the lived experience of receiving a diagnosis of autism in middle and older age	Qualitative Purposive sampling—recruited from online autism forums and messages posted on a blog run by the second author	N = 9 Gender: n = 5 Female, n = 4 Male Age: 52–54 years Diagnosis: N = 9 ASC	Free-associative narrative interview technique (Hollway and Jefferson 2008) TA (Braun & Clarke, 2006)	Five superordinate themes: 1. Early signs of autism 2. Awareness of being different 3. Receiving a diagnosis 4. The usefulness of a diagnosis 5. Support and coping

* Only aims, methods and findings relevant to the present review are reported

** Sample characteristics included as reported in the papers. If some characteristics are missing this is due to it not being collected or reported in the papers

Key: ADHD attention deficit hyperactivity disorder, AS Asperger syndrome, ASC autistic spectrum condition, ASD autistic spectrum disorder, HFA high functioning autism, IPA interpretative phenomenological analysis, NHS National Health Service, PDD pervasive developmental disorder, PTSD post-traumatic stress disorder, TA thematic analysis

diagnosis and (2) the free-associate narrative interview technique used which allows the interview to change dependent on the interviewee's experience.

Additionally, the paper by Powell & Acker, (2016) only included two qualitative questions and asked participants to describe their experiences in a few sentences. This reduced the quantity of qualitative information available, therefore limiting the extent to which its findings contribute to current understanding. Moreover, the samples used in the three studies were predominantly White, well-educated and middle-class (Atherton et al., 2022; Hickey et al., 2018; Lilley et al., 2021). No additional demographic data was provided in four studies (Leedham et al., 2020; Powell & Acker, 2016; Punshon et al., 2009; Stagg & Belcher, 2019). Cultural values have been recognised to shape beliefs about autism, behavioural expectations and experiences of stigma and discrimination (Grinker & Cho, 2013; Lilley et al., 2020; Norbury & Sparks, 2013). Therefore, it is possible the results are not transferable to other populations with different cultural and socioeconomic backgrounds.

Data Synthesis

Across the studies, two meta-themes were identified: feeling *"like an alien"* and the *"not guilty"* verdict. Meta-themes with respective subthemes are depicted in Table 4. The individual paper's contribution to the meta-themes and subthemes is shown in Table 5. Each meta-theme and respective subthemes are discussed in detail below. For further quotations evidencing each subtheme see Online Resource 3.

Feeling "Like an Alien"

This meta-theme conceptualises the experiences of difference shared by participants. Awareness of difference typically occurred in childhood and adolescence and continued into adulthood. Not all participants acknowledged their own difference; however, they were aware that others perceived them as different. Some participants viewed their differences positively, *"we are one rung up on the evolutionary ladder"* (Punshon et al., 2009, p.278), whereas others felt *"mental"*, *"wrong"* or *"defective"* (Leedham et al., 2020, p.139) because of them. This awareness of difference, generally associated with a range of distressing emotions, was often what prompted individuals to seek a diagnosis (Jones et al., 2014). Three subthemes were identified: *"Different—yes, special—yes, unique—yes, able—very much so, superior—yes, ... but defective—never!"*, *"I just was a square peg in a round hole"* and *"I felt so lacking as a person"*.

"Different—Yes, Special—Yes, Unique—Yes, Able—Very Much so, Superior—Yes, ... but Defective—Never!"

This subtheme highlights the positive ways in which participants viewed themselves: *"I knew I didn't think like others,*

but knew I was in many ways, superior to them" (Lewis, 2016, p.348). Academic success, creativity and curiosity were commonly reported as a source of positive difference: *"a number described themselves as 'nerds' [able to] 'out-think' most of [their] peers at high school..., always curious to start with; [someone] who read seven science fiction books in one day"* (Lilley et al., 2021, p.6). For some participants *"the solitary pursuit of interests allowed for more immersion in particular activities and experiences of mastery and achievement"* (Hickey et al., 2018, p.362). For others, being disconnected from people allowed for embracing the *"richness of their interior lives"* (Lilley et al., 2021, p.5), especially in childhood: *"as a child I was in my own world—carefree, happy I was pretty much my own person"* (Lilley et al., 2021, p.5).

"I Just Was a Square Peg in a Round Hole"

This subtheme identifies how despite the positive aspects of difference highlighted in some of the papers, many participants perceived it negatively. This was often exacerbated by receiving messages from others that they were *"odd, different and hard to understand"* (Atherton et al., 2022, p.9). Participants frequently reported that they felt marginalised, excluded and that they did not fit in with their peers: *"I had difficulties making friends and as a result I was severely bullied. I've been cut on my back with a razor, I've had my head pushed into a toilet, I've been physically beaten"* (Lupindo et al., 2022, p.9). Social misunderstandings were common across their life with participants reporting feeling both misunderstood and also misunderstanding others:

The biggest memories I have is starting primary school and literally being on the playground and feeling like I was on an alien planet. I couldn't understand these children and I didn't understand how to interact with them, and everything they did was like a foreign language. (Atherton et al., 2022, p.9)

Participants were aware of being different from their peers: *"I feel like I'm a different type of human to non-autistic humans"* (Stagg & Belcher, 2019, p.353) and commented on challenges they experienced including sensory sensitivity, insomnia, meltdowns, difficulties with education or employment. Many did not understand or were unable to explain their difference. In retrospect, this was likely due to the fact that they did not have a framework of an autism diagnosis to explain their characteristics: *"I always felt like I was just different enough to be able to recognise it, but not smart enough to figure out what my differences were so that I could fix it"* (Lewis, 2016, p.348). Most individuals felt the need to mask their autistic traits. Although masking could be advantageous for social participation, the consequences were complex. Individuals still felt disconnected from others

Table 4 Meta-themes and subthemes

Meta-themes	Subthemes
Feeling “like an alien”	<p>“Different—yes, special—yes, unique—yes, able—very much so, superior—yes, ... but defective—never!”</p> <p>“I just was a square peg in a round hole”</p> <p>“I felt so lacking as a person”</p>
The “not guilty” verdict	<p>“One moment of him and his team ... saying, yes, I’m insane or I’m not”</p> <p>“After years of feeling defective, I finally had the answers”</p> <p>“I belong somewhere with other people who are like me”</p>

Table 5 Summary of each paper’s contribution to each theme

Meta-theme	Feeling “like an alien”			The “not guilty” verdict			
	Subtheme	“Different—yes, special—yes, unique—yes, able—very much so, superior—yes, ... but defective—never!”	“I just was a square peg in a round hole”	“I felt so lacking as a person”	“One moment of him and his team ... saying, yes, I’m insane or I’m not”	“After years of feeling defective I finally had the answers”	“I belong somewhere with other people who are like me”
Atherton et al., (2022)		X			X	X	X
Hickey et al., (2018)	X	X	X		X		X
Leedham et al., (2020)		X	X	X	X		X
Lewis, (2016)	X	X	X	X	X		X
Lilley et al., (2021)	X	X	X	X	X		
Lupindo et al., (2022)	X	X	X	X	X		X
Powell & Acker, (2016)				X	X		X
Punshon et al., (2009)		X	X	X	X		X
Stagg & Belcher, (2019)		X	X	X	X		X

and the process of masking was stressful and exhausting. Masking negatively impacted the individual’s identity and increased the risk of self-harm behaviours, addiction and mental health conditions:

I was trying to cover it up and pretend I was ‘normal’ and pretend that everything was okay when inside I was dying of pain because it was all going wrong, and it was all difficult and nothing made sense. (Punshon et al., 2009, p.276)

“I Felt so Lacking as a Person”

This subtheme explores the distressing emotions that were experienced as a result of participants feeling different from others and internalised beliefs that they were “wrong”,

“broken” or “bad” (Leedham et al., 2020, p.138). Many shared feelings of loneliness as a result of limited social networks despite efforts to socialise and develop friendships which were experienced as distressing: “the most excruciating loneliness ... inside just complete and utter turmoil” (Lilley et al., 2021, p.7). In the absence of any other framework to explain their difference many individuals blamed themselves and developed negative self-concepts:

I thought of myself as weird and strange ... just odd ... I used to beat myself up a lot about the things that I failed to do. Because obviously it’s my fault because I should know ... I am clever enough ... obviously it’s because I’m not making an effort ... I am too lazy ... I am not interested in things other people are interested in, it’s obviously because I am weird and strange and

you know, different to everyone. (Punshon et al., 2009, p.276)

Mental health difficulties were common including anxiety, depression, eating disorders, suicidal ideation and suicide attempts; *“I had some suicidal tendencies, and I has some just general frustrations because I couldn’t quite understand what was happening inside. I felt isolated and anxious and felt like I couldn’t take it anymore”* (Lupindo et al., 2022, p. 10). These difficulties were associated with trauma, academic struggles, bullying and both their own and others’ lack of understanding of their experiences: *“I was exhausted trying to figure it out ... why things were so different for me ... by the time I had got to that diagnosis, I was already half dead, I was already in a functioning depressed state”* (Leedham et al., 2020, p.139).

The “Not Guilty” Verdict

This meta-theme illustrates the experience of receiving a diagnosis of autism in adulthood shared by participants. Gaining a diagnosis resulted in a complex mix of feelings, *“relieved but a bit daunted and overwhelmed”* (Powell & Acker, 2016, p.75), and significantly influenced their relationships with others. Three subthemes were identified: *“One moment of him and his team ... saying yes, I’m insane or I’m not”*, *“After years of feeling defective I finally had the answers”* and *“I belong somewhere with other people who are like me”*.

“One Moment of Him and His Team ... Saying, Yes, I’m Insane or I’m Not”

This subtheme highlights participants’ experiences of mental health services and the diagnostic process. Participants often accessed a variety of different services and received numerous medical opinions. Many found their experiences were not understood by professionals therefore they initially received alternative diagnoses which did not explain their difficulties. Misdiagnoses often led to failed support and reinforced participants’ feelings of being different:

[Clinician] would say, ‘oh, you’ve got borderline personality disorder (BPD)’ ... I explained to him exactly why I wasn’t BPD ... I wasn’t getting any answers, I just stopped going. I just stopped asking for help, I just stopped you know, looking for answers. (Leedham et al., 2020, p.139)

Strengths such as academic ability or social skills and stereotyped views were commonly reported as barriers for recognition and identification of autism: *“I speak*

neurotypical fluently. I don’t look autistic. They’ll say, ‘Well, you went to a mainstream school, you got two degrees. You’re in employment, in fact, successfully self-employed. Come on. Why waste time on you” (Atherton et al., 2022, p.8). For others, their family perceiving their behaviour as unique and not problematic led to not seeking professional support; *“I don’t think there was much concern about it ... my family’s really fairly accepting”* (Lupindo et al., 2022, p.9).

Lengthy assessment processes including multiple professionals created further barriers to appropriate assessment and identification. Moreover, clinicians’ lack of knowledge in the area further compounded the barriers to diagnosis. The approach of healthcare professionals often increased experiences of feeling misunderstood and blamed for their difficulties: *“It appeared to my clinical psychologist that I’d got Asperger syndrome although my clinical psychologist wasn’t trained to give that diagnosis ... [my psychiatrist] said, ‘How can I help you if you don’t tell me what’s wrong?’”* (Punshon et al., 2009, p.274). Some participants struggled to find a professional to diagnose them due to being adults and others were refused a formal assessment: *“The psychologist said that there would be no point in doing this formally as I was already an adult and there were no services in place for my situation”* (Lewis, 2016, p.351). This resulted in some participants opting for a private assessment. Others reported only receiving a diagnosis following seeking help for their children’s difficulties:

My daughter ... she didn’t cope in the normal ... then somebody told us that her brother was diagnosed with Asperger’s and that [therapist name] was leader in the field ... he called us back and he said ... he wants to see me next ... so then I waited for my session and then it was discovered (Lupindo et al., p.9).

For some participants, a diagnosis of autism afforded access to various support such as counselling, benefits and workplace adaptations which enabled an understanding of how autism affected their life: *“[it has had a] positive effect on my working conditions ... it helped me to get help from social services ... I have contacted local support groups ... done research”* (Powell & Acker, 2016, p.77). However, the support available for adults was frequently criticised as it was often limited: *“I am appalled and lament for the thousands of adult aspies who have struggled—and continue to struggle—to live in a world that is alien to them ... what of the adults? Why are we the forgotten ones?”* (Lewis, 2016, p.351). Additionally, after a long battle to gain a diagnosis, some participants expressed feeling anxious that their diagnosis and access to services would be taken away:

I am always dead paranoid that someone is going to say, ‘Oh we have made a mistake and you haven’t got

Asperger syndrome ... you are just depressed and psychotic [laughs]. So, you can't have any access to any of the services. Go away. (Punshon et al., 2009, p.274)

"After Years of Feeling Defective, I Finally Had the Answers"

This subtheme explores participants' individual experiences post-diagnosis. Participants expressed feelings of relief as they were able to make sense of their experiences after many years of living without a diagnosis. Difficulties such as making and maintaining friendships or romantic relationships, academic and employment difficulties and mental health challenges could be understood in the context of the diagnosis: *"after 50 years of not understanding the 'why' of myself, finding out I was an Aspie was a light in the darkness, best thing that happened to me"* (Lewis, 2016, p.350). When the autism diagnosis replaced a previous diagnosis participants were particularly pleased: *"not being labelled BPD or just stropy by the Community Mental Health Team (CMHT) means a lot to me"* (Powell & Acker, 2016, p.75). Despite the relief highlighted by participants, many felt *"devastated"* and saw the diagnosis as *"another nail in the coffin"* (Lewis, 2016, p.349). For some the process of re-evaluating their lives in the context of the diagnosis was painful and frustrating:

It was looking back and then suddenly realising there was this genetic connection and great feelings of inadequacy; that I must've been a really bad carer for my parents when they were terminally ill. And just 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)

Some participants shared that they did not feel comfortable with their new autistic identity given the potential to be seen only through a negative lens: *"I thought 'am I just anything other than these symptoms?' Um, that really upset me ... I sort of started doubting my ability to do my job"* (Leedham et al., 2020, p.139). Others reported worries due to the lifelong nature of the diagnosis: *"I am never going to be like one of these 'normal' people ... I thought 'I am stuck being like this now'"*. (Punshon et al., 2009, p.278) A period of grief following diagnosis was common among participants; this was associated with sadness at how their life may have been different had their needs been appropriately understood:

Disappointment, deeply felt, that I had to wait until I was 45 years old to get a diagnosis. Saddened, too, for all the lost opportunities that would likely have come about had I known and received intervention and loving understanding as a child. (Lewis, 2016, p.351)

Feeling angry about being failed by professionals previously was commonly reported: *"there's these glaring issues and you see how multiple times you were failed by various professionals that should have and could have seen issues"* (Atherton et al., 2022, p.10). However, a minority expressed feeling pleased that they had not received their diagnosis in childhood as they felt it could have limited their ability to reach their full potential and it enabled them to find ways to adapt: *"living without a diagnosis was a hard teacher, but a good one"* (Lewis, 2016, p.350). Increased understanding of their difficulties helped them *"to plan and prepare for situations, knowing how [they] may react, and how to avoid difficult situations ... so [they] can keep to places and activities [they are] comfortable with"* (Stagg & Belcher, 2019, p.354). It also enabled individuals to attribute negative experiences to autism leading to increased compassion and self-acceptance: *"having that knowledge was such a powerful thing because I could understand and forgive myself"* (Lilley et al., 2021, p.8).

Following their diagnosis, some participants shared that they felt able to show their true self after years of masking autistic traits: *"There's more accepting of who I am ... you don't try and copy other people and try and fit in. You're trying to be yourself"* (Lupindo et al., 2022, p.12). However, for others, autistic stereotypes provided further justification for continuing to mask: *"the feeling of looking out at people and knowing I had to hide aspects of myself and invent others never left"* (Lewis, 2016, p.350).

"I Belong Somewhere with Other People Who Are Like Me"

This subtheme explores participants' interpersonal experiences post-diagnosis. The diagnosis provided opportunities to meet others with autism which enabled them to share experiences, enhance their understanding of autism and feel accepted by others: *"you're accepted. You don't have to sort of hide anything ... the people, some of them are on my wavelength"* (Hickey et al., 2018, p.363). Participant's self-acceptance was largely influenced by how family and friends responded to their diagnosis:

"I'm fortunate enough that a lot of my friends tend to and my family as well they're very accepting and they don't perceive it as anything wrong. And because of that acceptance, it kind of made it easier for me to accept myself" (Lupindo et al., 2022, p.12-13).

Many participants found that their friends, family and work colleagues were more understanding of their difficulties; *"... it's more like they understand that OK, I have a diagnosis, and I have a disability. And that I'm not OK with work and stuff like that. So, I would say it's less stressful"* (Atherton et al., 2022, p.9). However, the disclosure of diagnosis was also at times met with unhelpful reactions

from others. Some significant others did not appreciate its magnitude:

I just expected him [husband] to say something ... or realise how massive this was for me and he didn't for ages, and about two weeks later I just said, 'look, this is huge for me ... to you I'm no different, but to me I'm completely different'. (Leedham et al., 2020, p.141)

Others, who held stereotyped or stigmatised views of autism or its genesis, either refuted any blame: “*there is a distinct reaction from my dad ... that it can't possibly be his fault that one of his children doesn't work properly. Something he made doesn't work properly*” (Punshon et al., 2009, p.279), or they felt relief they were not responsible for the participant's difficulties to date: “*I think my mum ... you know, often she felt that she was getting the blame ... not just from psychiatrists but also from other people*” (Punshon et al., 2009, p.279). Relationship changes were common post-diagnosis with some significant others being more supportive in light of new understanding of the experienced difficulties: “*... he'll [husband] now take the lead in situations where he knows I'm not comfortable, whereas before he just thought I was being awkward*” (Leedham et al., 2020, p.141). However, other participants experienced a negative change in their relationships and chose to end them: “*... the implication ... I was automatically wrong because I had this Asperger's thing ... So that was unexpected, and I had to walk away*” (Leedham et al., 2020, p.141). Finally, some reported others expected less of them or experienced discrimination, which fostered a sense of regret at seeking a diagnosis:

She started bullying me quite seriously from then on, and within about eighteen months I was out of a job, and I think 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)

Discussion

This meta-ethnography extends the current literature by drawing attention to the experiences of receiving a diagnosis of autism in adulthood. The findings are consistent with Huang et al.'s (2020) scoping review; however, this review provides a more detailed exploration of the themes including the experience of difference pre-diagnosis, the diagnostic process and individual and interpersonal experiences post-diagnosis. The review also illustrates the impact of the delayed diagnosis on the individual's mental health, access to support, relationships and life opportunities.

Furthermore, four of the eight studies reviewed focus on middle to late adulthood (Hickey et al., 2018; Leedham et al., 2020; Lilley et al., 2021; Stagg & Belcher, 2019) which is a particularly underserved group in autism research and practise (Happé & Charlton, 2012).

Prior to diagnosis participants had an awareness of difference but a poor understanding of why they were different from others; this has been documented in previous research (Baldwin & Costley, 2016; Huws & Jones, 2015; Müller et al., 2008). For some, this perceived difference was viewed positively, which suggests it is important for clinicians to recognise and value autistic individuals' strengths whilst providing support for areas of difficulty. For the majority, however, their differences were related to feeling excluded and social misunderstandings. Social interaction difficulties are the most commonly reported trait in this population (Hofvander et al., 2009; Kanai et al., 2011). As a strategy to facilitate fitting in, participants often engaged in masking. Similar to previous findings, masking was reported to be exhausting, stressful (Hull et al., 2017) and detrimental to mental health (Cage et al., 2018). Participants shared experiences of loneliness, negative self-perceptions and mental health problems as a consequence of not understanding their difficulties.

The diagnostic process was an intensely emotional time with various barriers impeding appropriate identification. Previous research also documented a range of barriers to diagnosis, in particular for females whose needs are often under recognised and misattributed to alternative diagnoses (Bargiela et al., 2016; Gould, 2017). Consistent with previous literature (Crane et al., 2016, 2018; Evans et al., 2022) a significant lack of professional support available post-diagnosis was highlighted.

Adults diagnosed with autism experience complex reactions with feelings of relief, anger and sadness commonly reported. The diagnosis was often highly valued as it enabled them to make sense of their difficulties, increasing compassion and self-acceptance, a finding which has been previously documented (Jones et al., 2014; Rosqvist, 2012; Tan, 2018). Having a framework to understand oneself where needs and strengths can be identified and supported is critical. The diagnosis provides autistic adults with an opportunity to reclaim parts of their life history which were misunderstood and develop coping strategies to manage current difficulties (Kanfiszer et al., 2017; Tan, 2018).

A diagnosis of autism enabled opportunities for shared experiences which were viewed positively. Previous research suggests interactions with other autistic adults are validating, fulfilling and normalising (Bargiela et al., 2016; Hickey et al., 2018; Tan, 2018). Consistent with previous research, adults described both supportive and unhelpful reactions from others post-diagnosis; the latter were commonly influenced by stereotyped or stigmatised views of autism (Crane et al., 2018).

Clinical Implications and Recommendations

Understanding the assumptions that lead to misdiagnoses or delayed diagnosis would be an important initiative. Participants frequently reported not feeling understood by professionals, therefore it is important that clinicians have a broad, comprehensive and up-to-date knowledge of autism for effective identification and support. Clinicians should receive training highlighting the different presentations of autism across the lifespan and considering other barriers to identification such as gender differences, cultural differences, high intelligence or masking. Furthermore, training should extend beyond an understanding of autism characteristics and focus on promoting respectful and effective therapeutic support (Nicolaidis et al., 2015); this would increase knowledge and reduce the stigma associated with autism (Gillespie-Lynch et al., 2015). NICE guidance suggests autism strategy groups should ensure the provision of multi-agency training (NICE, 2012).

Mental health difficulties were commonly reported pre-diagnosis. As traits of autism and mental illness symptoms may present similarly, co-occurring mental health conditions may be a further barrier to the diagnosis given the complexity of differential diagnosis (Lai & Baron-Cohen, 2015; Lehnhardt et al., 2013). Therefore, clinicians should consider using screening tools for adults presenting at mental health services to recognise possible signs of undiagnosed autism and avoid misdiagnosis. NICE guidance suggests for adults who do not have a moderate or severe learning disability the Autism Spectrum Quotient-10 items should be used (NICE, 2012). This would provide an opportunity for clinicians to identify autism and refer individuals for assessment (Geurts & Jansen, 2012). A score of 6 or more suggests a comprehensive assessment should be offered (NICE, 2012).

Progression from feeling misunderstood to self-acceptance only occurred following diagnosis. This highlights the need for timely diagnosis to enable individuals to better understand their needs. Diagnostic processes for adults are poor in comparison to those for children and lack formal support services (Huang et al., 2020). Compared to services available for children, adult services receive very little funding, support and assistance (Camm-Crosbie et al., 2019). Ensuring equitable access to assessment and support services for adults is essential and is in line with the national strategy for autistic children, young people and adults: 2021 to 2026 on improving early identification, reducing waiting times and improving diagnostic pathways for adults (Department of Health and Social Care & Department for Education, 2021).

Considering the complex mental health needs of individuals receiving a diagnosis of autism in adulthood (Geurts & Jansen, 2012; Hofvander et al., 2009) and emotional responses post-diagnosis (Jones et al., 2014; Lewis, 2016),

the lack of post-diagnostic support is a concern. Receiving a diagnosis is a complex and emotional life event which involves a reconceptualization of identity. Services should recognise adults will be coping with years of being misunderstood, excluded and criticised without understanding the cause. Access to mental health services is critical to support this process of reflection and adjustment as this is unlikely to be resolved within the assessment process. Diagnostic services often do not provide ongoing support (Crane et al., 2018; Evans et al., 2022); therefore, a collaborative multi-disciplinary effort is required to develop support pathways post-diagnosis. Creating therapeutic services where individuals can be supported with disclosure, identity, masking, mental health difficulties and sensory challenges is crucial. It is important that services are tailored to the individual's needs, in particular to their autism, to prevent withdrawal from services (Crane et al., 2019; NICE, 2012).

There is a lack of empirically supported mental health supports for autistic individuals (Benevides et al., 2020; NICE, 2012). Autism groups and meeting others with autism was viewed as beneficial, allowing for shared experiences and acceptance. Information on local support groups should be provided routinely as part of the diagnostic process. Preliminary research suggests autistic-led therapy for adults following diagnosis could be beneficial as a means of increasing understanding and knowledge by interacting with autistic peers (Crane et al., 2021). Therefore, services should explore the development of peer-led supports. Furthermore, for services providing support for coexisting mental health difficulties to autistic adults, interventions should be informed by existing NICE guidelines for the specific disorder (NICE, 2012). However, it is critical that staff have a core understanding of autism and the possible impact of treatment, and they should consider seeking advice from a specialist autism service regarding delivering and adapting interventions (NICE, 2012).

Limitations

This meta-ethnography has some limitations. Reviewed studies reported experiences of individuals who received their diagnosis across different healthcare systems around the world. It is recognised that there are different assessment processes in these respective settings. Furthermore, whilst some autism traits appear similar across cultures, other traits are specific to particular cultures and must be accounted for during assessment (Carruthers et al., 2018).

Time since diagnosis varied significantly across samples. Some participants received their diagnosis in the months prior to participation (Atherton et al., 2022; Powell & Acker, 2016), others had recently been diagnosed and/or received their diagnosis up to 20 years ago (Hickey et al., 2018; Leedham et al., 2020; Lilley et al., 2021; Punshon et al., 2009). Time since

diagnosis is likely to influence the findings as individuals make sense of their experiences and assimilate their autistic identity over time. Previous research indicates that a greater number of years since diagnosis is associated with less dissatisfaction with being autistic (Corden et al., 2021).

It is acknowledged that papers not written in English were excluded from the current review introducing a language bias (Butler et al., 2016). Due to the time and cost implications of translation, this was unavoidable.

Future Research

Studies conducted in Western countries dominate research on the experiences of autism diagnosis in adulthood. Disparities in culture, awareness of autism and healthcare systems in different countries will have important implications for the prevalence of autism and experience of the diagnostic process. Further research in non-Western countries would allow for consideration of these factors and inform policy development.

To address the underrepresentation of marginalised groups, researchers should promote diversity, equity and cultural humility, and ensure their research addresses the specific needs and interests of these groups (Maye et al., 2021). In addition, researchers should aim to recruit large representative samples or samples in which marginalised groups are over-represented to replicate previously accepted findings and gain insight into health outcomes among these groups (Robertson et al., 2017; West et al., 2016). To achieve this, culturally competent researchers should collaborate with marginalised communities to identify and eliminate barriers to participation and co-produce research.

Individuals diagnosed with autism in adulthood often wished they were diagnosed earlier (Baldwin & Costley, 2016; Lewis, 2016; Powell & Acker, 2016). Some research has focused on the unique experiences of individuals diagnosed in middle-to-late adulthood (Hickey et al., 2018; Leedham et al., 2020; Lilley et al., 2021; Stagg & Belcher, 2019). Previous research, however, has not compared experiences of adults diagnosed at different ages. Understanding the distinct needs of adults receiving an autism diagnosis at each developmental stage would help to inform the development of tailored supports. Future research should consider exploring whether experiences of the diagnostic process vary across adulthood.

Given many individuals diagnosed with autism in adulthood are supported by their parents or partners, future research should explore the experiences of supporting their autistic child or partner to adapt to the diagnosis. A large body of research explores the experiences of parents of children who receive a diagnosis. Due to differences of parenting an adult and the longer time taken to receive the diagnosis, the impact is likely to be different. NICE guidance (2012) and the Think Autism strategy (Social Care, Local Government

and Care Partnership Directorate, Department of Health, 2014) highlighted the impact on carers supporting individuals with a diagnosis of autism. This research could assist the development of appropriate therapeutic support for carers.

Conclusion

Broadening of diagnostic criteria and increased awareness of autism has resulted in a “*lost generation*” of individuals whose autism has remain undiagnosed until adulthood (Lai & Baron-Cohen, 2015, p.1013). Diagnosis can prompt a process of sense-making which can be disrupted by a lack of post-diagnostic support. Existing services for adults are limited and underfunded (Huang et al., 2020), with few evidence-based supports for autistic adults (NICE, 2012). This meta-ethnography provides further clarity on the experiences of adults prior to receiving their diagnosis, during the diagnostic process and post-diagnosis which can be used to inform the development of adult diagnostic and support services. The current understanding provides a starting point for enabling positive experiences across diagnostic services for adults. It also highlights the importance of healthcare systems being equipped for the needs of the “*lost generation*” as more adults seek an explanation for their differences.

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Data Availability All papers included in this review are in the public domain and can be found using academic databases and/ or Google Scholar.

Declarations

Ethical Approval Ethical approval was granted by the Faculty of Health and Life Sciences Ethics Committee at Coventry University. The procedures used in this study adhere to the tenants of the Declaration of Helsinki.

Competing Interests The authors declare no competing interests.

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Footnotes Throughout this paper identity-first language (e.g., autistic person) is used as this is preferred by most autistic people and is associated with less stigma and discrimination (Botha et al., 2021; Bottema-Beutel et al., 2021). Furthermore, in line with guidance for autism researchers non-ableist language alternatives have been used in order to avoid potentially ableist terms such as special interests or autism symptoms (Bottema-Beutel et al., 2021).