“From that moment, everything has changed”: The Experience of Women with Anorexia Nervosa Receiving a Diagnosis of Autism

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

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Overview

Autistic individuals with co-occurring mental health difficulties are more likely to receive an autism diagnosis later in life and experience longer and more intense treatment. This is particularly the case for autistic women with co-occurring eating disorders. Many studies have sought to estimate the prevalence rate of autistic individuals with co-occurring eating disorder, however little is known about their experience of diagnosis. This thesis therefore aimed to understand the current prevalence rate of autism in eating disorder populations and how autism diagnosis is experienced by autistic women with anorexia nervosa.

Part 1 consists of a systematic review and meta-analysis of 24 studies estimating the prevalence rate of individuals with eating disorders and co-occurring autism. Analysis combined all populations and results showed a similar pooled prevalence estimate to previous literature. Further subgroup analysis highlighted the estimated prevalence rate was not impacted by method of autism diagnosis and that participants with anorexia nervosa were most represented within the literature.

Part 2 consists of an empirical study of the experiences of autistic women receiving an autism diagnosis following treatment for an eating disorder. An inductive, qualitative approach was used based on a secondary dataset of 17 semi-structured interviews. Reflective thematic analysis (Braun & Clarke, 2022) was employed as the analysis framework which identified three themes of “The Search for Understanding and Support”, “A Shifting Moment”, and “Taking Control”. A discussion of the clinical implications of this research as well as limitations and suggestions for future research are included.

Part 3 is a critical appraisal of the process of undertaking the systematic review and empirical study. It consists of a discussion of reflections, learnings and issues significant to conducting research in this particular field.

Impact Statement

The outcomes of this thesis have the potential to directly improve the care of autistic individuals with eating disorders. It has generated important insights into the prevalence rate of autism within eating disorder populations across all genders, age and type of eating disorder. This prevalence rate will provide the necessary evidence to enable eating disorder services to plan how to identify autism early on in treatment. This will then allow appropriate treatment to be planned from the beginning of their referral. The thesis has also highlighted specifically how autistic women experience receiving a diagnosis of autism during treatment for an eating disorder. These important findings shed light on how the process of diagnosis can be as helpful as possible for autistic women and has the potential to help support autistic women with co-occurring eating disorder through their autism diagnosis journey. It also provides evidence for ensuring continued support is offered to autistic individuals and not just a one off diagnosis.

This research also highlights the importance of continued education about autism for healthcare professionals. As the systematic review suggests, over 1 in 5 individuals with autism have co-occurring eating disorder and so healthcare professionals in these services are highly likely to work with autistic individuals and therefore have a responsibility to ensure their understanding is up to date. The empirical paper has shown that autistic women often experience being passed around services with some refused support altogether. This could be reduced with increased education in how to adapt standard eating disorder treatment for autistic needs.

This thesis provides an argument for better joined up care between autism and eating disorder services. This has been highlighted both in the estimate prevalence rate from the systematic review and from the autistic women's narratives in the empirical paper. Better collaborative care between services has the potential to dramatically improve the support offered to autistic individuals.

In addition to the clinical impact discussed above, the research field of autism and eating disorder is growing and this thesis contributes significantly to this. The systematic review pulls together previous estimates of prevalence rates to provide a pooled estimate, which has not been attempted before. It highlights the methodological inconsistencies in the current literature and demonstrates how large scale studies can potentially skew the prevalence estimates. The empirical paper contributes to the developing narrative around how autistic women experience an autism diagnosis and shows there are similarities between how autistic women with an eating disorder experience similar challenges and life-altering experiences to autistic women without co-occurring mental health difficulties.

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Part 1: Literature Review

Is the Estimated Prevalence Rate of Autism in Eating Disorder Populations Influenced by Diagnostic Method? A Systematic Review and Meta-Analysis.

Abstract

Aims

The present review aimed to synthesize previous research to understand the current prevalence rate of autism across eating disorder (ED) populations. We aim to determine whether the prevalence estimates differ according to type of eating disorder and method of autism diagnosis.

Methods

A systematic search of PsycInfo, MedLine, EMBASE, AMED, CINAHL Plus and Web of Science was undertaken in line with PRISMA-P protocol (see appendix 1). Identified studies were entered into a meta-analysis and pooled prevalence rates were calculated. Sub-group analyses were conducted on type of eating disorder, method of autism diagnosis and age of participants.

Results

A total of 24 papers met eligibility criteria and were included in the review and meta-analysis. The majority of studies were conducted within anorexia nervosa (AN), with female-identifying participants, and using the Autism Quotient (AQ) or Autism Diagnostic Observation Scale (ADOS) to identify autism. The pooled prevalence estimate of autism across all ED types was 22%. Studies using the ADOS and the AQ produced similar prevalence estimates and there was an over-representation of autism particularly in AN, with a prevalence estimate of 18%.

Conclusion

Analyzed studies suggest that autism is over-represented in ED populations and the AQ and ADOS produce similar prevalence estimates. Further research should focus on the link between other EDs which co-occur with autism outside of AN, such as Avoidant Restrictive Food Intake Disorder (ARFID), and should include a wider age and gender range.

Introduction

The diagnostic entity of 'autism spectrum disorder' is a neurodevelopmental condition characterized by social communication and interaction differences, patterns of stereotyped behaviour, sensory sensitivities, and restricted interests (American Psychological Association, 2013). The language we use to describe autism in research is important and efforts should be made the reduce medical model and deficit-based language (Monk et al., 2022). Therefore, in line with language preferred by the autism community (Kenny et al., 2016) and by autistic researchers (Monk et al., 2022), the term "autism" will be adopted in this review as a direct synonym for the diagnostic entity called autism spectrum disorder.

Around 1% of the general population meet diagnostic criteria for autism (Elsabbagh et al., 2012) and autistic individuals are more likely to have co-occurring mental health difficulties than the general population (Lugo-Martin et al, 2019). Recent research suggests that autism is particularly over-represented in eating disorder populations, with up to 28% of patients with an eating disorder also meeting criteria for autism diagnosis (Huke et al, 2013; Carpita et al; 2022). Eating disorders (ED) can be defined as severe and persistent disturbances in eating behaviours with distressing thoughts and emotions around food, weight and shape. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) currently recognizes Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), Other Specified Feeding or Eating Disorders (OSFED) and Avoidant Restrictive Food Intake Disorder (AFRID) as diagnostic categories under the umbrella of eating disorders (APA, 2013). Eating disorders are distinct from feeding and eating *problems*, such as food selectivity or food avoidance, which may be experienced by autistic individuals particularly in childhood (Baraskewich et al., 2021) but tend to be more transitory and without the significant impairment to functioning that characterizes the DSM-5 definition of eating *disorder* (APA, 2013). Individuals with an ED and co-occurring autism are more likely to experience severe eating disorder symptomology, longer treatment on average for

their eating disorder, more inpatient stays, and worse overall treatment outcomes (Tchanturia et al., 2016).

The link between autism and EDs was first suggested in the clinical literature by Gilberg (1985) who described three cases of autistic individuals with familial history of anorexia nervosa (AN), and noted that autism and AN may be related conditions due to their similar cognitive profiles. Like autistic people, individuals with AN report a need for sameness, as well as similar difficulties in understanding emotions and taking the perspectives of others (Courty et al., 2013). Baron-Cohen et al (2013) termed this a “type S” profile, where skills in systemizing were found to be significantly better than the ability to empathize in both participants with AN and autistic participants. A shared underlying genetic vulnerability has also been suggested by large scale studies investigating the co-occurrence of AN and autism within families, where genetic vulnerability may be modulated by environmental factors to manifest as disordered eating (Koch et al., 2015).

The interaction between autism and ED is complex and individuals commonly experience them as intertwined. Brede et al (2020) proposed a model based on interviews with autistic women, their parents and professionals which highlights areas of autism-related traits that create both direct and indirect pathways to restrictive eating disorders. Food specific sensory sensitivities can lead to avoidance of these food groups, intolerance of uncertainty and rigidity in behaviour could lead to the use of food restriction to obtain control and predictability, and the social interaction that comes with mealtimes could lead to avoidance of eating with other people. This link may also be mediated by bullying and stressful life events, leading to high levels of distress, and the use of restrictive eating behaviours as a maladaptive coping mechanism for managing this distress. The consequence of these food related coping mechanisms is a “numbing down” of sensory and emotional experiences, and a feeling of calmness due to increased control and predictability. This in turn leads to the effects of starvation and the ED itself becoming a reinforcing and cyclical process.

Within ED populations, identifying an autism diagnosis is crucial for successful treatment adaption. It can provide an explanatory framework for past and current difficulties, allow development of a new sense of self and increased self-compassion (Kelly et al, 2022) and allow for creation of supportive, accepting, and autism-friendly social and physical environments (Lai & Baron-Cohen, 2015). Prior to autism diagnosis, autistic individuals often experience misinterpretations of their autism-related traits, with staff incorrectly assuming behaviors are driven by their ED and social communication difficulties misinterpreted as disengagement from treatment (Babb et al., 2021). Fewer therapeutic gains are seen from ED therapies such as Cognitive Remediation Therapy compared to ED patients without co-occurring autism (Tchanturia et al., 2016). However, after autism diagnosis, healthcare professionals are able to adjust their usual practice to accommodate autistic needs. Alternative approaches to standard ED treatments, such as DBT, can then be adapted to take account of different communication styles and offer in environments which have been adjusted to accommodate autism (Babb et al., 2021). This can therefore support engagement in ED treatment. Sessions facilitated in a 1-to-1 format may also be more beneficial for autistic individuals than therapy offered in a group setting (Li et al., 2022), which is often the norm in ED inpatient services. Implementation of autism-adapted treatment pathways for ED, such as The Pathway for EDs and Autism developed from Clinical Experience (PEACE pathway), which provides treatment resources and advice for clinicians, has shown promising results with reduction in the length of inpatient admissions for autistic individuals (Tchanturia et al., 2020).

While we know that autism and ED can co-occur, obtaining accurate estimates of the prevalence rate of autism in ED has proven challenging. The effects of starvation in patients with anorexia can exacerbate and mimic autistic traits, including cognitive rigidity and poor mentalizing ability (Keys et al, 1950; Hiller & Pellicano, 2013), meaning it can be difficult to disentangle autistic traits from acute ED illness state. However, social difficulties reported by autistic individuals remain high after recovery from AN (Nazar et al, 2018) and scores on

measures of autism traits remain stable during ED inpatient admission treatment (Tchanturia et al, 2019). Longitudinal studies have also shown that autistic social traits in childhood could represent a risk factor for developing disordered eating in adolescence, indicating that autism predates the ED (Solmi et al., 2021). This suggests instead these traits are life-long social communication differences rather than purely a result of starvation.

Much of the research has focused on AN, with estimates of those reaching the criteria for an autism diagnosis ranging widely from 8.8% to 24.5% (Boltri & Sapuppo, 2021). Huke et al's (2013) systematic review found an estimated prevalence of autism in AN populations of 22.9%, however they noted that six of their identified eight studies came from the same Swedish community sample of 51 participants who met the criteria for AN at age 16 years. While these papers provide an invaluable contribution to the literature surrounding autism and EDs, prevalence estimates taken from only one sample of participants are not necessarily generalizable to the wider population and therefore may not be representative of the true autism prevalence rate. It is also important when estimating prevalence rates to widen the focus to ensure all EDs are represented, as this link does not appear to solely exist within AN. Patients with BN and BED have also shown greater autistic traits compared to controls (Gesi et al., 2017) and significant correlations have been seen between scores on Orthorexia Nervosa (ON) measures and measures of autism traits (Dell'Osso et al., 2022). When including other ED diagnoses into prevalence estimates, Nickel et al (2019) found a much lower average prevalence of 4.7% compared to Huke et al's (2013) estimate of 22.9%, indicating the prevalence in other types of EDs may be much lower than originally thought.

The wide variety of tools used to measure autism in ED populations may also add to the challenge of determining an accurate prevalence rate and could account for the difference in observed estimates (Westwood & Tchanturia, 2017). Studies are not homogenous in how they measure autism, using a mixture of register-based data and clinical investigation tools, alongside a variety of study samples and diagnostic terminology (Nickel et al., 2019) making it difficult to compare studies. Little is known about how this may

be influencing the range of prevalence estimates and whether self-report measures, such as the Autism-Spectrum Quotient (AQ), could lead to different prevalence estimates for autism amongst those with ED, compared to observational tools such as the Autism Spectrum Observation Scale (ADOS). It should however be noted that despite the literature largely relying on measures such as the AQ or ADOS to identify autism within ED populations, an outcome on these measures which exceeds the defined clinical threshold does not equate to an autism *diagnosis*. Autism diagnosis can only be confirmed through a comprehensive multi-disciplinary assessment, as laid out in National Institute for Health and Care Excellence (NICE, 2012) guidance.The Autism-Spectrum Quotient (AQ) developed by Baron-Cohen et al (2001) was designed as a short and easy to use measure of autistic traits in individuals with average intelligence. The original study showed the AQ to have good face and construct validity, and it has subsequently been adapted into a shorter 10 question format termed the AQ-10 (Allison et al., 2012) and a children's version termed the AQC (Auyeung et al., 2008). Culturally adapted versions of the scoring systems are also available (Wakabayashi et al., 2007). The full AQ comprising of 50 questions and the abridged AQ-10 screening measure have performed well at discriminating between autistic individuals and individuals from the non-autistic general population (Booth et al., 2013), however when the AQ-10 was used to predict who would receive a formal diagnosis in a clinical sample, the measure performed no better than chance (Ashwood et al, 2016). The AQ focuses on current behaviour symptoms rather than developmental history of autism traits, so it has the potential to miss important information needed for a diagnosis of autism, such as symptoms presenting from an early developmental stage (APA, 2013). Additionally, the self-report format of the AQ may not be sensitive enough to detect subtle traits associated with autistic females, particularly due to ability to camouflage social difficulties (Lai et al., 2011). Due to the complex interplay between autism and ED, relying on this self-report measure to capture autism traits within ED populations may therefore be unreliable (Westwood et al., 2016) which presents challenges to clinicians and services. Nevertheless, when assessing the utility of the AQ in ED populations, individuals with AN were shown to have higher scores compared to healthy

controls (Westwood et al., 2016). This is in line with previous research indicating an increased prevalence of autism traits in AN compared to the general population (Huke et al, 2013). The AQ and its variants are widely used in clinical services as the self-report format makes it a cost effective means of quickly and easily capturing those with an increased likelihood of being autistic (Westwood et al, 2016). This also forms part of national guidance on identifying autism, with the National Institute for Health and Care Excellence (NICE) recommending that individuals who score at 6 or above on the AQ-10 should be offered a further comprehensive assessment for autism (NICE, 2012).

By comparison, the Autism Spectrum Observation Scale (ADOS) is seen as the "gold-standard" assessment tool for autism. Developed by Lord et al (2012), this tool is a standardized, semi-structured assessment of communication, social interaction, play, and restricted and repetitive behaviours in response to a series of activities designed to produce a more natural context for assessment. The ADOS allows clinicians to directly observe behaviors that are related to the DSM-5 diagnostic criteria for autism at different developmental levels and chronological ages, rather than relying on self-report information. Since the scoring criteria has been revised, the ADOS has shown good sensitivity and specificity which exceeded that of the old algorithm (Gotham et al., 2008). In ED populations, the revised algorithm has shown good ability to discriminate between behaviors associated with AN rather than underlying autism diagnosis, and was shown to not be correlated with self-reported depression, anxiety, eating disorder symptomology or BMI (Sedgewick et al., 2019). The ADOS forms part of national guidance for assessing and diagnosing autism (NICE, 2012), but should be completed within the context of a multi-disciplinary assessment and not relied upon solely for a diagnosis. After assessing 10 women using the ADOS who were accessing ED treatment, Mandy and Tchanturia (2015) found that five scored within the clinical range for a diagnosis of autism and an additional two were judged likely to have autism after clinical observation combined with participant and parent self-report of developmental history.

While both the AQ and ADOS have been widely used in ED populations, there has been no research to date looking at the impact that different methods of autism assessment have on the prevalence rate of autism. Previous research has identified a range of estimates between 8% and 24% using systematic review methods (Boltri & Sapuppo, 2021; Carpita et al, 2022; Huke et al, 2013), but to the authors knowledge none of these have included a meta-analysis element to calculate a pooled prevalence estimate. There has also been little investigation into alternative methods that may be used to assess the prevalence rate of autism in this population, and whether the prevalence rate differs among different ED diagnoses.

Rationale

Since the first initial discussion of a possible link between ED and autism by Gilbert (1985), there has been a growing body of evidence identifying increased rates of autism diagnosis and autism traits in ED populations. However, the evidence remains mixed when trying to identify accurate prevalence rates, which currently vary from 8% to 25% (Boltri & Sapuppo, 2021). Studies to date have focused mostly on autism within AN without a representative sample from other ED populations. Estimates have also been gathered using a wide variety of different methods of diagnosis, and little is known about the impact this could have on the prevalence rate; it remains unclear whether self-report measures such as the AQ, estimate a different prevalence rate to that of semi-structured tools like the ADOS. Before further research continues in this field, it is important to better understand how autism is being measured in ED populations and what the current prevalence rate is. This will subsequently support ED services to determine whether an autism measure should be introduced into routine practice, and if so which measure this should be, to enable treatment plans to be effectively adapted and any additional considerations captured early in the initial formulation.

Aims

The primary aim of this systematic review and meta-analysis is to understand the current prevalence rate of autism across all ED populations. We aim to build on the previous research carried out in AN populations and encompass all ED diagnoses, in order to determine whether the prevalence rate of autism differs among the various ED sub-populations. In addition to this, we aim to determine which methods of diagnosis are used to measure autism across ED populations and identify whether this has an impact on the estimated prevalence rate. In investigating how autism is measured in ED populations, we were also interested to note the language used to describe autism within the research.

Method

Study Design

The following review was completed in accordance with Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P) guidance (Shamseer et al., 2015), detailed in appendix 1.

Inclusion and Exclusion Criteria

The inclusion criteria were: 1) observational studies presenting new data estimating autism diagnoses or proportion of the sample with elevated autistic traits in any eating disorder population; 2) studies published in English up to the search date of 18/12/2022. These included studies of all age groups in any eating disorder population; and cross-sectional and longitudinal study designs. Studies were included regardless of the method used to estimate the prevalence of autism and/or high autistic traits.

Exclusion criteria were: 1) studies which did not provide a prevalence estimate or sufficient data to calculate one, such as those describing mean scores on measures only; 2)

correlational studies; 3) studies which have a qualitative research design; 4) articles which described a case series; 5) book chapters; 6) conference abstracts where the full article had not been published; 7) studies which focused on development of a new measure and did not provide a prevalence estimate; and 8) studies which sought to investigate feeding and eating difficulties with autism populations.

Search Strategy

An electronic search was conducted on 18th December 2022 across six databases: PsycInfo, MedLine, EMBASE, AMED, CINAHL Plus and Web of Science. The search term combinations of “autism” OR “ASD” OR “Aspergers” AND “eating disorders” OR “anorexia” OR “bulimia” were applied across all databases. Truncations of all the search terms were also used to ensure all variations of the words were captured in the searches. The exact search strategy is presented in table 1.

In order to find studies not detected by the electronic search, reference lists of review articles that fulfilled the above inclusion criteria of this review were used as a source for hand searching additional references.

Table 1

Search strategy used for database searching

(autis* OR asd OR asperger* OR autism spectrum disorder (explode term))	AND	((eating adj2 disorder*) OR anorexi* OR bulimi* OR eating disorders (explode term))

Identification of Articles

Firstly, article titles were screened and excluded if they did not reflect the focus of the review. Secondly, article abstracts were screened and removed if they did not meet the inclusion criteria of the review. Finally, all remaining full texts were screened for eligibility and any disagreements over eligibility were discussed with supervisors until an agreement was reached.

Quality Assessment

A quality appraisal tool developed for prevalence studies by the Joanna Briggs Institute (JBI) (see appendix 2) was used to assess the methodological quality of each included study and to determine the extent to which a study has addressed the possibility of bias in its design, conduct and analysis (Munn et al., 2015). For assessing the risk of bias in sample size and where no sample size calculation was reported in the study, the equation provided in the JBI tool was used (Naing et al, 2006). The confidence was set at 95%, the precision was set at 10%, and an estimated prevalence of 0.265 or 26.5% was used based on the pooled prevalence of ED participants who scored above the clinical cutoff of the ADOS-2, indicating the presence of autism symptoms from the systematic review of Nickel et al (2019). This gave an estimated adequate sample size of 299 which all studies were compared against.

Using this tool, articles were assigned a rating of yes (low risk of bias), unsure (moderate risk of bias) and no (high risk of bias) across nine questions each reflecting a different type of possible bias. Any discrepancies were discussed with supervisors and a consensus was reached. A selection of the articles were also independently rated for quality by a second quality appraiser outside of the research team. 10% of papers were reviewed and consensus was reached across all domains.

Data Analysis

The pooled prevalence of autism diagnosis and traits in ED populations with 95% confidence intervals (CI) were determined and expressed in forest plots using the metaprop function in STATA version 17 (StataCorp, 2021). A random effects model was employed and variation between studies was expressed by Inverse variance index (I^2) with values of 25%, 50% and 75% classified as low, moderate and high degrees of heterogeneity, respectively. Sub-group analysis was completed to investigate the moderating effects on the pooled prevalence of autism assessment method and ED type. An exploratory meta-regression was performed in STATA version 17 (StataCorp, 2021) using the metareg function (Harbord & Higgins, 2008) to examine the association between age of participants and prevalence rate of autism in ED populations.

Where studies aimed to assess the stability of autism symptoms over time and included assessments during ED recovery, the time point nearest recovery was taken, for example in Bentz et al (2017). This was theoretically driven by the notion that autism is a neurodevelopmental condition, so it's manifestations would be stable over time and therefore should be observable after recovery from the eating disorder. This would then reduce any possible bias in assessment results due to acute starvation effects. The agreed hierarchy of inclusion for studies using more than one timepoint within the same sample was therefore 1) recovered ED; 2) acute ED. Where studies were looking at the differences between the old and new ADOS-2 scoring algorithms, the prevalence rate gained from the revised algorithm was used, for example in Sedgewick et al (2019). Where studies analysed the same sample using more than one diagnostic method, the method closest to the "gold-standard" was used, for example in Kerr-Gafney et al (2021). The inclusion hierarchy where studies used more than one diagnostic method was therefore 1) ADOS; 2) clinical interview; 3) AQ; 4) other questionnaire methods; 5) International Classification of Diseases (ICD) codes on a medical file. This same criteria was also applied to the Gothenburg studies, where the study

which reported the number of autistic individuals who had met criteria in all 4 waves of the previous investigations using the same sample was included (Anckarster et al, 2012).

Results

Study Identification

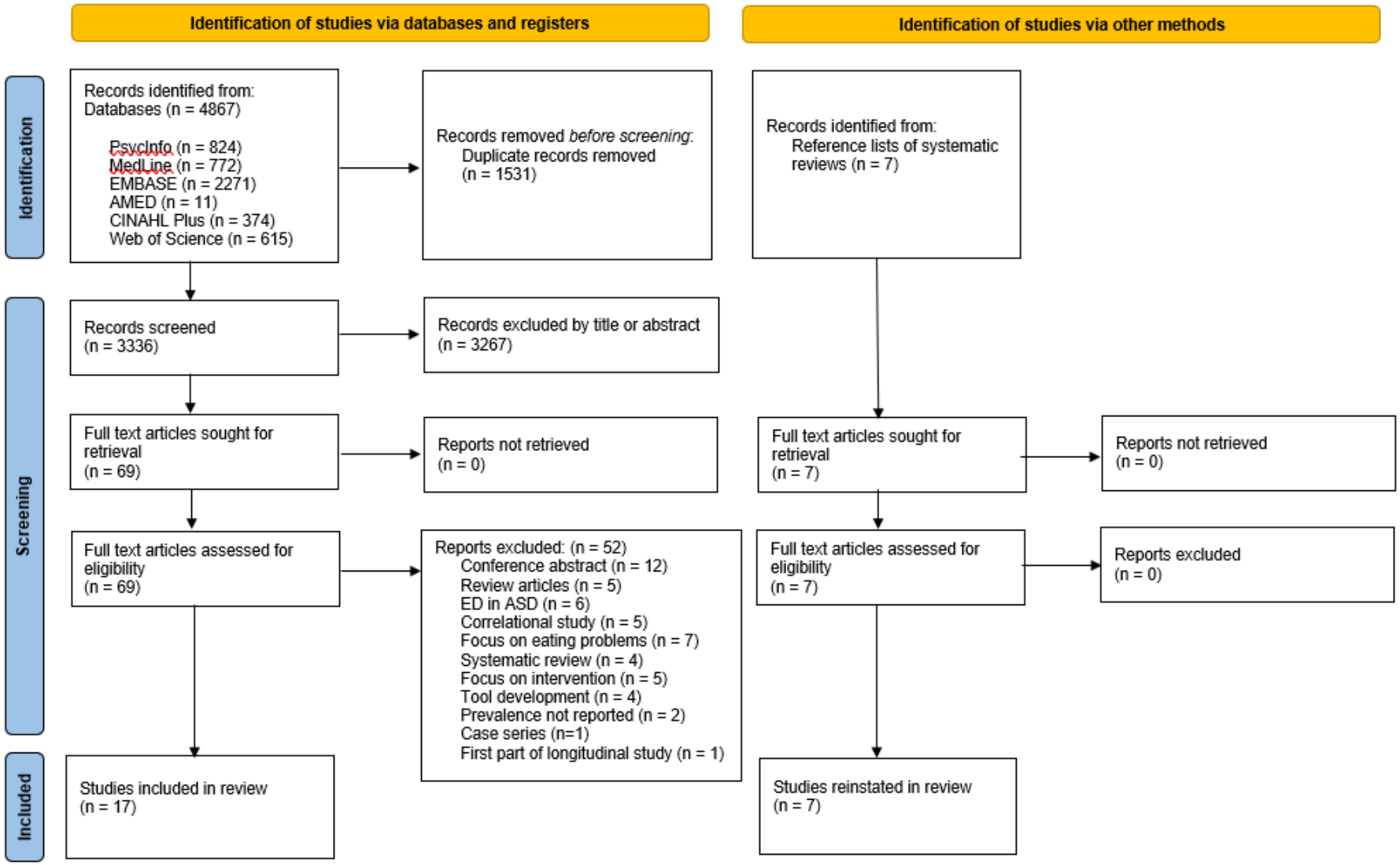
The database search yielded 4867 records, of which 3336 remained after the removal of duplicates. Duplicates' removal was performed using the EndNote Reference Manager (Clarivate, 2013). After screening by title and abstracts, 69 studies were identified as possibly relevant. Full text screening was then conducted and 52 studies were omitted. Studies that did not report a prevalence rate (n = 2), were correlational in nature (n = 5) or were a case series (n = 1) were excluded. Articles that were seeking to develop a new measure of autism and didn't provide an estimate of autism prevalence in eating disorder populations (n = 4) or focused on assessing the effectiveness of an intervention (n = 5) were also excluded. Studies that were only reported as a conference abstract without the full published articles available (n = 12) were omitted. Review articles (n = 4) and systematic reviews (n = 4) were also excluded. Articles which focused on eating *problems* instead of eating *disorders* (n = 7) were excluded along with articles which sought to assess the prevalence of EDs in autism (n = 6) as opposed to autism in ED populations. In addition, where studies were published separately but used the same sample to assess the prevalence of autism within acute phase of ED compared to recovered ED, the study assessing the acute sample was excluded (n = 1).

Finally, manual screening of six published systematic reviews on the same theme was conducted to identify articles potentially not captured by the database search. This yielded seven papers which were initially removed earlier in the screening process and so were reinstated. No new papers were identified. Figure 1 illustrates the selection of the studies in a PRISMA flow diagram.

One reviewer carried out the eligibility assessment of all the articles in line with previously established inclusion and exclusion criteria. Any dilemmas were discussed with the research team until a consensus was reached. At the end of the selection process, 24 studies met the inclusion criteria and were included in the review.

Figure 1

PRIMA-P Flow Diagram of Included Studies



Overview of Included Studies

Twenty-four studies fully met the eligibility criteria for this review. Studies were from the United Kingdom (n = 10), Sweden (n = 4), Italy (n = 4), Denmark (n = 3), Japan (n = 2) and France (n = 1) and ranged from a publication year of 2005 to 2022. Sample sizes ranged from 22 to 9985 participants.

Quality Assessment

The JBI quality appraisal tool for prevalence studies was not used to exclude studies but instead to assess the risk of potential bias, and to provide insights into the methodological strengths and weaknesses of the current extant literature (see appendix 2 for the full tool). Overall the studies showed a low risk of bias in all domains. However when assessing the risk of sampling bias, while the majority of studies sampled from a clinically relevant population, only 3 studies surpassed the calculated appropriate sample size. The results are presented visually in table 2, with green indicating low risk of bias, yellow indicating moderate risk and red indicating high risk.

Table 2

The risk of bias in each paper using the JBI Quality Tool for Quality of Prevalence Studies

	Appropriate sample frame?	Appropriate sample method?	Adequate sample size?	Subjects and setting detailed?	Sufficient data coverage for analysis?	Valid methods used for condition?	Standard, reliable measurement of condition?	Appropriate statistical analysis?	Adequate response rate?
Anckarsater et al. (2012)	+	+	−	+	+	+	+	+	+
Baron-Cohen et al. (2013)	+	?	−	+	+	+	+	+	+
Bentz et al. (2017)	+	+	−	+	+	+	?	+	+
Calderoni et al. (2015)	+	+	−	+	+	+	+	+	+
Courty et al. (2013)	+	?	−	+	+	+	+	+	+
Farag et al. (2021)	+	+	?	+	+	+	?	+	+
Inoue et al. (2021)	+	+	−	+	+	+	+	+	+
Karjalainen et al. (2019)	+	+	−	+	+	+	+	+	+
Kerr-Gafney et al. (2021)	+	+	−	+	+	+	+	+	+
Koch et al. (2015)	+	+	+	+	+	+	?	+	+
Nazar et al. (2017)	+	?	−	?	+	+	+	+	+
Numata et al. (2021)	+	+	−	+	+	+	+	+	+
Pooni et al. (2012)	+	+	−	?	+	+	+	+	?
Postorino et al. (2017)	+	+	−	+	+	+	+	+	+
Pruccoli et al. (2021)	+	?	−	+	+	+	+	+	+
Sedgewick et al. (2019)	+	?	−	+	+	+	+	+	+
Steinhausen et al. (2021)	+	+	+	+	+	+	?	+	+
Stewart et al. (2017)	+	?	?	+	−	+	?	+	+
Tchanturia et al. (2013)	+	+	−	+	+	+	+	+	+
Vagni et al. (2016)	+	+	−	+	+	+	+	+	+
Wentz et al. (2005)	+	+	−	+	+	+	+	+	?
Westwood et al. (2018)	+	+	−	+	+	+	+	+	+
Westwood et al. (2017)	+	+	−	+	+	+	?	+	+
Zhang et al. (2022)	+	+	+	+	+	+	?	+	+

Note. Red denotes high risk of bias; yellow denotes moderate risk of bias; and green denotes low risk of bias.

Qualitative Synthesis

As shown in table 3, four studies included more than one eating disorder population, but the majority of samples were diagnosed with AN (n = 27). A smaller proportion of studies assessed autism in BN (n = 3), BED (n = 2) and ARFID (n = 2). When regarding autism measures used within ED populations, the AQ and it's variants such as the AQ-10 and the AQC was the most frequently chosen measure (n = 8) followed by the ADOS (n = 7). The Ritvo Autism Asperger Diagnostic Scale–Revised (RAADS-R), Asperger Syndrome Diagnostic Interview (ASDI) and Development and Well-Being Assessment (DAWBA) were used by 1 study each, and 3 studies used the International Classification of Diseases (ICD) codes for autism taken from a participant's medical file as a method of ascertaining diagnosis.

In designing a second edition of the ADOS, the authors developed a new scoring algorithm for module 4 of the assessment schedule which was designed to be more sensitive to symptom severity (Lord et al., 2012). It also reflects a move to align the ADOS more closely to the DSM-5 criteria definition of autism with greater weight placed on sensory sensitivities and sensory-motivated behaviors of autistic people. This may have impacts on how the ADOS is used to diagnose autism in AN patients, as sensory sensitivities are one of the drivers for development of AN in autistic people (Brede et al., 2020). One study directly compared the two algorithms to ascertain whether this impacted the amount of participants with AN who met criteria for a diagnosis of autism (Sedgewick et al., 2019). Under the original algorithm, 19.7% of AN participants exceeded the clinical threshold for diagnosis compared to 27.3% of participants under the new scoring algorithm.

As table 3 shows, nineteen studies recruited from clinical samples with a mixture of inpatient and outpatient populations, 3 studies sampled from the community, 1 study used a mixture of both community and clinical samples and 1 study analysed secondary data. The majority of the included studies had only female-identifying participants (n= 14). The remainder included a mixture of female and male identifying participants (n = 10), however

these studies still had samples that consisted of over 85% female-identifying participants. Most studies sampled from an adolescent population (n = 11) or an adult population (n = 6), with fewer studies sampling only child participants (n = 3). Some studies samples across the lifespan and included child, adolescent and adult participants (n = 4). The mean age of the overall sample was 19.7 years with a range of means between 6.8 and 33 years. It should be noted that even in studies which sampled a wide age range, the mean age of the sample was still young. For example, Numata et al (2021) sampled 45 outpatients aged between 12 and 45 years, yet the mean was 26.2 ± 7.8 years and Sedgewick et al (2019) sampled patients aged between 12 and 53 years but again the mean age was young at 21.48 ± 3.95.

The average duration of ED was reported in 8 studies as a measure of illness severity. Among these studies, the average of the mean duration of ED was 5.46 years with a range of between 1 year and 10.59 years. In one study participants were currently in the acute phase of illness so did not provide an average duration (Posterino et al., 2017).

The use of language when talking about autism in research is important as many descriptions can be pejorative and portray a medical/deficit-focused view of autism (Monk et al., 2022). The terminology and language used to describe ED participants with co-occurring autism varied throughout the identified studies. The majority of studies referred to participants as those who had exceeded the clinical threshold for autistic symptoms (n = 9) with one additional study referring to this group as “clinically diagnosable autism spectrum disorder (ASD)”. Studies also referred to individuals with autistic traits (n = 5) or “high autism spectrum traits” (Vagni et al., 2016), and as “having a diagnosis of ASD” or “autism diagnosis within the autism spectrum” (n = 6). In one of these studies, the term ASD also included labels such as Asperger Disorder and Pervasive Developmental Disorder Not Otherwise Specified (Anckarsater et al., 2012), in line with DSM-IV nosology. One study referred to individuals with “markers of broader or medium autism phenotype” (Courty et al., 2013). One study referred to individuals with “ASD”, however used a measure which is designed as a

screening instrument to assess autistic *traits* rather than a measure to capture those who fit the *diagnostic* profile of autism spectrum (Inoue et al., 2021).

Gothenburg Studies

Several studies were identified during the initial phases of screening which used the same sample of 51 Swedish individuals diagnosed with adolescent-onset AN. The participants were originally recruited through screening all schools in Gothenburg, along with a comparison group selected by the school nurses who had no eating difficulties and were matched for age, gender and school (Rastam, 1992). The whole study group was followed up after six years (Gillberg et al., 1995), 10 years (Nilsson et al., 1999) and 18 years after the onset of AN (Anckarsater et al., 2012) to answer various different research questions, including about the co-occurrence of AN and about autism. These studies have been summarized previously in Huke et al (2013), but their findings highlighted a prevalence rate of autism in AN ranging from 8% to 28% (Carpita et al., 2022). For the purposes of the present review, one of the more recent studies met criteria for inclusion and was used in the below meta-analysis stage (Anckarsater et al., 2012) to avoid over-inclusion of one sample, and to ensure that each data point in the meta-analysis met the assumption of independence from the other data points. In this subsequent assessment of the participants 18 years after the initial recruitment, a comprehensive interview was completed using the ASDI along with the AQ to determine diagnosis of autism. The study also gave a prevalence estimate of 11.76% in this sample based on the number of participants who had received an autism diagnosis across all four waves of the study.

Table 3

An overview of studies identified by the systematic search.

Author and Year	Country	Mean Age (SD)	Gender	ED Sample Size and Diagnosis	Autism Spectrum Assessment Tool	Prevalence Estimate
Anckarsater et al. (2012)	Sweden		48 F 3 M	N = 51; AN	Clinical interview according to DSM criteria, ASDI and AQ	32% of AN participants were assigned an ASD diagnosis in at least one study within the project. 11.76% met criteria in all 4 waves of the studies.
Baron-Cohen et al. (2013)	UK	12 - 18	66 F 0 M	N = 66; AN	AQ	50.7% of participants met the Broader Autism Phenotype, Medium Autism Phenotype or Narrow Autism Phenotype thresholds.
Bentz et al. (2017)	Denmark	AN (current) 16.1 (1.5), AN (recovered) = 18.4 (1.6)	71 F 0 M	N = 71; 43 AN (current), 28 (recovered)	ADOS-2	16% among current AN patients and 21% among recovered AN patients exceeded an ADOS-Total score above the clinical cutoff for an autism spectrum classification according to the ADOS system.
Calderoni et al. (2015)	Italy	14.3 (1.9)	25 F 0 M	N = 25; AN	AQ	Using AQ categories, 28% of AN were classified as Broader Autism Phenotype; and 8% were classified as Narrow Autism Phenotype.
Courty et al. (2013)	France	23.9 (4.7)	14 F 1 M	N = 15; AN	AQ	1/3 of the AN sample shared markers of a broader/medium autism phenotype according to the AQ categories.
Farag et al. (2021)	UK	6.8 (3.4)	48 F 215 M	N = 263; ARFID	Clinical MDT Interview	Among patients with ARFID, comorbid autism was present in 58.3% of patients.

Inoue et al. (2021)	Japan	13.0 (1.9)	114 F 10 M	N = 124; 92 AN, 32 ARFID	AQC with adapted cut-off for Japanese population	Autism prevalence was 16.3% in the AN group and 12.5% in the ARFID group.
Karjalainen et al. (2019)	Sweden	19.6 (2.23)	36 F 0 M	N = 36; AN	AQ	Of the individuals in the AN group, 8.8% scored above the AQ cut-off in the first assessment and 3.1% scored above the AQ cut-off in the second assessment one year later.
Kerr-Gafney et al. (2021)	UK	AN (current) = 21.53 (4.15), AN (recovered) = 22.21 (3.47)	218 F 0 M	N = 218; 64 AN (current), 46 AN (recovered)	AQ-10, ADOS-2 and SRS-2	14.8% of AN participants and 18.2% of recovered AN participants scored above the AQ-10 cut off. 26.6% of AN participants and 15.2% of recovered AN participants scored above the ADOS-2 cut off.
Koch et al. (2015)	Denmark	Age at diagnosis <16 = 2336, >16 = 2670	4648 F 358 M	N = 5006; AN	Whether assigned an ICD-8 or ICD-10 code for infantile autism, atypical autism or Asperger syndrome on medical records	4.5% of AN cases had received an ASD diagnosis according to their medical record.
Nazar et al. (2017)	UK	16.9 (2.1)	137 F 12 M	N = 149; AN	DAWBA	15.4% had autism traits and 4% received a possible/probable autism diagnosis.
Numata et al. (2021)	Japan	26.2 (7.8)	42 F 0 M	N = 42; 5 BED, 23 BN, 8 AN binge/purge, 6 AN restrictive	AQ-10	60.0% of patients with BED, 4.3% of patients with BN, 12.5% of patients with AN binge/purge type, and 16.7% of patients with AN restrictive type exceeded the cut-off value of the AQ score.
Pooni et al. (2012)	UK	13.0 (2.4)	21 F 1 M	N = 22; 21 AN, 1 BN	3Di short version, DAWBA	4.5% of patients met criteria for autism according to the 3Di. 54.5% showed elevated rates of autism traits as measured by the RBS-R.

Postorino et al. (2017)	Italy	14.19 (1.56)	30 F 0 M	N = 30; AN	ADOS-2 and AQ-10	10% scored above the scored above the conventional ADOS-2 threshold for autism. After MDT review, none of these participants were given a diagnosis of autism.
Pruccoli et al. (2021)	Italy	15.8 (1.5)	20 F 3 M	N = 23; AN	ADOS-2 and AQ adolescent	22% obtained scores on the ADOS-2 compatible with a diagnosis of autism but only one of these patients had corresponding high scores on both AQ questionnaires. In total, 52% scored above clinical thresholds for ASD in at least one autism measure.
Sedgewick et al. (2019)	UK	21.14 (5.64)	112 F 0 M	N = 112; 66 AN (current), 46 (recovered)	ADOS-2	Under the original algorithm, 19.7% of AN participants and 15.2% of recovered AN participants scored above the ADOS-2 clinical cut off. Under the new algorithm, 27.3% of AN participants and 19.6% of recovered AN participants scored above the ADOS-2 clinical cut off.
Steinhausen et al. (2021)	Denmark	8–32 (median = 17.3)	9331 F 654 M	N = 9985; AN	ICD categories for autism spectrum disorder seen on a patient's medical records	0.6% of patients with AN had a concurrent autism diagnosis.
Stewart et al. (2017)	UK	14.6 (1.76)	289 F 0 M	N = 289; AN	AQ	6.9% had a score on the AQ above the cut-off.
Tchanturia et al. (2013)	UK	26.35 (8.08)	66 F 0 M	N = 66; AN	AQ-10	25.8% of AN participants scored above the clinical cut-off.
Vagni et al. (2016)	Italy	AN = 19.8 (1.0); BN = 24.5 (1.6); BED = 27.0 (1.9)	67 F 0 M	N = 67; 29 AN, 25 BN, 13 BED	Italian version of the RAADS-R	28% of AN participants, 40% of BN participants and 31% of BED participants showed high autism spectrum traits.

Wentz et al. (2005)	Sweden	27.4 (8.4)	30 F 0 M	N = 30; 13 AN, 9 BN	ASDI	33% of participants reached the clinical threshold for autism diagnosis, all of whom had AN.
Westwood et al. (2018)	UK	12 - 18	40 F 0 M	N = 40; AN	ADOS-2, if scored above clinical cut off parents completed 3Di	52.5% scored at or above clinical cut off on ADOS-2. Of these, 4 scored above cut off on 3Di. Diagnosis was given to 10% of the participants.
Westwood et al. (2017)	UK	18 - 47	60 F 0 M	N = 60; AN	ADOS-2	23.3% of participants with AN scored above clinical cut off on ADOS-2.
Zhang et al. (2022)	Sweden	16 - 39	3125 F 64 M	N = 3189; AN	Registered clinical diagnoses of autism at any point in life on their medical file	4.2% of patients were diagnosed with autism at least twice on their medical records.

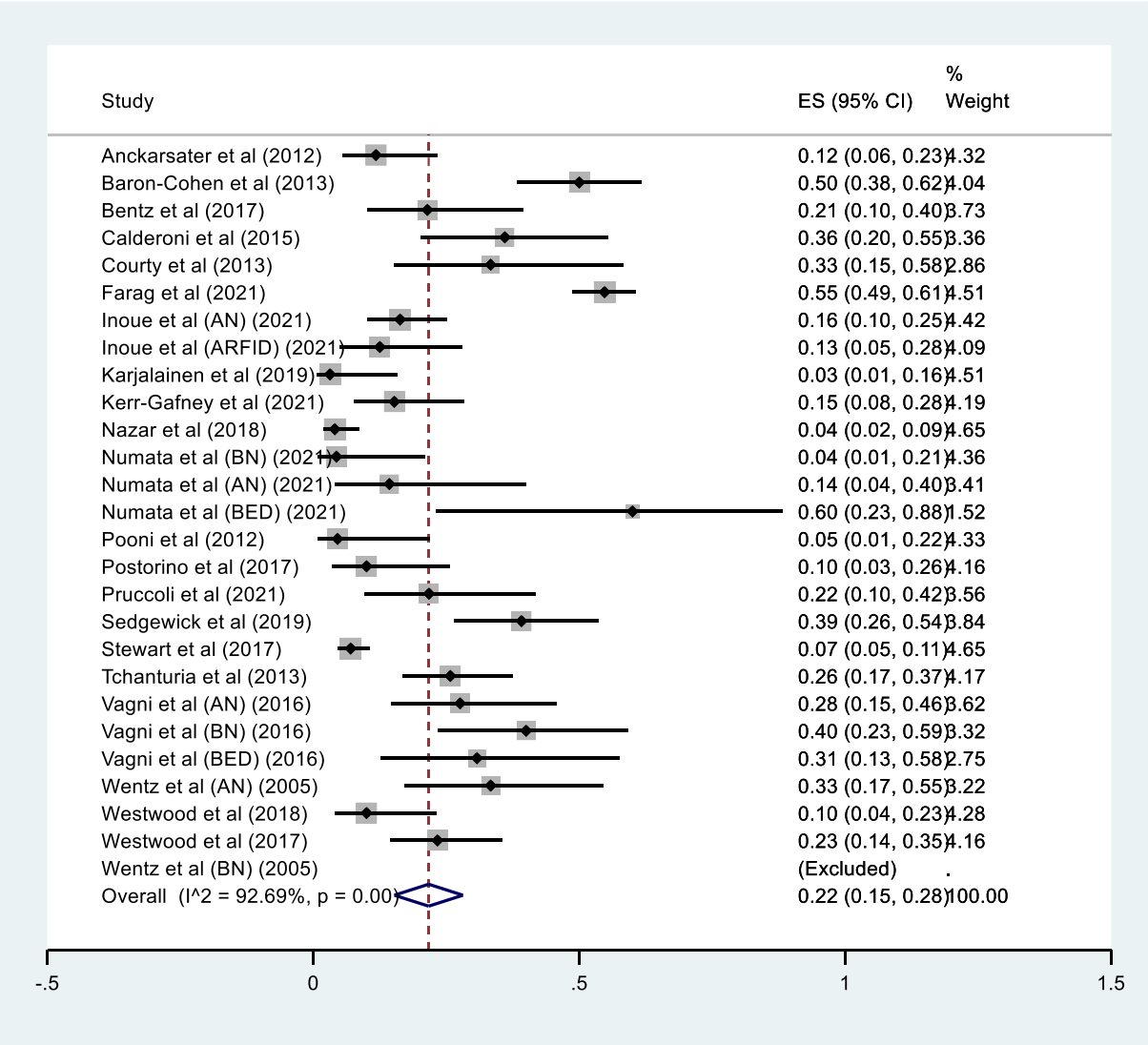
Quantitative Synthesis (Meta-Analysis)

A meta-analysis was conducted to assess the pooled prevalence of autism in eating disorders across studies. The Q analysis showed significant results (Chi square = 710.05, $p < 0.001$), indicating a high heterogeneity between studies ($I^2 = 96.06\%$). The pooled prevalence was 13%, 95% CI [0.11, 0.15].

Studies using ICD codes from patient medical files as a method of identifying autism diagnosis in eating disorder populations (n = 3) were all weighted heavily towards the overall pooled prevalence estimate at almost 10% each due to their large sample sizes. Due to the significant difference in how these studies identified an autism diagnosis compared to the rest of the studies which used direct clinical measurement, they were removed from further analysis. This increased the overall pooled prevalence to 22%, 95% CI [0.15, .28], ($I^2 = 92.69\%$, $p < 0.001$), shown in Figure 2.

Figure 2

Forest-plot of the pooled prevalence rate of autism in participants with eating disorders.



Method of Diagnosis

Subgroup analysis was completed to investigate whether the prevalence rate of autism was influenced by autism diagnostic method, shown in Figure 3. For the purpose of the analysis, the variants of the AQ utilized by some studies, such as the AQC and the AQ-10, were collapsed in to one category. The Q analysis showed significant results (Chi square = 80.59, $p < 0.001$), indicating a high heterogeneity among studies ($I^2 = 87.59\%$). The

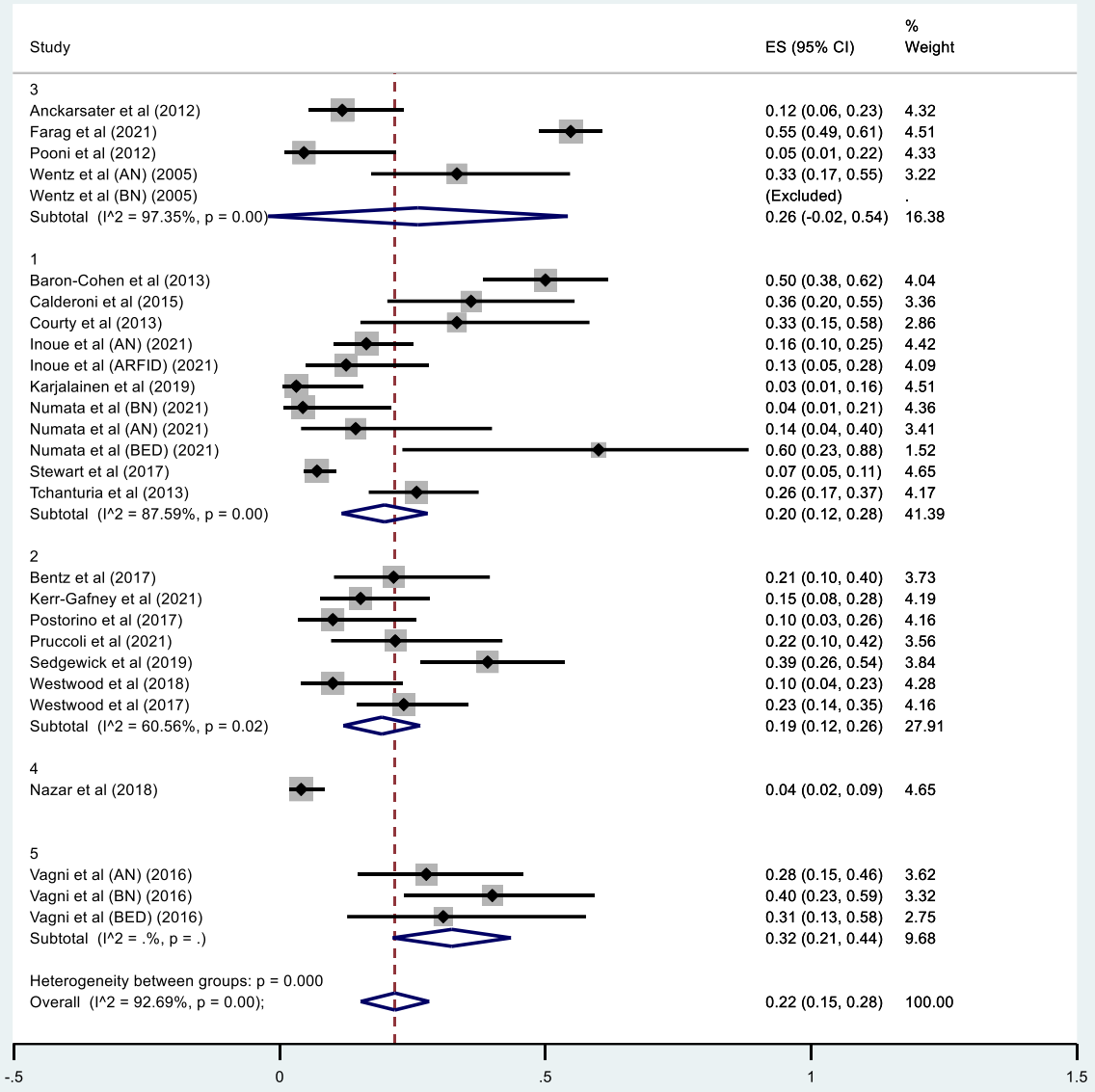
prevalence rate of high autistic traits in EDs measured solely by the AQ was 20%, 95% CI [0.12, 0.28]. In comparison, studies using the ADOS to diagnose autism within ED populations also showed significant results in the Q analysis (Chi square = 15.21, p = 0.02) but indicated moderate heterogeneity among studies (I^2 = 60.56%). These studies were a slightly more homogenous group than studies which used the AQ. The prevalence rate of autism in EDs as measured by the ADOS was 19%, 95% CI [0.12, 0.26].

Studies which used clinical interview methods such as the 3Di and ASDI to diagnose autism in eating disorder populations indicated a prevalence of 26%, 95% CI [0.02, 0.58]. The Q analysis showed significant results (Chi square = 113.3, p < 0.001), indicating a high heterogeneity among studies (I^2 = 97.35%).

One study used the RAADS-R across different types of eating disorders, which indicated a prevalence of 32%, 95% CI [0.21, 0.44] and one further study used the DAWBA which indicated a prevalence of 4%, 95% CI [0.02, 0.09]. Due to the small number of studies in these subgroups, tests of heterogeneity were not possible.

Figure 3

Forest-plot of the pooled prevalence rate of autism in participants with eating disorders, split by method of autism diagnosis.



Note. 1 = AQ, 2 = ADOS, 3 = Clinical Interview, 4 = DAWBA, 5 = RAADS-R

Type of Eating Disorder

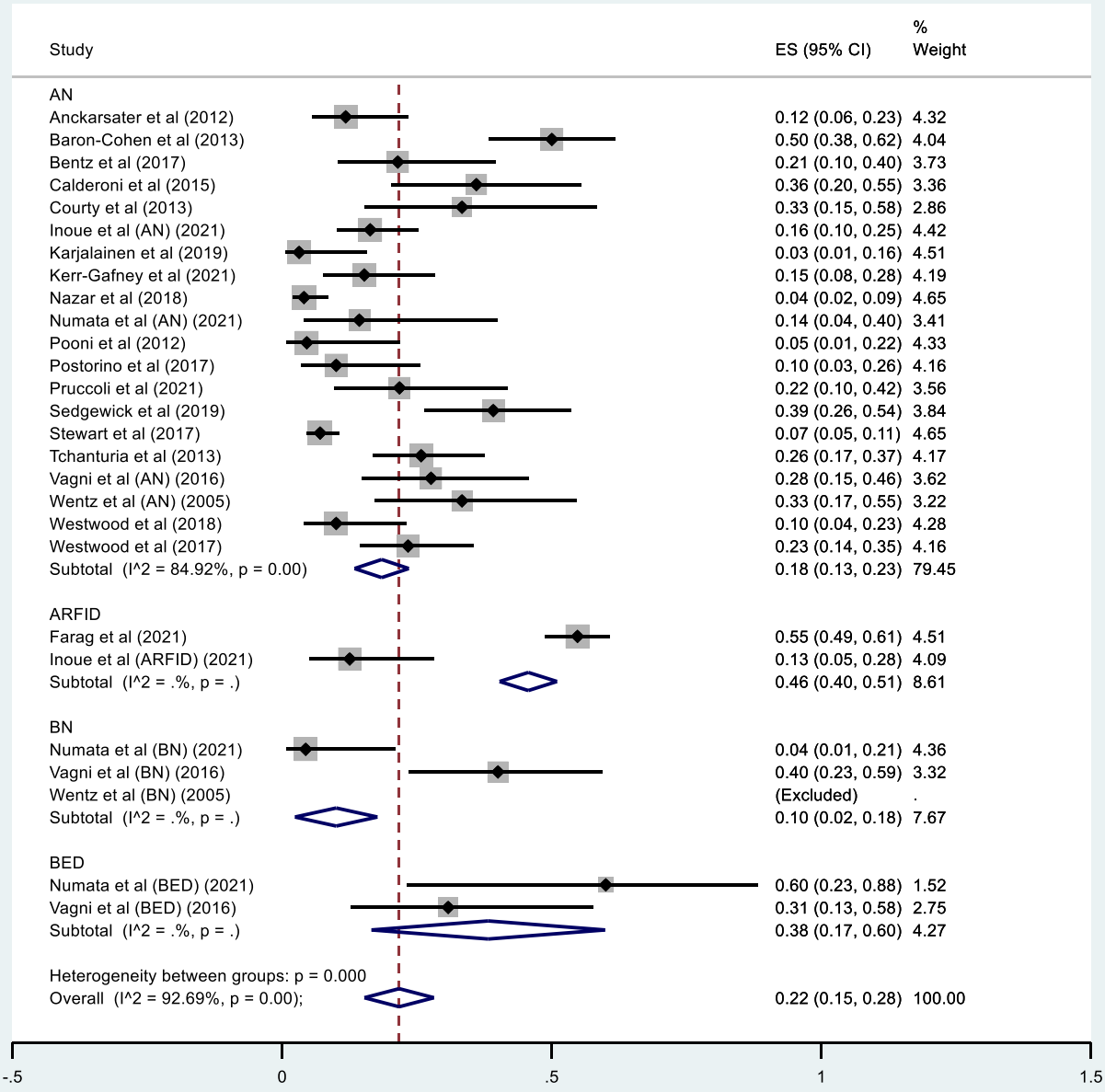
Further subgroup analysis was completed to determine whether the prevalence rate of autism was different among different eating disorder populations, shown in Figure 4. Anorexia nervosa (AN) was the most frequent eating disorder described throughout the

studies (n = 20) and the Q analysis showed significant results (Chi square = 341.89, $p < 0.001$), indicating a high heterogeneity between studies ($I^2 = 92.69\%$). The pooled prevalence of autism among AN was 18%, 95% CI [0.13, 0.23].

Two studies described the prevalence rate of autism in ARFID, 3 studies described the prevalence in BN, and a further 2 studies described the prevalence in BED. Due to the small number of studies in these subgroups, tests of heterogeneity and pooled prevalence estimates were not possible.

Figure 4

Forest-plot of the pooled prevalence rate of autism in participants with eating disorders, split by eating disorder type.



Age of Participants

A random effects meta-regression was performed to determine whether age of the participants affected the overall pooled prevalence rate. Age was not found to significantly influence prevalence rate of autism in eating disorders (coefficient = -0.014, p = 0.978, 95%

CI [-1.04, 1.01]), indicating there was no consistent relationship between age and prevalence rate of autism in ED populations.

Discussion

The aim of this systematic review was to understand the current prevalence estimate of autism across all ED populations. It also aimed to determine whether the prevalence rate of autism differs among the type of ED diagnosis, and whether methods of autism diagnosis influence the estimated prevalence. Results from the meta-analysis show that overall 22% of individuals with EDs meet criteria for co-occurring autism, across all age groups and ED sub-populations.

This is in line with estimates reported in systematic reviews by Huke et al (2013) of 22.9% and Nickel et al (2019) of 26.5%, derived from the average of ED patients who scored above the cut-off on the ADOS-2. These estimates were calculated using means ascertained from their identified studies however, whereas the present study uses a meta-analysis to determine pooled prevalence estimates across studies. Our meta-analysis includes nine additional studies which were published between 2019 and 2022 and not included in previous estimates. Inclusion criteria in the present study were also widened to include ARFID, BN and BED in addition to AN, and looked across adult and child populations. To reduce bias in our meta-analysis, where studies reported more than one prevalence estimate across time with the same sample, the estimate taken during the recovery stage of illness was used. Out of the 24 included studies, only one study was included which used the Swedish community sample (Anckarsater et al., 2012) which previously dominated the literature surrounding autism and AN prevalence estimates (Huke et al., 2013). Therefore the present systematic review and meta-analysis provides an important addition to the current literature surrounding ED and autism.

This review highlighted three studies which used ICD codes from patients' medical files to measure prevalence of autism diagnoses in large community samples. This method of diagnosis produced a much smaller prevalence estimate of autism across EDs of 2%. While this method is based on ICD criteria, the participants in these studies were not directly assessed by the researchers, resulting in a lack of transparency in how the actual *process* of diagnosis was completed for each participant. Variation in diagnostic method is therefore highly likely (Koch et al., 2015; Steinhausen et al., 2021; Zhang et al., 2022). While one study ensured validity by requiring two occurrences of autism diagnosis to meet inclusion criteria (Zhang et al., 2022), there is the potential that this method of using ICD codes may have missed individuals who presented to an eating disorder clinic but then didn't have the opportunity to undergo a diagnostic assessment for autism. Previous literature indicates for example that autistic women with co-occurring ED tend to present to services without an autism diagnosis and don't receive this till on average 9 years after their ED diagnosis (Babb et al., 2021). Therefore, it is possible that these studies skewed the first calculated prevalence estimate of 13% and are not studies of how many patients with ED are autistic, but instead how many patients with ED are *diagnosed* as autistic. When these studies were removed from the analysis, a prevalence rate of 22% was seen which may be closer to the true prevalence. A similar phenomenon was observed by Nickel et al (2019), who found an average prevalence of 4.7% when other diagnostic methods were included in their estimates, compared to the 26.5% when using only the ADOS-2. This highlights the need to improve autism diagnosis in ED populations to ensure validity in how autism is identified.

The AQ and ADOS produced similar prevalence estimates of autism across all types of ED type (20% vs 19% respectively). This was similar to the overall pooled prevalence estimate of 22%, indicating that the AQ and the ADOS may be equally able to recognize autism across ED populations. However, it's important to consider whether the AQ and the ADOS are identifying the same individuals with ED as autistic. Scores on the self-report AQ have been found to not significantly predict receipt of an autism diagnosis, with up to 64% of

those who scored below the AQ cut-off found to be false negatives who were in fact autistic (Ashwood et al., 2016). When looking at ED populations, the AQ-10 was found to reliably discriminate between autistic and non-autistic women with co-occurring AN, but had low sensitivity indicating a high rate of false negatives (Adamson et al., 2022). Moreover, Pruccoli et al (2021) found that five participants with AN exceeded the threshold for diagnosis on the ADOS-2, but only one of these had corresponding high scores on the AQ questionnaires. The present meta-analysis highlights that studies reporting prevalence as estimated by the ADOS showed lower heterogeneity compared to studies using the AQ (60.56% vs 87.59% respectively), indicating the ADOS may produce more reliable estimates of autism in ED populations.

When looking at other measures of autism, studies which utilized clinical interview techniques such as the 3Di and the ASDI indicated a prevalence of 26%, 95% CI [0.12, 0.26]. While studies using the RAADS-R demonstrated a higher prevalence estimate of 32%, 95% CI [0.21, 0.44], and studies using the DAWBA showed a much lower prevalence estimate of 4%, 95% CI [0.02, 0.09], these estimates were derived from one study each making it difficult to draw any firm conclusions here. More research is needed into how reliable measures outside of the AQ and ADOS are to capture prevalence estimates of autism in ED.

The present study suggests that autism is particularly over-represented in AN, with an estimated prevalence of 18%, 95% CI [0.13, 0.23]. While this could indicate that co-occurring autism is most commonly diagnosed in patients with AN, our systematic review highlights that the current literature is most saturated with reports of autism in AN. Drawing firm conclusions about the prevalence of autism among other types of EDs proved difficult due to the smaller numbers of studies available in the current literature. While estimates of the prevalence rate of autism in ARFID yielded a higher pooled prevalence of 46%, 95% CI [0.40, 0.51], ARFID was only investigated by two studies, each of which yielded substantially different autism prevalence estimates (Farag et al., 2021; Inoue et al., 2021). These results

therefore need to be interpreted with caution. Similarly, two studies reported on autism among patients with BED which yielded a prevalence estimate of 38%, 95% CI [0.17, 0.60] (Numata et al, 2021; Vagni et al., 2016) and a further three studies investigated autism within BN, yielding an estimated prevalence of 10%, 95% CI [0.02, 0.18]. Therefore, further research should focus on how autism co-occurs with other types of EDs to draw more firm conclusions about prevalence estimates outside of AN.

When age was added to the meta-analysis as a potential moderating variable using a meta-regression, age did not significantly influence the prevalence estimate. The average age of the participant samples identified in the review was 19 years, but according to the analysis this didn't account for the heterogeneity seen in the studies. While this suggests there was no consistent relationship between prevalence of autism and age, it was not possible to conclude that the spread of the ages within the studies was sufficient to detect this effect. In future observational studies, attention should be paid to ensuring participants are sampled from across the lifespan to fully capture any possible effect.

The majority of studies identified in the present systematic review sampled female-identifying participants only. Fourteen out of the 24 identified studies investigated ED in only female-identifying participants, with 10 of these investigating autism in female-identifying participants with AN. Where male-identifying participants were included in the sample, they were in the minority of participants. This therefore highlights the significant under-representation of the male experience of autism and ED within the current literature.

Small sample sizes were seen frequently in the studies identified in this systematic review. When using the JBI tool for prevalence studies to assess for bias (Munn et al., 2015), only three studies exceeded the calculated appropriate sample size needed to detect an effect. All of these three studies utilized national patient registers and identified autism diagnosis with ICD codes on their medical files, which as previously discussed may be a flawed method. It may therefore be difficult to generalize the findings to the wider ED patient

population based on these small sample sizes. Focus is therefore needed on larger scale clinical studies.

A variety of language was used throughout the identified studies to describe autism. Many studies referred to autistic participants as those who exceeded a defined clinical threshold of each measure. This medicalized language has the potential to pathologize the experience of autistic individuals (Monk et al., 2022) and as researchers we should be careful to use language which doesn't perpetuate this view of autistic participants. Several studies used language in line with a spectrum view of autism, which may be closer to capturing the diverse experience individuals with ED and co-occurring autism describe (Brede et al., 2020). It's also important to ensure researchers are accurate in using the language which describes what they are aiming to describe. Inoue et al (2021) for example used the terms "ASD" and "autistic traits" interchangeably, however they only employ the AQC which was designed as a measure of autistic *traits*. This language has the potential to further confuse the research field. Language used to describe autism should be carefully thought about to encourage an inclusive, non-pathologizing frame in further research. It's important to recognize that research into estimating the prevalence of autism in ED populations is fundamentally for those individuals with ED and co-occurring autism, therefore the language used should reflect their preferences.

Limitations

The high heterogeneity seen among all the prevalence estimates identified by the meta-analysis highlights significant variability between the studies. It is difficult to draw firm conclusions when the design, samples and diagnostic methods varied widely between the studies. The studies identified also sampled either only female-identifying participants or had a minimal number of male-identifying participants and of these studies, AN was the most frequently investigated. Therefore, it is possible that the prevalence estimate derived from

the present meta-analysis in fact represents the prevalence of autism within female-identifying participants with anorexia.

For the purposes of the analysis, we combined studies utilizing the AQ and AQ-10 into one category. This was to increase the power to detect an effect due to the small numbers of studies using the AQ compared to the AQ-10. Therefore, it is not possible to conclude whether the AQ produces a different prevalence rate in its longer and more detailed format than the AQ-10, but this could be an avenue for further research.

It should also be noted that there may be differences within the scoring algorithm of the ADOS which could influence prevalence estimates that this study wasn't able to detect. Sedgwick et al (2019) found an increase of almost 8% in the proportion of participants with AN who met criteria for autism diagnosis as measured by the ADOS-2. This was the only study which explicitly mentioned which scoring algorithm was used to calculate the ADOS-2, so we were unable to include this information in our meta-analysis calculations.

Clinical Implications

As previously discussed, most of the studies identified in the present review were focused on assessing autism within AN. More research is needed to assess the prevalence of autism in other eating disorder populations to gain a more accurate prevalence estimate across eating disorders. This could be particularly helpful in presentations such as ARFID, which has most recently been included in the DSM-5 (APA, 2013) and shares many similarities with autism such as sensory sensitivity (Harris et al., 2019).

This study adds important findings to the discourse around autism and eating disorders. With a prevalence estimate of over 1 in 5 individuals with eating disorders showing autistic traits or autism symptoms at diagnostic threshold, it would be reasonable for services to offer autism screening as part of routine outcome measures. This would enable every individual to have the chance for possible co-occurring autism to be discovered and

treatment adapted appropriately for their needs. Where possible, a reliable, standardized measure such as the ADOS-2 should be used however this may not always be practically possible due to service demands on resources. The present meta-analysis suggests that the AQ and its variants produce similar estimates of autism in ED populations and may therefore be helpful as a screening measure in the absence of a full ADOS assessment, particularly when combined with other subscales such as the Glasgow Sensory Questionnaire and the Camouflaging Autistic Traits Questionnaire (Adamson et al., 2022). This could also be a useful tool to guide formulation and subsequent treatment adaptions in ED services, particularly for those with AN, with individuals reaching clinical cut off offered a more full MDT assessment and ADOS in line with NICE guidance (NICE, 2012).

References

Adamson, J., Brede, J., Babb, C., Serpell, L., Jones, C. R., Fox, J., & Mandy, W. (2022). Towards identifying a method of screening for autism amongst women with restrictive eating disorders. *European Eating Disorders Review,* 30(5), 592-603. https://doi.org/10.1002/erv.2918

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief “red flags” for autism screening: The short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(202–212), e7. https://doi.org/10.1016/j.jaac.2011.11.00 3

*Anckarsater, H., Hofvander, B., Billstedt, E., Gillberg, I. C., Gillberg, C., Wentz, E., & Rastam, M. (2012). The sociocommunicative deficit subgroup in anorexia nervosa: Autism spectrum disorders and neurocognition in a community-based, longitudinal study [Psychological & Physical Disorders 3200]. *Psychological Medicine*, *42*(9), 1957-1967. https://doi.org/10.1017/S0033291711002881

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

Ashwood, K. L., Gillan, N., Horder, J., Hayward, H., Woodhouse, E., McEwen, F. S., Findon, J., Eklund, H., Spain, D., Wilson, C. E., Cadman, T., Young, S., Stoencheva, V., Murphy, C. M., Robertson, D., Charman, T., Bolton, P., Glaser, K., Asherson, P., Simonoff, E., … Murphy, D. G. (2016). Predicting the diagnosis of autism in adults using the Autism-Spectrum Quotient (AQ) questionnaire. *Psychological medicine,* 46(12), 2595–2604. https://doi.org/10.1017/S0033291716001082

Auyeung, B., Baron-Cohen, S., Wheelwright, S., & Allison, C. (2008). The Autism Spectrum Quotient: Children's Version (AQ-Child). *Journal of autism and developmental disorders, 38(7)*, 1230–1240. https://doi.org/10.1007/s10803-007-0504-z

Babb, C., Brede, J., Jones, C. R. G., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Mandy, W., & Fox, J. R. E. (2021). 'It's not that they don't want to access the support . . . it's the impact of the autism': The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals. *Autism, 25(5),* 1409–1421. https://doi.org/10.1177/1362361321991257

Baraskewich, J., von Ranson, K. M., McCrimmon, A., & McMorris, C. A. (2021). Feeding and eating problems in children and adolescents with autism: A scoping review. *Autism*, *25*(6), 1505-1519. https://doi.org/10.1177/1362361321995631

*Baron-Cohen, S., Jaffa, T., Davies, S., Auyeung, B., Allison, C., & Wheelwright, S. (2013). Do girls with anorexia nervosa have elevated autistic traits? *Molecular Autism*, *4*(1), 24. https://doi.org/10.1186/2040-2392-4-24

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of autism and developmental disorders*, *31*, 5-17. https://doi.org/10.1023/A:1005653411471

*Bentz, M., Jepsen, J. R. M., Pedersen, T., Bulik, C. M., Pedersen, L., Pagsberg, A. K., & Plessen, K. J. (2017). Impairment of social function in young females with recent-onset anorexia nervosa and recovered individuals. *Journal of Adolescent Health*, *60*(1), 23-32. https://doi.org/10.1016/j.jadohealth.2016.08.011

Boltri, M., & Sapuppo, W. (2021). Anorexia nervosa and autism spectrum disorder: A systematic review. *Psychiatry Research,* 306. https://doi.org/10.1016/j.psychres.2021.114271

Booth, T., Murray, A. L., McKenzie, K., Kuenssberg, R., O'Donnell, M., & Burnett, H. (2013). Brief report: An evaluation of the AQ-10 as a brief screening instrument for ASD in adults. *Journal of autism and developmental disorders*, *43*, 2997-3000. https://doi.org/10.1007/s10803-013-1844-5

Brede, J., Babb, C., Jones, C., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Fox, J. & Mandy, W., (2020). “For me, the anorexia is just a symptom, and the cause is the autism”: Investigating restrictive eating disorders in autistic women. *Journal of Autism and Developmental Disorders*, 50(12), 4280-4296. https://doi.org/10.1007/s10803-020-04479-3

*Calderoni, S., Fantozzi, P., Balboni, G., Pagni, V., Franzoni, E., Apicella, F., Narzisi, A., Maestro, S., & Muratori, F. (2015). The impact of internalizing symptoms on autistic traits in adolescents with restrictive anorexia nervosa. *Neuropsychiatric disease and treatment*, *11*. http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc12&NEWS=N&AN=2015-01149-001

Carpita, B., Muti, D., Cremone, I. M., Fagiolini, A., & Dell'Osso, L. (2022). Eating disorders and autism spectrum: links and risks. *CNS Spectrums, 27(3),* 272-280. https://doi.org/10.1017/S1092852920002011

Clarivate (2013). *EndNote 20.* [Referencing Software]. https://endnote.com/

*Courty, A., Maria, A. S., Lalanne, C., Ringuenet, D., Vindreau, C., Chevallier, C., Pouga, L., Pinabel, F., Philippe, A., Adrien, J. L., Barry, C., & Berthoz, S. (2013). Levels of autistic traits in anorexia nervosa: A comparative psychometric study. *BMC Psychiatry*, *13*, 222. https://doi.org/10.1186/1471-244X-13-222

Dell'Osso, L., Cremone, I. M., Chiarantini, I., Arone, A., Casagrande, D., Massimetti, G., Carmassi, C., & Carpita, B. (2022). Investigating Orthorexia Nervosa With the ORTO-R in a Sample of University Students With or Without Subthreshold Autism Spectrum: Focus on Dietary Habits and Gender Differences. *Frontiers in Psychiatry*, 13, 900880. https://doi.org/10.3389/fpsyt.2022.900880

Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., . . . Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research, 5(3),* 160-179. https://doi.org/10.1002/aur.239

*Farag, F., Sims, A., Strudwick, K., Carrasco, J., Waters, A., Ford, V., Hopkins, J., Whitlingum, G., Absoud, M., & Kelly, V. B. (2022). Avoidant/restrictive food intake disorder and autism spectrum disorder: Clinical implications for assessment and management. *Developmental Medicine & Child Neurology*, *64*(2), 176-182. https://doi.org/10.1111/dmcn.14977

Gesi, C., Carmassi, C., Luciano, M., Bossini, L., Ricca, V., Fagiolini, A., Maj, M., & Dell'Osso, L. (2017). Autistic traits in patients with anorexia nervosa, bulimia nervosa or binge eating disorder: A pilot study. *European Psychiatry, 41*, S100-S100. https://doi.org/10.1016/j.eurpsy.2017.01.310

Gillberg, C. (1985). Autism and Anorexia Nervosa: Related Conditions? *Nordic Journal of Psychiatry, 39,* 307-312. http://doi.org/10.3109/08039488509101911

Gillberg IC, Rastam M, Gillberg C (1995). Anorexia nervosa 6 years after onset : part I. Personality disorders. *Comprehensive Psychiatry 36,* 61–69. https://doi.org/10.1016/0010-440X(95)90100-A

Gotham, K., Risi, S., Dawson, G., Tager-Flusberg, H., Joseph, R., Carter, A., ... & Lord, C. (2008). A replication of the Autism Diagnostic Observation Schedule (ADOS) revised algorithms. *Journal of the American Academy of Child & Adolescent Psychiatry*, *47*(6), 642-651. https://doi.org/10.1097/CHI.0b013e31816bffb7

Harbord, R. M., & Higgins, J. P. (2008). Meta-regression in Stata. *The Stata Journal*, *8*(4), 493-519. https://doi.org/10.1177/1536867X0800800403

Harris, A. A., Katzman, D. K., Norris, M. L., & Zucker, N. L. (2019). 1.50 AVOIDANT/RESTRICTIVE FOOD INTAKE DISORDER (ARFID) AND ASD. *Journal of the American Academy of Child and Adolescent Psychiatry*, *58*(10 Supplement), S162-S163. https://doi.org/10.1016/j.jaac.2019.08.072

Hiller, R., & Pellicano, L. (2013). Anorexia and autism: a cautionary note . *Psychologist*, *26*(11), 780. https://thepsychologist.bps.org.uk/volume-26/edition-11/letters

Huke, V., Turk, J., Saeidi, S., Kent, A., & Morgan, J. F. (2013). Autism spectrum disorders in eating disorder populations: A systematic review. *European Eating Disorders Review,* 21(5), 345-351. https://doi.org/https://dx.doi.org/10.1002/erv.2244

*Inoue, T., Otani, R., Iguchi, T., Ishii, R., Uchida, S., Okada, A., Kitayama, S., Koyanagi, K., Suzuki, Y., Suzuki, Y., Sumi, Y., Takamiya, S., Tsurumaru, Y., Nagamitsu, S., Fukai, Y., Fujii, C., Matsuoka, M., Iwanami, J., Wakabayashi, A., & Sakuta, R. (2021). Prevalence of autism spectrum disorder and autistic traits in children with anorexia nervosa and avoidant/restrictive food intake disorder. *BioPsychoSocial Medicine*, *15*. https://doi.org/10.1186/s13030-021-00212-3

*Karjalainen, L., Rastam, M., Paulson-Karlsson, G., & Wentz, E. (2019). Do autism spectrum disorder and anorexia nervosa have some eating disturbances in common? *European Child & Adolescent Psychiatry*, *28*(1), 69-78. https://doi.org/10.1007/s00787-018-1188-y

Kelly, C., Sharma, S., Jieman, A. T., & Ramon, S. (2022). Sense-making narratives of autistic women diagnosed in adulthood: a systematic review of the qualitative research. *Disability & Society*, 1-33. https://doi.org/10.1080/09687599.2022.2076582

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20(4),* 442-462. https://doi.org/10.1177/1362361315588200

*Kerr-Gaffney, J., Hayward, H., Jones, E. J. H., Halls, D., Murphy, D., & Tchanturia, K. (2021). Autism symptoms in anorexia nervosa: a comparative study with females with autism spectrum disorder. *Molecular Autism*, *12*(1), 47. https://doi.org/10.1186/s13229-021-00455-5

Keys, A., Brožek, J., Henschel, A., Mickelsen, O., & Taylor, H. L. (1950). *The biology of human starvation. (2 Vols.).* Univ. of Minnesota Press.

*Koch, S. V., Larsen, J. T., Mouridsen, S. E., Bentz, M., Petersen, L., Bulik, C., Mortensen, P. B., & Plessen, K. J. (2015). Autism spectrum disorder in individuals with anorexia nervosa and in their first- and second-degree relatives: Danish nationwide register-based cohort-study. *The British Journal of Psychiatry*, *206*(5), 401-407. https://doi.org/10.1192/bjp.bp.114.153221

Lai M-C, Lombardo MV, Pasco G, Ruigrok ANV, Wheelwright SJ, Sadek SA, et al. (2011) A Behavioral Comparison of Male and Female Adults with High Functioning Autism Spectrum Conditions. *PLoS ONE 6(6*): e20835. https://doi.org/10.1371/journal.pone.0020835

Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, *2*(11), 1013–1027. https://doi.org/10.1016/S2215-0366(15)00277-1

Li, Z., Halls, D., Byford, S., & Tchanturia, K. (2022). Autistic characteristics in eating disorders: Treatment adaptations and impact on clinical outcomes. *European eating disorders review : the journal of the Eating Disorders Association, 30(5),* 671-690. https://doi.org/10.1002/erv.2875

Lord C, Rutter M, DiLavore P, Risi S, Gotham K, Bishop S. (2012). ADOS-2 Manual (Part 1): Modules 1–4. In: Autism Diagnostic Observation Schedule, 2nd ed. Torrance: CA West Psychol Serv.

Lugo-Marin, J., Magan-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., Diez, E., & Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*, 59, 22-33. https://doi.org/10.1016/j.rasd.2018.12.004

Mandy, W., & Tchanturia, K. (2015). Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. *Molecular Autism*, *6*, 6. https://doi.org/10.1186/2040-2392-6-6

Munn, Z., Moola, S., Lisy, K., Riitano, D., & Tufanaru, C. (2015). Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and cumulative incidence data. *Int J Evid Based Healthc*, *13*(3), 147-153. https://doi.org/10.1097/xeb.0000000000000054

Monk, R., Whitehouse, A. J., & Waddington, H. (2022). The use of language in autism research. Trends in Neurosciences. https://doi.org/10.1016/j.tins.2022.08.009

*Nazar, B. P., Peynenburg, V., Rhind, C., Hibbs, R., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Micali, N., & Treasure, J. (2018). An examination of the clinical outcomes of adolescents and young adults with broad autism spectrum traits and autism spectrum disorder and anorexia nervosa: A multi-centre study. *International Journal of Eating Disorders*, *51*(2), 174-179. https://doi.org/10.1002/eat.22823

National Institute for Health and Care Excellence. (2012). Autism spectrum disorder in adults: diagnosis and management [CG142]. https://www.nice.org.uk/guidance/cg142

Naing L, Winn T & Rusli BN. (2006). Practical issues in calculating the sample size for prevalence studies. *Archives of Orofacial Sciences*.1:9-14. https://www.scribd.com/doc/63105077/How-to-Calculate-Sample-Size

Nickel, K., Maier, S., Endres, D., Joos, A., Maier, V., Tebartz van Elst, L., & Zeeck, A. (2019). Systematic review: Overlap between eating, autism spectrum, and attention-deficit/hyperactivity disorder. *Frontiers in Psychiatry*, *10*. https://doi.org/https://dx.doi.org/10.3389/fpsyt.2019.00708

Nilsson, E. W., Gillberg, C., Gillberg, I. C., & Raastam, M. (1999). Ten-year follow-up of adolescent-onset anorexia nervosa: personality disorders. *Journal of the American*

Academy of Child & Adolescent Psychiatry, *38*(11), 1389-1395. https://doi.org/10.1097/00004583-199911000-00013

*Numata, N., Nakagawa, A., Yoshioka, K., Isomura, K., Matsuzawa, D., Setsu, R., Nakazato, M., & Shimizu, E. (2021). Associations between autism spectrum disorder and eating disorders with and without self-induced vomiting: an empirical study. *Journal of Eating Disorders*, *9*(1), 5. https://doi.org/10.1186/s40337-020-00359-4

*Pooni, J., Ninteman, A., Bryant-Waugh, R., Nicholls, D., & Mandy, W. (2012). Investigating autism spectrum disorder and autistic traits in early onset eating disorder. *International Journal of Eating Disorders*, *45*(4), 583-591. https://doi.org/10.1002/eat.20980

*Postorino, V., Scahill, L., Peppo, L., Fatta, L., Zanna, V., Castiglioni, M., Gillespie, S., Vicari, S., & Mazzone, L. (2017). Investigation of Autism Spectrum Disorder and Autistic Traits in an Adolescent Sample with Anorexia Nervosa. *Journal of Autism & Developmental Disorders*, *47*(4), 1051-1061. https://doi.org/10.1007/s10803-016-3023-y

*Pruccoli, J., Solari, A., Terenzi, L., Malaspina, E., Angotti, M., Pignataro, V., Gualandi, P., Sacrato, L., Cordelli, D. M., Franzoni, E., & Parmeggiani, A. (2021). Autism spectrum disorder and anorexia nervosa: an Italian prospective study. *Italian Journal of Pediatrics*, *47*(1), 59. https://doi.org/10.1186/s13052-021-01006-7

Rastam, M. (1992). ANOREXIA-NERVOSA IN 51 SWEDISH ADOLESCENTS - PREMORBID PROBLEMS AND COMORBIDITY. *Journal of the American Academy of Child and Adolescent Psychiatry*, *31*(5), 819-829. https://doi.org/10.1097/00004583-199209000-00007

*Sedgewick, F., Kerr-Gaffney, J., Leppanen, J., & Tchanturia, K. (2019). Anorexia nervosa, autism, and the ADOS: How appropriate is the new algorithm in identifying cases? *Frontiers in Psychiatry*, *10*. https://doi.org/10.3389/fpsyt.2019.00507

Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P., & Stewart, L. A. (2015). Preferred reporting items for systematic review and meta-

analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ : British Medical Journal*, *349*, g7647. https://doi.org/10.1136/bmj.g7647

Solmi, F., Bentivegna, F., Bould, H., Mandy, W., Kothari, R., Rai, D., ... & Lewis, G. (2021). Trajectories of autistic social traits in childhood and adolescence and disordered eating behaviours at age 14 years: A UK general population cohort study. *Journal of Child Psychology and Psychiatry, 62(1),* 75-85. https://doi.org/10.1111/jcpp.13255

StataCorp. (2021). Stata Statistical Software: Release 17. College Station, TX: StataCorp LLC. https://www.stata-uk.com/software/stata

*Steinhausen, H.-C., Villumsen, M. D., Horder, K., Winkler, L. A.-D., Bilenberg, N., & Stoving, R. K. (2021). Comorbid mental disorders during long-term course in a nationwide cohort of patients with anorexia nervosa. *International Journal of Eating Disorders*, *54*(9), 1608-1618. https://doi.org/10.1002/eat.23570

*Stewart, C. S., McEwen, F. S., Konstantellou, A., Eisler, I., & Simic, M. (2017). Impact of ASD traits on treatment outcomes of eating disorders in girls. *European Eating Disorders Review*, *25*(2), 123-128. https://doi.org/10.1002/erv.2497

Tchanturia, K., Adamson, J., Leppanen, J., & Westwood, H. (2019). Characteristics of autism spectrum disorder in anorexia nervosa: A naturalistic study in an inpatient treatment programme. *Autism*, *23*(1), 123–130. https://doi.org/10.1177/1362361317722431

Tchanturia, K., Larsson, E. & Adamson, J. (2016). How anorexia nervosa patients with high and low autistic traits respond to group Cognitive Remediation Therapy. *BMC Psychiatry, 16*, 334. https://doi.org/10.1186/s12888-016-1044-x

Tchanturia, K., Smith, K., Glennon, D., & Burhouse, A. (2020). Towards an improved understanding of the anorexia nervosa and autism spectrum comorbidity: PEACE pathway implementation. *Frontiers in Psychiatry,* 11, 640. https://doi.org/10.3389/fpsyt.2020.00640

*Tchanturia, K., Smith, E., Weineck, F., Fidanboylu, E., Kern, N., Treasure, J., & Cohen, S. B. (2013). Exploring autistic traits in anorexia: a clinical study. *Molecular Autism*, *4*, Article 44. https://doi.org/10.1186/2040-2392-4-44

*Vagni, D., Moscone, D., Travaglione, S., & Cotugno, A. (2016). Using the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) disentangle the heterogeneity of autistic traits in an italian eating disorder population. *Research in Autism Spectrum Disorders*, *32*, 143-155. https://doi.org/10.1016/j.rasd.2016.10.002

Wakabayashi, A., Baron-Cohen, S., Uchiyama, T., Yoshida, Y., Tojo, Y., Kuroda, M., & Wheelwright, S. (2007). The autism-spectrum quotient (AQ) children's version in Japan: a cross-cultural comparison. *Journal of Autism and Developmental Disorders*, *37*, 491-500. https://doi.org/10.1007/s10803-006-0181-3

*Wentz, E., Lacey, J. H., Waller, G., Rastam, M., Turk, J., & Gillberg, C. (2005). Childhood onset neuropsychiatric disorders in adult eating disorder patients. A pilot study. *European Child & Adolescent Psychiatry*, *14*(8), 431-437. http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med6&NEWS=N&AN=16341499

Westwood, H., Eisler, I., Mandy, W., Leppanen, J., Treasure, J., & Tchanturia, K. (2016). Using the Autism-Spectrum Quotient to measure autistic traits in Anorexia Nervosa: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, *46*(3), 964-977. https://doi.org/https://dx.doi.org/10.1007/s10803-015-2641-0

*Westwood, H., Mandy, W., & Tchanturia, K. (2017). Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Molecular Autism*, *8*, 12. https://doi.org/10.1186/s13229-017-0128-x

*Westwood, H., Mandy, W., Simic, M., & Tchanturia, K. (2018). Assessing ASD in adolescent females with anorexia nervosa using clinical and developmental measures: A preliminary investigation. *Journal of Abnormal Child Psychology*, *46*(1), 183-192. https://doi.org/10.1007/s10802-017-0301-x

*Zhang, R. Y., Birgegard, A., Fundin, B., Landen, M., Thornton, L. M., Bulik, C. M., & Dinkler, L. (2022). Association of autism diagnosis and polygenic scores with eating disorder severity. *European Eating Disorders Review*, *30*(5), 442-458. https://doi.org/10.1002/erv.2941

Part 2: Empirical Paper

“From that moment, everything has changed”: The Experience of Women with Anorexia Nervosa Receiving a Diagnosis of Autism

Abstract

Aims

Autism and eating disorders (ED) frequently co-occur, particularly in autistic women. Individuals are often undiagnosed when they present to mental health services and many receive their autism diagnosis during or after their treatment for ED. This study sought to understand the experiences of autistic women with co-occurring anorexia nervosa receiving an autism diagnosis.

Methods

Secondary data analysis was conducted on 17 semi-structured interviews of women with co-occurring autism and anorexia nervosa (AN) using reflexive thematic analysis (Braun & Clarke, 2021) . Participants were originally recruited using social media, the Autistica research network and contacts of the research team. Their ED status was varied at the time of the interviews but all had experienced a clinical diagnosis of autism, were female-identifying and above the age of 18.

Results

Participants spoke about experiences of searching for a place to fit, both prior to autism diagnosis and after. Many autistic women experienced missed opportunities for autism diagnosis in their life along with misdiagnoses and misunderstandings from healthcare professionals. The participants tended to receive their autism diagnosis at the point of mental health crisis and experienced being passed between autism and ED services. On receiving their diagnosis, participants spoke about a feeling that everything made sense but also of shock and upset. Some participants were left wondering what difference diagnosis would make to them. Participants felt that the autism label enabled them to take control of their lives and now they could forge a new path forward in their lives.

Conclusion

It is concluded that while autism diagnosis is a positive experience for many women, a range of emotions were experienced. Diagnosis is most helpful when appropriate post-diagnosis support for autism is received and subsequent ED treatment is adapted to their needs. Clinical implications and suggestions for further research are also discussed.

Introduction

In part 1 of the thesis, a systematic review and meta-analysis was completed which estimated that overall 22% of individuals with EDs meet criteria for co-occurring autism, across all age groups and ED sub-populations. When looking further at type of ED, it was found that 18% of individuals specifically with anorexia nervosa (AN) met criteria for co-occurring autism and that this estimate was sampled mainly from female-identifying participants. However, despite these findings that an estimated 1 in 5 women with ED are autistic , we don't yet know how they experience the process of autism diagnosis.

Autism, referred to by the Diagnostic Statistics Manual version 5 (DSM-5; APA, 2013) as autism spectrum disorder (ASD), is a life-long, neurodevelopmental condition that affects the way people engage in the world around them. It is categorized by differences in social communication and interaction, patterns of stereotyped behaviour, sensory sensitivities, and restricted interests (APA, 2013). This is considered to exist along a spectrum, with strengths and difficulties varying widely across autistic people (Duvall et al., 2021). Autism is also viewed as a dimensional condition rather than a categorical one, with those meeting diagnostic criteria representing the extreme of traits that exist along a continuum within the general population (Kim et al., 2018). Autism is often conceptualized by clinicians and researchers through a medical model lens, resulting in autism being viewed as abnormal or atypical and deficit-based language therefore used to describe autism. Identity-first and strengths-based language will be used in the present study in line with the view that autism

is an important and integral part of an individual's identity. This language is preferred by the autistic community and autistic researchers alike (Monk et al., 2022). The term "woman" will also be used to refer to individuals who are female-identifying.

Autism is diagnosed based on the presence or absence of a series of observable social and non-social behaviours (Cook et al., 2021) and to obtain a clinical diagnosis based on the DSM-5 criteria, an individual must have specific autistic experiences which cause significant difficulties in everyday functioning, and be present from the early developmental period (APA, 2013). While it is estimated that around 1% of the general population meet diagnostic criteria for autism (Elsabbagh et al., 2012), rates of diagnosis vary according to gender. The male-female ratio of diagnosis is estimated at 4.46:1 in childhood, reducing to 2.57:1 in adulthood (Posserud et al, 2021). This indicates that men are diagnosed more often with autism than women across the lifespan, but it could also possibly highlight that women are diagnosed more often in adulthood. It is important to note here that research into autism with participants whose gender does not match their sex assigned at birth and with those who self-identity as outside of the gender binary is still a limited but growing field (Kung et al., 2023).

Atherton et al (2021) found that late autism diagnosis was associated with reduced quality of life, and that on average women receive a diagnosis of autism several years later than men. While some have argued that these differences in diagnosis rates may indicate a specific female phenotype of autism, where women present with fundamentally different autistic characteristic than autistic men particularly around social communication differences (Green et al., 2019), autistic women only differ from autistic men on a minority on quantifiable outcome measures (Baldwin & Costley, 2016). Bargiela et al (2016) found that some of the challenges of being an autistic female did not directly come from an individual's autistic difficulties, but instead from how their difficulties played out within a culture where specific expectations are placed on females. Therefore, difference in rates of diagnosis may instead be exaggerated by the influence of gender role on autistic characteristics.

One example of this is the use of camouflaging. This refers to the conscious or unconscious use of strategies by autistic individuals to either compensate for social difficulties or to mask autistic behaviours (Hull et al., 2019). Autistic girls have been shown to demonstrate more frequent use of camouflaging behaviours than autistic boys in childhood (Cook et al., 2021). Qualitative studies detail autistic women's experiences of deliberately learning and using neurotypical skills in adulthood, such as carefully observing peers and reading psychology books, but also unconsciously, by mimicking others without realizing they are doing so (Bargiela et al., 2016). While this may enable an autistic woman to "fit in" more within a non-autistic society, the deliberate effort to camouflage can lead to exhaustion and confusion around one's true identity. This can also delay diagnosis as autism traits are then less likely to be identified by their teachers or primary care workers in childhood (Dean et al., 2017; Lai et al., 2017), leading to less onward referral for assessment (Loomes et al., 2017).

Another factor impacting autism discovery in women is co-occurring mental health difficulties. Autistic people of all genders have been shown to experience more anxiety, depression and eating disorder symptoms than the general non-autistic population (Lugo-Martin et al., 2019), with estimates of up to 70% of autistic adults scoring in the clinically significant range on at least one measure of mental health symptomology (Lai et al., 2011). However, when looking at gender differences within this, autistic women were significantly more likely to experience symptoms of anxiety and eating disorders (ED) than autistic men (Sedgewick et al., 2021). Although higher rates of mental health difficulties are also observed in women in the non-autistic population (McManus et al., 2016), in autistic women this can result in diagnostic overshadowing. This is defined as when emphasis is placed on the co-occurring condition as driving an individual's difficulties rather than autism (Lai et al., 2015), and may mean that autistic women reach services for a mental health related reason instead.

While diagnostic overshadowing may result in delayed autism diagnosis, living without discovery of autism can further impact mental health. Barnard et al (2001) found that 32% of parents reported their autistic adult children had experienced mental ill health. This figure rose however to 50% if their diagnosis wasn't discovered until after they were 30 years of age, which is much higher than the estimated 1 in 6 adults in the non-autistic population who meet diagnostic criteria for mental health conditions (McManus et al., 2016). This indicates that living without knowledge of co-occurring autism may have a significant impact on mental health. Some autistic women even report that it wasn't until reaching a point of mental health "breakdown" that their autism was identified (Harmens et al., 2022).

Whilst a diagnosis of autism may be considered by some as a social construct, where an arbitrary boundary is simply placed within a continuum of behaviours (Molloy & Vasil, 2002), receiving a clinical autism diagnosis can be helpful. In a recent systematic review, women who were diagnosed with autism later in life describe finding it a positive experience as it provided them with an explanatory framework for their difficulties and allowed them to re-write their narratives in a new autistic frame (Kelly et al, 2022). Being able to connect with other autistic women was found to be key to this positive integration into sense of self, as well as appropriate tailored support from health and social care professionals, which was possible because of this diagnostic label. Similar themes were found in a blog-based study, where autistic women described their autism diagnosis brought self-understanding and self-acceptance, as well as improving relationships with those around them (Harmens et al., 2022). Diagnosis also allowed for autistic women to seek appropriate support services and to create a supportive, autism-friendly social and physical environment around them (Lai & Baron-Cohen, 2015).

However, autism diagnosis does not always translate to better support for autistic women. Many describe experiences of inadequate provision of support post-diagnosis and being offered an autism diagnosis without any follow-up appointments, which can leave autistic individuals feeling directionless (Crane et al., 2018). In describing their experience

with formal services, autistic women reported a lack of professional knowledge which for many led to misdiagnoses prior to autism discovery. Dell'Osso and Carpita (2023) highlight that diagnostic criteria for autism is developed from the typical male presentations of autism, potentially leading to an under-recognition of autism in women who subsequently receive other kinds of diagnosis instead, such as borderline personality disorder (BPD). This can occur particularly in autistic women without a language or intellectual impairment. This risks incorrect treatment being offered for their struggles, which may leave some in worse mental health (Harmens et al., 2022). Autistic women also report that healthcare professionals are not always able to recognize the specific challenges of autistic women post-diagnosis or were unaware of them, leading them to be less able to provide tailored support (Kelly et al, 2022). Autism characteristics were also assumed by some mental health professionals as being driven by mental health challenges, such as ED, instead of co-occurring autism (Babb et al., 2021).

While mental health conditions and autism often co-occur in women, and late diagnosis can have an impact on the mental health of autistic women, less is known about the specific experience of late diagnosed autistic women who have accessed treatment for a mental health reason first. When looking at eating disorders, autistic people receive their first autism diagnosis on average 6.1 years after their first ED diagnosis (Zhang et al, 2022) and up to 23% of women with anorexia nervosa (AN) meet clinical criterion for autism outside of a formal diagnosis (Westwood et al, 2017). This indicates that women are often undiagnosed with autism at the time of developing an ED and presenting to services. Patients with eating disorders who have co-occurring autism experience longer ED treatment on average and more frequent inpatient stays (Zhang et al., 2022). Autistic women also tend to access a broader range of healthcare services and ED treatments than non-autistic women, and experience their care as significantly less beneficial (Babb et al., 2022). These factors may therefore lead to a more confusing experience of autism diagnosis for women with co-occurring ED.

The interaction between autism and ED is however complex. While some argue the effects of starvation on the brain, particularly in restrictive eating disorders, can mimic or exacerbate autistic traits (Keys et al, 1950; Hiller & Pellicano, 2013), social difficulties have also been shown to persist throughout ED treatment and beyond recovery (Tchanturia et al., 2019; Nazar et al., 2018). Specific autistic experiences and symptoms of ED can also have a reinforcing and maintaining effect on each other and women experience them as being interlinked (Brede et al., 2020). Given this multifaceted relationship, combined with the fact that autistic women are more likely to experience mental health difficulties than autistic men and are more likely to discover their autism later in life, autistic women who have experienced treatment for an eating disorder may experience their autism diagnosis differently to autistic women without co-occurring ED.

Rationale

Gender disparities exist in the rates of autism diagnosis, with autistic women on average experiencing a diagnosis discovery much later in life than autistic men. This is thought to be in part due to co-occurring mental health difficulties, which can create diagnostic overshadowing particularly in autistic women.

While autism diagnosis is generally experienced as positive for autistic women, who find it enables them to understand themselves better, find support systems and receive adapted and tailored support from services, there is little data understanding whether autistic women with a co-occurring eating disorder report similar experiences.

Aims

Through the use of reflexive thematic analysis of interviews with autistic women with co-occurring anorexia nervosa, it is hoped that the present study will provide an understanding of the journey to discovery of autism.

This study also has the potential to highlight how services can better support women with co-occurring eating disorder with the process of autism diagnosis, and enable them to successfully integrate this within their sense of self. Moreover, it is hoped that this study will highlight how we can identify autistic women in ED services earlier and more accurately, and provide insight on how best to navigate the journey to autism discovery specifically in ED services.

Method

Study Design

The present study is a secondary data analysis of qualitative data previously collected for Brede et al (2020) and Babb et al (2021). Data was generated from semi-structured interviews with individual participants and all data was anonymized and given pseudonyms by the original research team. The researcher did not have access to the participant's personal data and each transcript had any personal identifying information removed prior to the present researcher accessing it.

Ethical Approval

Ethical approval was obtained from University College London (UCL) for the original data collection (12973/001; see appendix 3). In line with the ethics application, appropriate approval was sought from the original research team to access the secondary data.

Participants

For secondary analysis, data obtained should be adequate, relevant and not excessive (Tripathy, 2013). While the existing data set interviewed autistic women, parents of autistic women and healthcare professionals working in ED services, it was decided that to answer the present research question interview data from autistic women would be most appropriate.

Participants were originally recruited from across the United Kingdom using social media, the Autistica research network (Autistica, 2019) and through existing contacts of the research team. The inclusion criteria were: 1) above the age of 18; 2) self-reported clinical diagnosis of autism; 3) current or past experience of AN; 4) female-identifying; and 5) living in the UK. In the original studies, the Autism Spectrum Quotient 10 (AQ-10) (Allison et al., 2012) was used to confirm autism status and two participants who did not score above the clinical threshold were excluded. For the purposes of the present study, these two participants were included as (i) it is not certain that the AQ-10 is more accurate than the clinical autism assessment that lead to their autism diagnosis (e.g., Westwood et al., 2016) and (ii) they had lived experience of receiving an autism diagnosis. One participant withdrew from the study prior to interview, resulting in a total of 17 autistic women as the present dataset. Demographics are presented below in table 4.

Participants' ED status was varied at the time of the interview with some reporting they were still living with ED while others considered themselves recovered. All autistic women had been in contact with ED and other mental health services prior to receiving their autism diagnosis, often for several years before. Most notably, on average the women were diagnosed with autism 11.5 years after their diagnosis of AN. At the time of the interviews, 11 autistic women were in full-time employment, held part-time jobs or voluntary posts while one was retired. Four autistic women were currently studying at university level, while one had interrupted their studies due to the impact of the ED on their life.

Table 4

The demographic information of the participants included in the reflexive thematic analysis.

Demographics	Mean (SD)	Range
Age (years)	32.6 (10.3)	23 - 58
Age at AN diagnosis (years)	17.9 (6.0)	11 - 34
Age at autism diagnosis (years)	29.4 (11.3)	14 - 56
Current BMI (n = 7)	18.5 (3.1)	15.3 – 23.1

Materials

For the original data collection, semi-structured interview schedules were developed by the research team, and two autistic women with experience of AN advised on its construction. The questions were guided by the research topic of autistic women's experience of AN. The interview was divided into three parts with questions relating to the experience of autism and autism diagnosis, the experience of ED and factors that may underlie the development of ED, and their experience of ED services. The last two parts of the interview schedule were analyzed to answer different research questions (Brede et al., 2020; Babb et al., 2021). The present study focused solely on questions in the interviews relating to the experience of autism and autism diagnosis (see appendix 4).

The interview schedule was designed to be able to be adapted to different communication needs and to be used in a flexible manner, for example, some participants opted to be sent the interview schedule ahead of time. Interviews were conducted either in person, via video call or on the phone, depending on the participant's location, availability and preference. Interviews lasted between 43 minutes and 2 hours and were recorded and transcribed verbatim, with identifiable characteristics being removed. Only the transcripts were available for the current study.

Data Analysis

Reflexive thematic analysis (TA) was used to identify and analyze patterns of meaning across the data (Braun & Clark, 2021). This approach allowed for flexibility in engaging with the data which fit the aim of capturing autistic women's experiences as there was no one particular theory guiding how we engaged with the data. While TA has been widely used in qualitative research, the addition of reflexivity helps to reduce researcher bias and subjectivity by critically reflecting on the researcher's own position in relation to the data, which may influence how we engage with the data (Braun & Clarke, 2021). In accordance with this approach, a reflexive research journal was kept throughout the process of analysis. Data were interpreted within a critical realist (CR) framework. CR argues that the world is theory-laden, but not theory-determined and retroductive analysis is possible within a given dataset to answer specific research questions (Fletcher, 2017). Analysis therefore aimed to capture the three levels in CR of empirical, actual and real mechanisms as told by the participants from their lens of reality.

The following steps were completed in conducting the data analysis.

1. Transferring the data

All transcripts from the original interviews were anonymized prior to the author accessing them and any personal identifying information had been removed. Transcripts were password protected before being transferred to the author using UCL's secure email server. The password was sent to the author separately.

2. Inputting of data into NVivo

All transcripts were imported into the software package NVivo (released in March 2020) for ease of data management and coding.

3. Familiarization with the data

The author read all interview transcripts twice to immerse herself in the dataset. As per the ethics application, audio files had been deleted immediately after the previous research was completed, so only the transcripts were used for familiarization.

4. Coding

The author worked systematically through the transcripts line-by-line, reading each data item closely and tagging sections of the text using the “highlight code” function in NVivo where meaning was noticed which related to the participants experience of autism diagnosis. An inductive orientation was taken to the dataset. While it can be difficult to maintain a purely inductive orientation because who we are shapes what we notice about the data and the stories we tell about them (Braun & Clarke, 2021), the use of reflective research journal throughout the coding aimed to support a continued inductive stance of engagement with the data. Coding was both latent and semantic in nature and for the purposes of the analysis they were viewed as two ends of the spectrum sitting along a continuum (Braun & Clarke, 2021) as both were considered important to the research question. This is also in-line with the CR framework.

5. Code checking

Having one person coding the data is viewed as good practice for reflexive TA (Braun & Clarke, 2021) as different coders will make sense of the data differently. Once the author had coded the data, she went through two different transcripts with their supervisor to ensure a balance was struck between being detailed without being overly fine-grained.

6. Combined codes into themes

Codes which were potentially connected and captured larger patterns of meaning were combined into candidate themes (Braun & Clarke, 2021) which had a central organizing concept. Candidate themes were reviewed several times against codes both within each interview and across the dataset. The author then met with her supervisor to discuss how the codes and candidate themes generated might be understood and collated

into broader themes. Interpretation was discussed explicitly to maintain awareness of our positions in relation to the data to ensure reflexivity throughout. These discussions occurred on several occasions to ensure a fresh perspective on the candidate themes each time until an initial thematic structure was reached.

7. Revising and refining themes

The author met with the research team to discuss using a reflexive stance whether the proposed thematic structure provided a sufficiently rich, meaningful and accurate depiction of the data both within and across transcripts. There were a few cases where themes appeared inconsistent with the data or lacked sufficient depth, and so a partial re-organization of the themes took place before a final thematic structure was reached. The final themes and sub-themes are detailed in table 2. The candidate themes which make up each sub-theme and broader theme are detailed in appendix 5.

Positionality Statement

For all researchers, the experiences we have in life impact the positionality we bring to our work which will inform the questions we chose to ask, the data we gather and the interpretations we make (Foote & Bartell, 2011). Acknowledging positionality is integral to qualitative research to enable a continued reflexive stance and should be used especially with novice researchers (Holmes, 2020). Therefore, below details the positionality of the author and acknowledgement of her potential biases.

The author's interest in autism developed in her early 20s when she worked supporting young autistic children. She saw how autistic individuals flourished with the right understanding, support and adjustments in the environment around them. Through clinical psychology training, she gained experience of a clinicians view of autism diagnosis during her 6-month placement in an autism assessment service. During this time, she was trained to administer the ADOS-2 and saw first-hand the varying impact receiving an autism

diagnosis can have on individuals and their families. This left her keen to learn more about how this could be facilitated in as helpful way as possible. This placement also highlighted to her the number of autistic individuals who presented with co-occurring mental health difficulties, and she noticed the dilemmas this brought up in the team and how this was often viewed as added “complexity”. Throughout the data analysis stage of the present study, the author was working clinically with children with eating disorders, many of whom had co-occurring autism or were undergoing assessments to confirm this. This enabled her to experience the practicalities of how autism assessments were undertaken with those with co-occurring ED. Together these experiences developed a strong desire to support autistic individuals and their families through this often complicated process of diagnosis discovery. However, this may also mean that she could come to the dataset with an assumption of what it means to be autistic with co-occurring mental health difficulties, biasing how she engages with the data. She will need to be mindful of this throughout analysis to ensure she is looking closely at the data collected and not assuming experiences seen in her clinical work.

The author identifies as non-autistic and is aware that this may influence how she engages with the data from autistic participants. Social communication differences are one of the key features of autism, therefore the author may risk missing some of the underlying meaning behind the women’s words. The process of continued reflexivity will therefore be key throughout to reduce any bias. Being female-identifying may also influence how the author engages with the data collected from women compared to if she identified as a different gender. The author believes this provides a strength to data analysis by understanding some of what it means to be a woman in society and is aware of how the participants may engage with the world around them because of this, but it also cautious of not generalizing her own experience to others.

Results

Themes

Analysis of 17 semi-structured interviews led to the generation of nine sub-themes which were grouped into three broader themes. These are presented in table 6. The candidate codes which were combined into each sub-theme are presented in appendix 5. The demographics of the sample included in the analysis are stated below in table 5.

Table 5

The demographic information of the participants included in the reflexive thematic analysis.

Demographics	**Mean (SD)**	**Range**
Age (years)	32.6 (10.3)	23 - 58
Age at AN diagnosis (years)	17.9 (6.0)	11 - 34
Age at autism diagnosis (years)	29.4 (11.3)	14 - 56
Current BMI (n = 7)	18.5 (3.1)	15.3 – 23.1

In the following description, themes are explained and illustrated with quotes from the interviews. Participants are identified by anonymized codes and for ease of reading, repeated words and non-words have been deleted along with the addition of an ellipsis to remove extra segments. Any connecting words added by the author to aid understanding are highlighted using square brackets.

Table 6

The themes and sub-themes identified through reflexive thematic analysis.

Themes	Sub-Themes
1. The Search for Understanding and Support	1.1 Searching for a Place to Fit 1.2 Mis(sed) Diagnosis and Misunderstanding 1.3 Journey to Crisis Point 1.4 Passed from Service-to-Service Post Diagnosis
2. A Shifting Moment	2.1 Everything Makes Sense 2.2 Shock and Upset 2.3 What Differences Does Diagnosis Make?
3. Taking Control	3.1 A Communication Tool 3.2 Forging my own Path Post-Diagnosis

Theme 1: The Search for Understanding and Support

This theme describes the participant's experience of searching for understanding of themselves and support for their struggles. This was described both prior to and after autism diagnosis, and from those around them as well as formalized services. This included searching for a place to fit; experiences of missed diagnosis, misdiagnosis and misunderstandings; a journey to crisis point; and experiences of being passed from service to service post-diagnosis.

1.1 Searching for a Place to Fit

The participants spoke about their experiences of feeling different throughout their lives. They described being acutely aware of the reactions others had to them and feeling othered by society. This left many thinking that they could never truly fit in anywhere despite wanting to, which brought feelings of loneliness.

AW12: I've always felt different and like I didn't fit in… you're just kind of limited by society's norms to do this and this, and this is the way to do it, when that doesn't work for everyone.

AW11: I've always felt like I'm on the outside looking in, so not knowing… it's like that description of being in a room of people but feeling so alone, it's like I don't know how to be in a social situation easily, I just find it too much.

Receiving the diagnosis of autism therefore felt for some like they finally had a place to fit and could find a community where they belonged. This enabled them to subsequently be themselves without the burden of societal norms.

AW08: …it also made me feel less alone because then I realised that there are other people who also have both [ED and autism], and other people have similar experiences.

AW17: Finally I could be me, and could find people I fitted in with. And I now have all these fantastic autistic friends. I fit in with them. It's amazing.

This led some to express that it's essential for autism to be diagnosed to enable people to find their place in the world.

AW16: I think a big part of [my struggles] is the autism and not being diagnosed and not really understanding why and trying to fit in…

After receiving their autism diagnosis, some participants began to recognize autistic traits in their family, as if noticing they fit in somewhere after all.

AW13: And my father, my late father, my mum says, "oh he was definitely autistic", and I can see it. She's the only neurotypical one in the family. He definitely definitely was autistic, he couldn't cope with social situations at all.

However, for others, receiving an autism diagnosis didn't open up places and opportunities to fit in. They described not feeling supported by their friends and family post diagnosis, and the search for a place to fit and to be understood continued.

AW11: I don't think people reacted in a good way particularly… I think people misbelieve me, they see me as so functional and they see how much I'm able to achieve, but they don't see how much pedaling is going on beneath the surface…

1.2 Mis(sed) Diagnosis and Misunderstanding

The majority of participants discussed experiences of autism being suspected at previous points in their life, particularly in childhood when they faced struggles at school. Despite these opportunities for earlier autism discovery, this was never followed through by services meaning their autism wasn't formally diagnosed until much later in adulthood. This was also usually after they began presenting to services for their struggles with eating disorder.

AW15: I was diagnosed when I was 56, but I was told I had it a lot earlier. Various people who helped me in education and that suspected, mostly teachers I think suspected it was autism…

AW05: I think at that stage my mum wondered about autism, well Asperger's syndrome or autism, just because something a friend of a friend had mentioned. And she asked the psychiatrist I was seeing at the time do you think [name] has autism, and she said no she's got a sense of humour… like "she can't be".

Experiences of misdiagnosis were also common prior to autism discovery. Many were given incorrect diagnostic labels such as borderline personality disorder, and some reported experiences of receiving not just one diagnostic label but several.

AW16: …they previously diagnosed me with borderline personality disorder but I didn't relate to it at all…

AW13: I mean I did get a diagnosis aged 16 of OCD and depression and then the diagnoses just kept coming. Social anxiety blah blah blah. So, I seemed to collect a whole set of mental health diagnoses…

This highlights the misunderstandings services have of the autistic experience in individuals with co-occurring mental health difficulties, which is possible exacerbated by a lack of understanding about the female autistic experience.

AW10: …what confused me at the time was at the assessment they were talking a lot about how autism presents differently in females and males. And they didn't seem a very clear definition of the boundaries of the diagnostic criteria they applied to females.

The experiences of misdiagnoses, being misunderstood by services and the resulting diagnosis coming later in life led some participants to look back over their lives and think about what an earlier diagnosis could have given them. For some, this was with a lens of compassion for their past selves and the struggles they faced moving through life without a formal diagnosis, but for others this brought frustration and sadness about how much difference an earlier diagnosis could have made to their lives.

AW08: I don't know if its right to look back but sometimes I look back and reframe my life and think, if only I'd known different, I could have possibly managed this with some adaptions, I could have possibly done that, I possibly wouldn't have been so hard on myself on achieving things or just struggling to achieve things.

1.3 Journey to Crisis Point

Not only did the majority of participants tend to receive their diagnosis of autism later in life despite experiencing challenges since childhood, but the diagnosis tended to came at the point of breakdown and burnout in their lives. It seemed as though it was only at this point when other treatment options for their eating disorder had been exhausted did mental health teams then consider whether something else was at play, such as underlying autism.

AW03: I think I had years of struggling with my mental health and anorexia and I reached a point where I was just, I was completely burned out, and I had, I suppose a breakdown. After that point I had to stop work. …They spend about half a day with me and at the end of the assessment they suggested I had ASD.

AW05: I had this kind of burnout, depression, period where I just.… I think this was about the time when I also got referred to a psychiatrist by the university mental health worker, I think they both started to mention to me, we think you might be on the autistic spectrum.

This meant that many participants were left searching for an understanding of why they were struggling so much with their eating disorder, why they were struggling to cope with life, and why they weren't starting to feel better despite all the treatment they were being offered.

AW15:…what's wrong with me because I'm just going mad. I can't fit in, I can't get on with people, I can't hold down a job, so if it's not what everybody's saying it is [eating disorder] or what it could be, what on earth is it? I was starting to think I had a brain tumour and all sorts of things because I couldn't cope.

The diagnostic process was diverse across the participant's accounts. This perhaps reflects the crisis point that many of the participants were at when autism was suggested, resulting in a varied process depending on whether they were currently receiving inpatient ED treatment or were able to be seen as an outpatient.

AW18: I think I was either 16 or 17. But I was in hospital at the time with an eating disorder.

AW16: it was quite quick for me after that, it was probably like 3 or 4 months, because I was already in the system I guess for years. So I was quite quick to get diagnosed.

AW08: I had to wait because they had a long backlog I assume umm I had to wait until may, I had a letter to say I was on the waiting list, and had to wait for the umm, 9 months for the assessment.

1.4 Passed from Service-to-Service Post Diagnosis

Even when the diagnosis was made, participants described a continued search for understanding and support from eating disorder and autism services. Participants spoke about being offered either treatment with an eating disorder service *or* support from an autism service, but rarely both. They often experienced being passed around from service to service, with some even being refused treatment.

AW03: since coming out of [specialist ED] hospital, I have been passed from different service to different service, who have all said "no we can't help".

AW05: I think there wasn't a kind of, the services don't seem to meet…. So you have an Asperger's service, an autism service, around if you're lucky, an eating disorders service around, if you're lucky. But… There doesn't seem to be a kind of merging of them.

This left participants with a feeling of not being listened to and a continued experience of not fitting in, which had been so often repeated throughout their lives.

AW11: I go to the autism service, and even going there I find really difficult. I feel like I don't even fit in with – I can notice that we have similarities but at the same time I still don't know how to connect with people very well.

The participants also described a significant lack of available support to them after diagnosis. Services tended to offer an autism diagnosis without any ongoing support , meaning many didn't have the space to process the diagnosis or understand how they could

integrate this into their lives. This tended to vary across the country, with some living in rural areas describing no specialist service available at all.

AW12: Umm not so much, because when I went to see the [autism service] they were like well we don't see people, we just diagnose them.

AW08: They had no capability or capacity to offer any more services because I think there were only the two people who were assigned to the [autism] service, so there's no… they just signposted me to, like, national autistic society, but there's no ongoing support they can offer, whereas I am aware that in other areas its remarkably different.

Participants did describe some helpful support post-autism diagnosis, particularly when both the eating disorder and autism and the links between the two were thought about. However, this was rarely offered to them by services.

AW03: Then I found out about a charity that provide autism specialist counselling. I contacted them, and I had that…and that has been incredible. Because I feel, we work on the autism, but we also work on the eating disorder as well, so it is like a more holistic, I suppose, and that has been really effective.

AW05: I was thinking I need to see someone who knows about both problems really, in order for the eating disorder, taking in also the autism/Asperger elements of me as well.

Theme 2: A Shifting Moment

This theme captures how receiving an autism diagnosis affected the participants. This relates to both the emotional impact immediately at the point of diagnosis and afterwards, and how this became a shifting moment in the participant's narrative. Notably, most felt that everything suddenly made sense both with their current struggles and when looking back over their lives. For some, the autism diagnosis brought shock and upset, however for others they felt indifferent and ambivalent to the diagnosis.

2.1 Everything Made Sense

Participants spoke about always having a felt sense that something else was going on within them. They described feeling that a diagnosis of eating disorder didn't fully explain their difficulties both at present or across their life.

AW03: There were a lot of differences that weren't explained by the anorexia. And we would try constantly "there is something else, there is something else". And after all these years, I finally found what this something else was.

The overarching reaction was therefore that receiving a formal diagnosis of autism made sense. It was as though this became like a light-bulb moment, suddenly shedding light on why they had struggled in life previously.

AW01: …because suddenly everything was like, you know, it made sense.

AW03: …from that moment everything has changed.

This brought a feeling of overwhelming relief which was described by the majority of participants.

AW08: At first I felt overwhelming relief….mum asked me when we left, I remember her asking how did you feel about it? And I turned and I said to her relieved.

AW16: Yeah, it was a relief, it felt positive. I didn't feel negative about it at all, I was really happy.

For many of the participants, autism diagnosis provided a reason and an answer to why they had problems and struggles across their life. It gave an explanatory framework for their mental health struggles and in particular they could make links between autism and their eating disorder, beginning to hypothesize about why and how this may have occurred. This was something that didn't feel possible prior to diagnosis.

AW17:…knowing about autism, knowing about mental health in autism, I now understand that all these things came on the foundation of the autism.

AW08: I think the anorexia is, for me, perpetuates my life perhaps. The differences I experienced in life which I think in hindsight are related to my undiagnosed autism.

Being able to give a name to their struggles subsequently became a shift in their narrative for some participants, enabling a better understanding of themselves. This brought a feeling of self-acceptance.

AW02: And it can be, kind of reassuring at times, that you have an answer for like why, why you struggle with some things…

AW12: I've always felt different and like I didn't fit in and it was kind of like oh actually that's because I am different and I don't particularly fit in and that's okay. And then I could kind of see ways of working with it as a strength rather than letting it hold me back.

2.2 Shock and Upset

For some participants, feelings of shock and upset was described when receiving their autism diagnosis. This was often in the weeks following diagnosis and in addition to the feelings of relief and self-acceptance described above, which left many feeling confused and questioning who they were now.

AW08: But then, in the proceeding… it's only been a few weeks [since diagnosis], but sometimes I felt very upset…

The shock and upset may have been for some due to a realization that autism is a different type of diagnosis to that of an eating disorder, both in terms of duration and type of support.

AW05: I think also a little bit of sadness about kind of, I thought always one day my mental health would improve and I'd be able to do more, and actually I thought okay maybe not. Maybe this is, I actually have to accept these limitations and not kind of do what I want to do.

AW01: [Autism is] not something you get rid of, while an eating disorder, people gave me the impression that if I recover from an eating disorder, my life would be, you know, the difficulties would all go away.

This mixture of feelings left some participants with a worry of how they would tell their friends and family about their autism diagnosis, or if they would at all.

AW13: I spoke to my mum about it and I thought how do I say to her [psychiatrist] thinks I'm autistic?

For some participants, the shock and upset felt after receiving the autism diagnosis was in part due to their families reactions to the autism diagnosis. Participants described their families finding understanding their diagnosis really difficult and they noticed it brought up feelings of guilt within their parents.

AW15: …so to start with it was really difficult because [Mum] didn't understand. So she still carried on being angry with me and everything…

AW01: I think my parents were quite, especially my mom, a bit guilty….just because, maybe because, she didn't push even more to investigate I guess. Especially when I was younger…

Subsequently this left some participants needing a period of time after their diagnosis to process the information they'd been given about themselves. Participants described a range of reactions during this time from not having considered autism applied to them to an outright rejection of the diagnosis.

AW11: Weirdly, I'd considered it for my daughter… But no, I'd never considered it for myself.

AW10: You know, I don't feel I can objectively say whether or not I am autistic, I really don't, because I've never really understood what it should look like.

2.3 What Difference Does Diagnosis Make?

While the feeling that autism made sense described above was widespread, it was not universal for all participants. For a small group, receiving the diagnosis instead brought indifference and ambivalence, wondering how this would make a difference when the autistic characteristics have always been part of them.

AW18: I think they've just always been there. I didn't know it was autism until I got diagnosed, I just thought it was how I was.

This ambivalence and absence of a shifting moment was reflected as being unsure how autism affects them, or not being supported to develop a full understanding of what autism is and how it might apply to them.

AW02: When people say to me, if I say to someone that I have Asperger's, then they're like oh how does that affect you, I'm like, I don't really know. I really don't.

AW10: I didn't really feel it was me, but then again I didn't really feel I had enough information to make an informed judgement… I'm still quite ambivalent, yes.

Some questioned how helpful it was receiving an autism diagnosis and what difference being diagnosed would actually make to their lives, as their difficulties didn't automatically improve post-diagnosis as they had perhaps hoped.

AW10: Well it makes you wonder what is the value of receiving the diagnosis? And as I say you know, what I've read about it says how there's so much heterogeneity in how it presents… I've never really found any clear guidelines on the boundaries of how it might represent, and what it is and what isn't.

This may also reflect the experience of receiving a diagnosis later in life, as many participants had had to find a way to function throughout their life pre-diagnosis anyway.

AW08: But I think for me and possibly for others it is a slightly different ball game, when it's been undiagnosed for decades and I've had to function, which I have. And I'm now in my early 40's umm and I think it's slightly different... I have to function for myself, I have to manage in society, I have to function, I have to work…

Theme 3: Taking Control

This theme details the experiences participants had of being able to take control after receiving a diagnosis of autism. They discussed being able to use the diagnosis as a communication tool and felt able to then forge their own path in their life post-diagnosis using this new information about themselves.

3.1 A Communication Tool

Many of the participants described that receiving the diagnostic label of autism in itself was helpful. As social communication differences are a fundamental part of autism, this label seemed to give them a tool they could use to easily explain their difficulties. They were then able to help others understand them, without their differences being misinterpreted.

AW06: If someone says something like "labels are for packages, not for people" or something, I'm like well actually it's quite useful to know what's in a package, I would want to know if I'm opening a tin of baked beans or a tin of fruit.

AW13: I know that I find some things difficult and my difficulties in doing these things can be misconstrued as me being unfriendly or difficult or whatever, so I'm just trying to really explain how autism affects me [to others].

For some, having the diagnostic label of autism became a method for advocating for their needs. Participants could explain to others why certain adjustments were needed, which subsequently enabled them to cope better.

AW14: But actually I think a lot of it, of why I'm coping better now than I was a few years ago, is having the autism diagnosis and being able to say this is why I need it to be like this and if I can keep it like this I do better.

The autism label gave them a way to express their emotional struggles beyond using their behaviour and for some this enabled them to feel friends and family could understand them better.

AW03: With this information I was then able to explore all the difficulties. I had the words to communicate, whereas before my way of communication was very much by not eating.

AW15: [Mum has] come to understand what it's like for me. And it's helped a great deal in that respect in that she understands. And all my friends and people like that sort of accept and know and help me now.

Some participants described receiving an autism diagnosis enabled the eating disorder service they were under to better understand their needs. Good examples of joined up care were described following diagnosis, where autism services were able to help plan their eating disorder treatment for example. Positive experiences of therapy post-diagnosis were also described, often because this new knowledge enabled therapists to adapt treatment to their needs and consider autism within their formulation.

AW11: that was kind of a bit of a turning point in that [therapist] understood like how best to communicate with me so she gave me written summaries after my appointments, she gave me written information, we used kind of goal setting to help plan my care.

3.2 Forging My Own Path Post-Diagnosis

The majority of the participants described how an autism diagnosis enabled them to make adaptions to their work lives and in their treatment for eating disorder, which often wasn't possible prior to diagnosis.

AW11: My work have been completely aware the whole way through and they're looking at adjustments, so I went to occupational health yesterday to try and sort some of that out.

AW03: So [the inpatient unit] created a different space that was separate, because I think they realised for my stay there, it wasn't appropriate for me to go through the whole treatment programme.

Participants also described taking control of their lives by making their own adaptions to how they lived, creating a life which was welcoming and accommodating of their autism.

AW13: There are times where I wish I wasn't autistic because life would've been a lot easier. But now that I know that I am, it's a reason and I know how to make my life more autistic-friendly.

AW06: So like generally I'll have headphones and sunglasses with me, and it'll be like the middle of winter and I'll still have sunglasses with me.

Many participants described viewing their autism as a strength post-diagnosis and could see what it added to their lives instead of what it took away. This brought self-compassion and confidence, which wasn't possible prior to diagnosis.

AW05: I felt I could start to forgive myself a bit, for not being what I wanted to be. Like not trying to kind of force myself to do things, not force myself to put up with noise if it's stressful for me.

AW13: …part of me felt well actually I can be a bit more compassionate to myself because it's not my fault that I find certain things difficult…because I was born this way, so it was

almost as if it was a reason, not an excuse, but a reason for why I found things difficult because I was very self-critical of why I found certain things really difficult [before diagnosis].

Some of the participants discussed that having a diagnostic label meant they could do their own research into autism and find support groups, which subsequently helped them learn how to manage better. While this may reflect the fact they weren't given very much information about autism when they were diagnosed and there was little formalized support available from services, taking control of their learning about autism also meant they could find their own way to understanding themselves.

AW05: I was doing other reading, maybe going on autism websites or like blogs, of people describing things, and thinking yeah this is me.

AW15: I've been able to join some online support groups so it means I can help other people and other people can help me.

Receiving an autism diagnosis therefore meant for some that they could finally move forward with their lives, armed with this new knowledge about themselves.

AW02: I kind of had a new lease of life after that, when I was able to move forward and start seeking somewhere else to live.

AW03: It wasn't closure, it was almost like that was the start for the next chapter of my life.

Discussion

Using reflexive thematic analysis of a secondary qualitative dataset, the present study aimed to understand the journey to autism diagnosis experienced by women with co-occurring AN. Whilst previous literature has explored how autistic women experience autism discovery, and the impact this can have on their mental health, little research has focused on understanding the diagnosis journey of autistic women with co-occurring eating disorders . To shed light on this gap in the literature, the present study focused on autistic women with AN. The autistic women interviewed discussed a continued search for understanding and

support, both prior to and after receiving their autism diagnosis. They reported missed opportunities for diagnosis earlier in their lives and many mis-diagnoses along the way to autism discovery. Autism diagnosis generally occurred at the point of crisis in their lives and resulted in being passed between ED and autism services post-diagnosis, creating a feeling of being refused help and support. The autistic women in this study experienced receiving their diagnosis as a shifting moment in their life, with some feeling that autism made sense and helped explain their continued struggles, while others described feeling shocked and upset upon receiving the diagnosis. For some, there was the absence of a shifting moment and they were instead left questioning how this new information would make a difference to them. Taking control was also a key theme in the present study with autistic women describing how the diagnosis itself became a communication tool to explain their needs and make adaptions, allowing them to forge their own path in life post-diagnosis and move towards the life they wanted to live.

Our findings corroborate previous quantitative studies that autistic women are diagnosed later in life (Atherton et al., 2021) and that individuals with eating disorders receive an autism diagnosis often many years after their ED diagnosis (Zhang et al., 2022). In addition, this study highlights that not only did diagnosis occur in adulthood, but it also tended to occur at the point of mental health crisis in their lives. It was only after long, unsuccessful treatment for ED when all other avenues had been tried did professionals consider something else may be underlying their struggles. This is something that doesn't appear to be unique among autistic women with co-occurring AN. Harmens et al (2022) found that breaking point also led to identification of autism for autistic women with other co-occurring mental health diagnoses, such as depression and PTSD. This may highlight the role of diagnostic overshadowing in the autism diagnosis journey (Lai et al., 2015) and relate to the experience of professionals assuming that specific autism characteristics are the result of mental health struggles (Babb et al., 2021). It is therefore important that services

consider a neurodevelopmental picture *alongside* mental health diagnoses from the first presentation to services to reduce the likelihood of autistic women reaching breaking point.

In the present study, autistic women generally described how helpful having a diagnostic label of autism was for them. It enabled them to communicate their needs to friends, family and formalized support services, allowing them to advocate for their needs which in turn boosted their wellbeing. This finding replicated previously identified patterns in the qualitative literature, where autistic adults report having an official diagnostic label helps them communicate their needs and experiences to others (Huang et al., 2022). This is crucial given that autism is defined as a pattern of social communication differences (APA, 2013), and having information they can easily use to communicate with others empowered the autistic women. Moreover, not only did they feel this label could be readily accepted by other people and allow adaptions to be made, but it also made sense to them and appeared to provide an explanation for feeling othered by society. This was similar to previous literature focusing on autistic women without co-occurring mental health diagnoses (Kelly et al., 2022; Crane et al., 2018; Harmens et al., 2022) but importantly appeared to still be the case for autistic women with co-occurring AN symptomatology. In addition to these findings, autistic women in the present study also reported feeling they didn't fit in with an eating disorder diagnosis and had a felt sense that something else was behind their struggles. They also felt different to other patients with AN they met during inpatient treatment, which perpetuated the experience of being othered. Being able to connect to a community can reduce the feelings of being an outsider (Harmens et al., 2022) and finding a community where they could fit in also appeared important to the autistic women interviewed. Many women took the initiative to find this themselves through online communities, reading books and research, which was only possible once receiving the diagnostic label.

When it comes to receiving formal support, autistic women report that healthcare professionals are not always able to recognize the specific challenges of autistic women or were unaware of them, leading them to be less able to provide tailored support (Kelly et al,

2022). This was replicated in the present study, where autistic women with AN also reported experiencing a lack of understanding of their needs, despite already being open to services at the time of autism diagnosis. They discussed experiences of professionals lacking understanding of the specific presentation of autism in women and the interaction between autism and ED. This resulted in them being passed from service to service, leaving some without any appropriate support. The Pathway for EDs and Autism developed from Clinical Experience (PEACE pathway) provides treatment resources and advice for clinicians and explains what tailored, autism-adapted ED support should look like. For example, it is important to address possible sensory sensitivities, reduce use of open-ended questions and metaphors, and offer individual instead of group therapy (Tchanturia et al., 2020).

Kelly et al (2022) describe how important appropriate support is to enable integration of autism into sense of self in a positive, strengths-based way. This could include use of the affirmative model suggested by Swain and French (2000) which aims to embrace positive social identities and diverse ways of being in society. It challenges the dominant societal narrative about the "tragedy" of disability and instead encourages development of a positive individual and collective identity. National Institute for Health and Care Excellence (NICE) guidance also sets out that adults who receive a diagnosis of autism should be offered a follow up appointment to discuss implications of the diagnosis and future care and support they may require, as well as psychosocial interventions and interventions for co-existing mental health difficulties where needed (NICE, 2012). However, how often this happens within services is uncertain. Autistic women in this study reported shock and upset as well as indifference and ambivalence to the diagnosis. This was most often the case for the autistic women who also reported feeling unsupported and abandoned post-diagnosis and were offered a diagnostic assessment without adequate follow up. Navigating the gap between autism diagnosis and support requires significant knowledge, time, finances and personal resources (Huang et al., 2022) and autistic adults often report wanting more information, advice and professional assistance to find support after diagnosis than they receive (Crane

et al., 2018). Appropriate post-diagnosis support and clear information about autism is therefore crucial for autistic women to adjust, adapt and process what autism means to them while also finding a community. This may alleviate the feeling of diagnosis being a burden and further affecting their mental health.

It is also possible that internalized stigma was at play for some of the autistic women interviewed in the present study. Many reported feelings of shock and upset, not knowing how to discuss diagnosis with their friends and family, and a sadness that the life-long diagnosis of autism was different to their diagnosis of ED which felt treatable. While additional information and support as discussed above may go some way to supporting autistic women to process the diagnosis, the underlying experience of stigma should not be minimized. Stigma can be defined as a social phenomenon where a group of individuals experience labelling, negative stereotyping, linguistic separation, and power asymmetry (Anderson et al., 2022). Autistic individuals experience frequent exposure to stigma and negative meanings attached to autism by society (Botha et al., 2022). Experiences of internalized stigma are common too and have been shown to be more severe in autistic individuals aged over 35 years (Bachmann et al., 2019) indicating that late-diagnosed autistic individuals may be at higher risk of developing internalized stigma. In addition, camouflaging has also been theorized as a response to autism-related stigma, with higher camouflaging being positively associated with measures of stigma (Perry et al., 2022). Autistic women are more likely to use camouflaging behaviours (Cook et al., 2021) and be diagnosed later in life (Posserud et al., 2021), therefore it is possible that stigma could be underlying some of the emotional reactions to diagnosis reported by the participants in this study. While they didn't explicitly name this as stigma, many of the autistic women in the present study reported negative experiences with healthcare professionals not understanding their presentations. Further research should therefore focus on whether autism-related stigma underlies the different emotional reactions to autism diagnosis, as this could be an important focus for post-diagnosis support.

Clinical Implications

The availability of support for autistic women, especially when diagnosed later in life, appears to be inadequate despite available NICE (2012) guidance. There is significant unmet need after adulthood autism diagnosis of formalized support (Huang et al., 2022), with autism diagnosis not necessarily leading to better support, which was shown to be particularly the case for autistic women with co-occurring eating disorder in the present study. The participants reported multiple experiences of being passed between autism services and eating disorder services, which could represent services having an unclear understanding of which service criteria autistic women with co-occurring mental health diagnoses fall into and may represent a situation where individuals cannot be open to one service at a time. While this may be the result of how services are commissioned, it ultimately leaves autistic women unsupported at a crucial time in their lives. Autistic women experience their autism and eating disorder as very intertwined (Brede et al., 2020) therefore services separating out the two and focusing on one but not the other is potentially unhelpful. Autistic women in the present study discussed helpful experiences of formal support were when both autism *and* eating disorder were considered in formulation and treatment, therefore further work is need to bring these services together for autistic individuals with co-occurring eating disorder.

The present study replicated previous findings that autistic women experience multiple incorrect diagnosis, misunderstandings and missed opportunities for diagnoses earlier in life (De Broize et al., 2022; Leedham et al., 2020) on their journey to autism discovery. This may in part due to the lack of understanding mental health professionals have of autism and in particular the female experience of autism. A recent systematic review found that healthcare professionals report only moderate levels of autism knowledge and self-efficacy in working with autistic individuals, and often lack training in this area (Corden et al., 2022). This was not limited to one particular professional group as papers in this review were sampled from different healthcare background and across countries. The autistic

women interviewed for the present study often felt that an earlier diagnosis could have made a significant difference to their lives, with autism-specific adaptions and understanding of their communication differences. As healthcare professionals play a key role in identifying and supporting autistic individuals, more training is needed to identify autism earlier. Recently, the Health and Care Act 2022 introduced specific requirements that NHS services must ensure their staff receive learning disability and autism training within their role. This led to the creation of The Oliver McGowan Mandatory Training on Learning Disability and Autism (Health Education England, 2022) which all health and social care staff are required to undertake and provides information to increase awareness of the support autistic people or people with a learning disability may need and what this support should look like. Specific training initiatives such as this may help support professionals to identify autism earlier in an autistic individuals life and reduce health and care inequalities, enabling them to receive the care and support they need to flourish.

Limitations

One limitation of this study is that the qualitative data was a secondary dataset gathered originally for different research questions. While there were a set of direct questions on the present research topic in the interview schedule and it was decided there was sufficient breadth and depth in the interviews to answer the present research question, the author had not collected the data herself. This may have meant at times there were insufficient follow up questions asked related to experience of autism diagnosis, meaning some deeper level information may have been missed.

The present study sought to explore the experiences of autistic women with co-occurring eating disorders. Due to the complex and specific interplay between *restrictive* ED and autism, it is possible that the findings of this study only represent experiences of autism diagnosis and co-occurring AN and may not reflect experiences of autism and other co-

occurring eating disorders. The autistic women interviewed discussed key themes of feeling that AN didn't fully explain their differences, diagnoses generally came at the point of breakdown and that their interaction with services post-diagnosis was often unhelpful. It is not clear whether this is specific to the experience of AN and therefore further research needed to ascertain whether these present findings are also demonstrated in other co-occurring eating disorder and mental health conditions. Furthermore, the present research was conducted only with autistic women. Therefore it may be possible that autistic men with co-occurring eating disorders, could experience autism diagnosis differently.

This study analysed a secondary dataset of semi-structured interviews. However, due to the method used to recruit autistic women for the original dataset, it is possible there was selection bias in the sample. Recruitment used social media platforms, the charity Autistica's research network and contacts of the research team (Brede et al., 2020; Babb et al., 2021). The sample was therefore self-selecting and the conclusions drawn from the present study do not represent the experience of those who did not or could not volunteer to participate. The sample would also have only included autistic women who were already linked in to support from Autistica or who used social media to follow accounts related to autism research. The views of autistic women who are not linked in to these resources or who do not use social media are therefore not represented in this analysis, further biasing the sample.

Conclusion

The present study highlights that receiving an autism diagnosis is an important moment in the lives of autistic women with co-occurring AN. . While it is not always possible for there to be one unified service pathway on how this is done due to the complexity of the interaction between autism and ED, this study highlights that autism should be identified as early as possible into treatment for co-occurring eating disorder . This can allow for tailored

support to be offered and can reduce the likelihood of misdiagnosis. Autism diagnosis can allow for autistic women to begin to understand their individual formulations such as the links between autism and ED, and increase self-compassion and acceptance. It also provides empowering information to enable them to find a community and informal support, but also to advocate for their needs with others and within services. While experiences of shock, upset and ambivalence are also common upon receiving an autism diagnosis, this study suggests that autistic women who were offered appropriate support post-diagnosis then had a space to process this range of emotions, enabling them to integrate autism positively into their sense of self and understand how to adapt their life to their needs. Further work is needed to ensure that all healthcare professionals have a good understanding of autism particularly in women, and where possible treating for ED should be continued within their existing supporting service with joined up working with specialist autism services.

References

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief “red flags” for autism screening: The short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(202–212), e7. https://doi.org/10.1016/j.jaac.2011.11.003

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

Andersen, M. M., Varga, S., & Folker, A. P. (2022). On the definition of stigma. *Journal of evaluation in clinical practice, 28(5)*, 847-853. https://doi.org/10.1111/jep.13684

Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2021). Autism through the ages: A mixed methods approach to understanding how age and age of diagnosis affect quality of life. *Journal of Autism and Developmental Disorders*, 1-16. https://doi.org/10.1007/s10803-021-05235-x

Autistica. (2019). Discover - Autism Research Network. Autistica. Retrieved 21/06/2023 from https://www.autistica.org.uk/our-research/discover-network

Babb, C., Brede, J., Jones, C. R., Serpell, L., Mandy, W., & Fox, J. (2022). A comparison of the eating disorder service experiences of autistic and non-autistic women in the UK. *European Eating Disorders Review, 30(5),* 616-627. https://doi.org/10.1002/erv.2930

Babb, C., Brede, J., Jones, C.R., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Mandy, W. & Fox, J.R., (2021). ‘It’s not that they don’t want to access the support... it’s the impact of the autism’: The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals. *Autism, 25(5),* 1409-1421. https://doi.org/https://dx.doi.org/10.1177/1362361321991257

Bachmann, C. J., Höfer, J., Kamp-Becker, I., Küpper, C., Poustka, L., Roepke, S., ... & Hoffmann, F. (2019). Internalised stigma in adults with autism: A German multi-center

survey. Psychiatry research, 276, 94-99. https://doi.org/10.1016/j.psychres.2019.04.023

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, *368*(9531), 210-215. https://doi.org/10.1016/s0140-6736(06)69041-7

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism, 20(4),* 483–495. https://doi.org/10.1177/1362361315590805

Bargiela, S., Steward, R. & Mandy, W. (2016). The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *J Autism Dev Disord 46,* 3281–3294. https://doi.org/10.1007/s10803-016-2872-8

Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). Ignored or ineligible. The reality for adults with autism spectrum disorders. *London: National Autistic Society*. https://www.autismoandalucia.org/wp-content/uploads/2018/02/NAS-IgnoredAdultsASD.pdf

Botha, M., Dibb, B., & Frost, D. M. (2022). " Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 37(3), 427-453. https://doi.org/10.1080/09687599.2020.1822782

Braun, V., & Clarke, V. (2021). Thematic Analysis: A Practical Guide. London : SAGE Publications Ltd.

Brede, J., Babb, C., Jones, C., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Fox, J. & Mandy, W., (2020). “For me, the anorexia is just a symptom, and the cause is the autism”: Investigating restrictive eating disorders in autistic women. *Journal of Autism and Developmental Disorders, 50(12),* 4280-4296.

Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical Psychology Review, 89,* 102080. https://doi.org/10.1016/j.cpr.2021.102080

Corden, K., Brewer, R. & Cage, E. A Systematic Review of Healthcare Professionals' Knowledge, Self-Efficacy and Attitudes Towards Working with Autistic People. *Rev J Autism Dev Disord*, 9, 386–399 (2022). https://doi.org/10.1007/s40489-021-00263-w

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of autism and developmental disorders, 48*, 3761-3772. https://doi.org/10.1007/s10803-018-3639-1

De Broize, M., Evans, K., Whitehouse, A. J. O., , J., Eapen, V., & Anna Urbanowicz, A. (2022). Exploring the Experience of Seeking an Autism Diagnosis as an Adult. *Autism in Adulthood*. *4:*2, 130-140. https://doi.org/10.1089/aut.2021.0028

Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. *Autism*, *21*(6), 678-689. https://doi.org/10.1177/1362361316671845

Dell'Osso, L., & Carpita, B. (2023). What misdiagnoses do women with autism spectrum disorder receive in the DSM-5? *CNS Spectrums, 28*(3), 269-270. https://doi.org/10.1017/S1092852922000037

Duvall, S., Armstrong, K., Shahabuddin, A., Grantz, C., Fein, D., & Lord, C. (2021). A road map for identifying autism spectrum disorder: recognizing and evaluating characteristics that should raise red or "pink" flags to guide accurate differential diagnosis. *The Clinical Neuropsychologist*, 1-36. https://doi.org/10.1080/13854046.2021.1921276

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International journal of social research methodology*, *20*(2), 181-194. https://doi.org/10.1080/13645579.2016.1144401

Foote, M. Q., & Gau Bartell, T. (2011). Pathways to equity in mathematics education: How life experiences impact researcher positionality. *Educational studies in mathematics*, *78*, 45-68. https://doi.org/10.1007/s10649-011-9309-2

Green, R. M., Travers, A. M., Howe, Y., & McDougle, C. J. (2019). Women and autism spectrum disorder: Diagnosis and implications for treatment of adolescents and adults. *Current psychiatry reports*, *21*(4), 1-8. https://doi.org/10.1007/s11920-019-1006-3

Harmens, M., Sedgewick, F., & Hobson, H. (2022). The quest for acceptance: a blog-based study of autistic women's experiences and well-being during autism identification and diagnosis. *Autism in Adulthood, 4(1),* 42-51. https://doi.org/10.1089/aut.2021.0016

Health and Care Act (2022). *Part 6: Mandatory training on learning disability and autism, Section 181.* https://www.legislation.gov.uk/ukpga/2022/31/section/181

Health Education England. (2022). *The Oliver McGowan Mandatory Training on Learning Disability and Autism.* https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism

Hiller, R., & Pellicano, L. (2013). Anorexia and autism: a cautionary note . *Psychologist*, *26*(11), 780. https://thepsychologist.bps.org.uk/volume-26/edition-11/letters

Holmes, A. G. D. (2020). Researcher Positionality--A Consideration of Its Influence and Place in Qualitative Research--A New Researcher Guide. *International Journal of Education, 8(4),* 1-10.

Huang, Y., Arnold, S.R.C., Foley, KR. *et al.* (2022). A Qualitative Study of Adults' and Support Persons' Experiences of Support After Autism Diagnosis. *J Autism Dev Disord* https://doi.org/10.1007/s10803-022-05828-0

Hull, L., Mandy, W., Lai, MC. *et al.* (2019). Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *J Autism Dev Disord, 49*, 819–833. https://doi.org/10.1007/s10803-018-3792-6

Kelly, C., Sharma, S., Jieman, A. T., & Ramon, S. (2022). Sense-making narratives of autistic women diagnosed in adulthood: a systematic review of the qualitative research. *Disability & Society*, 1-33. https://doi.org/10.1080/09687599.2022.2076582

Keys, A., Brožek, J., Henschel, A., Mickelsen, O., & Taylor, H. L. (1950). *The biology of human starvation. (2 Vols.).* Univ. of Minnesota Press.

Kim, J. Y., Son, M. J., Son, C. Y., Radua, J., Eisenhut, M., Gressier, F., . . . Fusar-Poli, P. (2019). Environmental risk factors and biomarkers for autism spectrum disorder: an umbrella review of the evidence. *Lancet Psychiatry*, *6*(7), 590-600. https://doi.org/10.1016/s2215-0366(19)30181-6

Kung, K.T.F. (2023). Autistic Traits, Gender Minority Stress, and Mental Health in Transgender and Non-Binary Adults. *J Autism Dev Disord*. https://doi.org/10.1007/s10803-022-05875-7

Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry, 2(11),* 1013-1027. https://doi.org/10.1016/S2215-0366(15)00277-1

Lai, M. C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: setting the scene for future research. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(1), 11-24. https://doi.org/10.1016/j.jaac.2014.10.003

Lai, M. C., Lombardo, M. V., Pasco, G., Ruigrok, A. N., Wheelwright, S. J., Sadek, S. A., Chakrabarti, B., MRC AIMS Consortium, & Baron-Cohen, S. (2011). A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PloS one*, *6*(6), e20835. https://doi.org/10.1371/journal.pone.0020835

Lai, M. C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., Happé, F., Baron-Cohen, S., & MRC AIMS Consortium (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism : the international journal of research and practice*, *21*(6), 690–702. https://doi.org/10.1177/1362361316671012

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*(1), 135-146. https://doi.org/10.1177/13623613198534

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(6), 466-474. https://doi.org/10.1016/j.jaac.2017.03.013

Lugo-Marin, J., Magan-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., Diez, E., & Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*, 59, 22-33. https://doi.org/10.1016/j.rasd.2018.12.004

McManus S, Bebbington P, Jenkins R, & Brugha T. (2016). *Mental health and wellbeing in England: Adult psychiatric morbidity survey 2014.* https://webarchive.nationalarchives.gov.uk/ukgwa/20180328140249/http://digital.nhs.uk/catalogue/PUB21748

Molloy, H., & Vasil, L. (2002). The Social Construction of Asperger Syndrome: The pathologising of difference?, *Disability & Society,* 17:6, 659-669, https://doi.org/10.1080/0968759022000010434

Monk, R., Whitehouse, A. J., & Waddington, H. (2022). The use of language in autism research. *Trends in Neurosciences.* https://doi.org/10.1016/j.tins.2022.08.009

National Institute for Health and Care Excellence. (2012). Autism spectrum disorder in adults: diagnosis and management [CG142]. https://www.nice.org.uk/guidance/cg142

Nazar, B. P., Peynenburg, V., Rhind, C., Hibbs, R., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Micali, N., & Treasure, J. (2018). An examination of the clinical outcomes of adolescents and young adults with broad autism spectrum traits and autism spectrum disorder and anorexia nervosa: A multi-centre study. *International Journal of Eating Disorders*, *51*(2), 174-179. https://doi.org/https://dx.doi.org/10.1002/eat.22823

Perry, E., Mandy, W., Hull, L., & Cage, E. (2021). Understanding camouflaging as a response to autism-related stigma: A social identity theory approach. *Journal of Autism and Developmental Disorders,* 1-11. https://doi.org/10.1007/s10803-021-04987-w

Posserud, M-Bt, Solberg, B., Engeland, A., Haavik., & Klungsøyr, K. (2021). Male-female ratios in autism spectrum disorders by age, intellectual disability and attention deficit/hyperactivity disorder. *Acta Psychiatrica Scandinavica.* 144. https://doi.org/10.1111/acps.13368

QSR International Pty Ltd. (2020) NVivo (released in March 2020), https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

Sedgewick, F., Leppanen, J. & Tchanturia, K. (2021). Gender differences in mental health prevalence in autism. *Advances in Autism, 7(3),* 208-224. https://doi.org/10.1108/AIA-01-2020-0007

Swain, J., & French., S. (2000). Towards an Affirmation Model of Disability. *Disability & Society, 15* (4), 569–582. https://doi.org/10.1080/09687590050058189

Tchanturia, K., Adamson, J., Leppanen, J., & Westwood, H. (2019). Characteristics of autism spectrum disorder in anorexia nervosa: A naturalistic study in an inpatient treatment programme. *Autism*, *23*(1), 123–130. https://doi.org/10.1177/1362361317722431

Tchanturia, K., Smith, K., Glennon, D., & Burhouse, A. (2020). Towards an improved understanding of the anorexia nervosa and autism spectrum comorbidity: PEACE pathway implementation. *Frontiers in Psychiatry, 11,* 640. https://doi.org/10.3389/fpsyt.2020.00640

Tripathy J. P. (2013). Secondary Data Analysis: Ethical Issues and Challenges. Iranian journal of public health, 42(12), 1478–1479.

Westwood, H., Eisler, I., Mandy, W., Leppanen, J., Treasure, J., & Tchanturia, K. (2016). Using the Autism-Spectrum Quotient to measure autistic traits in Anorexia Nervosa: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, *46*(3), 964-977. https://doi.org/https://dx.doi.org/10.1007/s10803-015-2641-0

Westwood, H., Mandy, W., & Tchanturia, K. (2017). Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Molecular Autism*, *8*, 12. https://doi.org/10.1186/s13229-017-0128-x

Zhang, R. Y., Birgegard, A., Fundin, B., Landen, M., Thornton, L. M., Bulik, C. M., & Dinkler, L. (2022). Association of autism diagnosis and polygenic scores with eating disorder severity. *European Eating Disorders Review*, *30*(5), 442-458. https://doi.org/10.1002/erv.2941

Part 3: Critical Appraisal

Introduction

This critical appraisal outlines the main considerations and reflections which arose whilst conducting the present research. Reflections detailed as part of this critical appraisal were explored continually throughout this research process as a reflexive research journal. This tool is used to provide researchers a space to reflect on and interrogate assumptions, and consider how these shape the research. It is also used to consider the emotional impact of research (Braun & Clarke, 2021).

The following reflection points will be discussed and will cover both reflections on the research process and the research context:

1. Changing my research project
2. Conducting research using a secondary dataset
3. Acknowledging data was collected prior to the Covid-19 pandemic
4. Clinical experience of working with autistic individuals with co-occurring eating disorders alongside undertaking this research
5. My positionality as a non-autistic woman
6. Assumptions about the importance of diagnosis
7. Impact of the research

The Research Process

Changing My Research Project

I came to this project much later in the research process than originally planned. When beginning the thesis, I was originally completing a different project investing the experiences of stigma individuals with functional seizures experience within the healthcare system. I had planned to interview ambulance clinicians to understand their experience of working with individuals with functional seizures and was closely working with the London

Ambulance Service (LAS) to facilitate recruitment. Due to recruiting NHS professionals, I needed to go through the NHS ethics process. I had no prior experience of NHS ethics and so was unfamiliar with this process, but this was something that we had originally factored in to the timescales developed for the project. However, we experienced many unforeseen delays in the ethics process. After being granted approval by the research ethics committee (REC), the LAS also determined that we needed to go through their own internal ethics process before beginning to recruit. An additional research ethics process would have resulted in the project not being able to be completed within the time constraints of the Doctorate in Clinical Psychology (DClinPsy). Therefore, to ensure I could complete a piece of research to a sufficient standard, I decided to change project to the present topic.

This led me to reflect on completing research within the NHS and how practically difficult this can be. Research within the NHS is vital to transform services, improve outcomes for patients, and ensure continued delivery of evidence-based practice. This is reflected in the recently published research strategy for allied healthcare professionals (Health Education England, 2022) which encourages clinicians to actively participate in research alongside clinical work. However, practically speaking this can be very challenging due to time consuming processes involved in research, such as NHS ethical approval. Having experienced this first-hand, I can understand how challenging completing research could be alongside clinical work, leading to many important projects remaining unfinished or some not attempting this at all. Clinicians have much to offer the research community however as they are directly connected to the clinical populations many research projects aim to help. This could enable them to understand what research questions need to be asked to improve patient care. The research strategy for allied healthcare professionals (Health Education England, 2022) therefore lays out strategies for supporting clinicians with research in a sustainable way, which will be crucial for innovation within care we offer to patients.

A Secondary Data Set

Due to the present thesis project being my second project, I had less time to complete this in than originally planned. Therefore the decision was taken to use a secondary dataset to ensure the project could still be completed to a high standard within the given timeframe. Secondary data analysis refers to a research process which uses existing data to answer a research question. This type of research can answer important research questions while minimizing time, cost and resource expenditure (Castle, 2003). The dataset used for the present study consisted of interviews conducted and transcribed by two previous researchers to answer questions about eating disorders in autistic women. While there was a clear opportunity to answer further questions within this dataset and there was sufficient data to do so, completing analysis on a secondary qualitative dataset brought forth particular dilemmas.

Firstly, I had not personally conducted the interviews. This meant I needed to undergo the process of familiarization thoroughly in order to fully immerse myself in the data. While this is a common process within the first stages of reflexive thematic analysis (Braun & Clarke, 2021), it felt especially important be able to understand the autistic women's stories as I had not met them. I found it particularly challenging to immerse myself in the data as I only had the transcripts to read and did not have the audio recordings due to data confidentiality. While this could be helpful as it meant I came to the data with a more objective stance, this left me feeling at times slightly disconnected from their stories. I wondered whether I had missed the subtlety in the autistic women's stories that brings their words to life as I did have the nuances of body language and tone of voice experienced in a face to face interview. Therefore to help with this, I found myself imagining each participant while reading their whole interview through several times. This enabled me to visualize them as a whole person and feel more connected to the data.

After having read the interviews through several times, the second challenge I faced when used this secondary dataset was to select the material relevant to my research

question. Two previous papers have been published using this data (Brede et al., 2020; Babb et al., 2021) and so much of the data had been used to answer other research questions. I aimed to focus on the interview questions which had not been analyzed previously and related to the autistic women's experiences of autism diagnosis. However, there is a risk with this method of selecting appropriate data to analyze that I may have been too selective and didn't capture data occurring later in the interview outside of the questions specifically about this topic. I noticed a particular tension between wanting to do justice to the richness of the autistic women's experience while also needing to filter out information that wasn't as relevant to my question. There were also situations within the questions where if I had been conducting the interviews to answer my specific research question, I may have asked follow up questions. This would have enabled me to clarify certain points and develop a richer, in-depth analysis. In order to strike this balance, I found it helpful to have a continued discussion with my supervisor about certain pieces of information to include in my dataset or not, and also to work with the original researcher who conducted the interviews to understand from them why certain questions weren't asked.

The Research Context

Influence of Covid-19

Throughout the reflective thematic analysis I was mindful that this data had been collected at a certain point in time within a certain context. This left me wondering whether themes presented in the empirical paper would still reflect the experiences of autistic women going through the process of autism diagnosis in the present day. The data was collected through interviews taking place in 2019, prior to the Covid-19 pandemic. While the original researchers collecting the data needed to make adjustments for the emerging pandemic, such as completing the interviews over video call instead of in person, all the women had received their autism diagnosis prior to this point. Covid-19 caused significant disruption to

NHS services, with the challenge of changing how services were provided while protecting patients and staff from Covid-19 infection. This was happening amid huge increase in demand and continued lack of resources.

Many autistic individuals experienced significant disruption in the services they accessed on a regular basis prior to the pandemic due to staff shortages, community resource closures, and reduced access to specialized services (Eshraghi et al., 2020). The Covid-19 pandemic also further exacerbated existing healthcare inequalities for autistic people and many reported experiencing substantial barriers to accessing services (Oakley et al., 2021). This led me to wonder how the Covid-19 pandemic may have influenced the experiences of autism diagnosis for individuals within the mental health system, such as the autistic women who participated in the present study. There is a possibility that many autistic women with co-morbid eating disorder (ED) weren't offered a diagnosis while services attempted to manage the immediate crisis of Covid-19. It is also possible that what little support was available prior to the pandemic became further stretched and the experiences the participants shared of being passed from service to service with no post-diagnosis support exacerbated. It is important to acknowledge therefore that the themes found in the present study may not reflect the journey of autistic women to diagnosis in the present day, and further research could be done to investigate whether there are different experiences during and post-Covid 19 that were not captured here.

Clinical Experience of Autism and Eating Disorders

Whilst undertaking this research, I was working as a trainee clinical psychologist in a children's mental health inpatient setting. Many of the children I worked with had severe eating disorders and were being assessed for co-occurring autism. In addition, most of whom were female-identifying. This similarity between the young people I worked with clinically and the interview transcripts I was reading had a bi-directional impact on me. I

found my clinical work impacted the way I engaged in the data, and the way I engaged with the data impacted how I worked clinically.

Firstly, it led me to have an increased personal investment in identifying an accurate prevalence estimate of autism within eating disorder populations through my systematic review. I had seen first-hand the power of research in determining clinical protocol and pathways through mental health services. While the inpatient unit I worked on admitted many autistic patients with co-occurring eating disorder, most children were undiagnosed at the point of reaching our service. There was no specific protocols on how to assess children for autism during their eating disorder treatment, and screening measures for autistic traits were not a routine part of initial assessment. This led to many children experiencing a varied process of autism diagnosis depending on whether the team felt this was appropriate at this stage in their eating disorder treatment. Through reading the literature surrounding the topic and investigating the prevalence rate of autism within eating disorder populations, I became passionate about advocating for earlier diagnosis within the inpatient unit. This could enable an adapted environment for autistic children but also tailored treatment plans. I also advocated for the use of measures of autistic traits in the initial assessment phase to allow for planning admission right from the start of referral.

Secondary, I found that when undertaking the qualitative analysis, my concurrent clinical experience meant I often drew parallels between the transcripts I was reading and the autistic children I was seeing on the inpatient ward with eating disorders. While this was helpful to increase my personal connection to data which I had not collected myself, I found that it also risked me coming to data with an existing lens of what it means to be autistic with co-occurring eating disorder. This at times endangered making assumptions about themes based on what I had seen clinically and biasing my results, rather than objectively focusing on the words the participants used to describe their own experiences of autism diagnosis. I had to be cautious of this throughout the analysis phase and found the use of reflective discussions with my supervisor and use of a reflexive research log helpful to ensure I

focusing solely on the data from the interviews and limit the impact of bias. Through reading previous literature, analyzing the interviews and highlighting themes within the data, I felt more able to advocate for the voice of the autistic experience of eating disorders in my clinical work. I noticed many clinicians felt that due to the possible effects of acute starvation mimicking and exacerbating autistic traits (Keys et al, 1950; Hiller & Pellicano, 2013), they didn't feel autism diagnosis was appropriate during ED treatment. I was however able to argue that my research indicated autism diagnosis allows for adapted treatment and answers many questions about the challenges autistic women have faced throughout their lives and is an important part of the formulation. I also advocated for appropriate support post-diagnosis and encouraged therapeutic sessions specifically focused on helping the young people on the inpatient unit to understand what autism meant to them.

My Position as a Non-Autistic Woman

The experiences we have in life impact the lens we bring to our work, which will in turn inform the questions we chose to ask and the interpretations we make (Foote & Bartell, 2011). While it is impossible to remove all biases from qualitative research, acknowledging and reflecting on how our lens may have influenced our work helps reduce their impact. Braun & Clarke (2023) note personal positioning is particularly important when researching socially minoritized groups and when researchers may be more socially powerful and positioned as privileged outsiders. While I am also female-identifying like the participants in the present study, I became acutely aware throughout the research of my position as neurotypical or non-autistic.

Being non-autistic means I will have moved through my life without many of the societal barriers placed in the way of autistic individuals by a non-autistic society. This also means that I brought a different frame to the analysis of autistic women's narrative than an autistic researcher may have done. As autism involves differences in social communication

(APA, 2013), I wondered whether my non-autistic lens may have missed important nuances within the autistic women's stories. There is a risk that I made assumptions about the meaning behind the words they used in the interviews or lost the rich detail of their experiences due my way of understanding how they talked about their experiences. This was potentially further exacerbated by the fact that I did not conduct the interviews and didn't have the audio recordings to listen to, so I was purely relying on the words without the non-verbal communication nuances.

I am acutely aware that the majority of research in autism is still undertaken *on* autistic people, rather than *with* them and is often not concerned with improving the day-to-day lives of autistic individuals (Chown et al., 2017). While I was keen to do justice to the voices of the autistic women in the sample and use this research as a method for improving how autism is diagnosed within eating disorder populations, I am still doing this from the a position outside the autism community. To help increase the inclusivity of this research, I was keen to involve autistic women in the thematic analysis process. This was something the previous researchers had done at two points during the analysis process, where they consulted with autistic advisors who commented on the interpretations made by the researchers (Brede et al., 2020; Babb et al., 2021). However, due to time constraints on the present project this was not possible. When this work is written up for publication this is something I am however keen to do to ensure the research is conducted *with* autistic people and not *on* them.

Assumptions About Diagnosis

Prior to beginning this research I aligned with more of a social constructionist view on diagnosis. Social constructionism is a diverse set of theories which proposes that our world is formed of social constructs. These are ideas which have been created by a particular society at a particular time and are a common organizing theme within Western medicine

(Barker, 2010) with it's reliance of diagnostic labels. By extension of this idea, I had previously assumed that a diagnosis of autism could also be viewed a social construct, where an arbitrary boundary is simply placed within a continuum of behaviours which are demonstrated to varying degrees in everyone (Molloy & Vasil, 2002).

However, upon reading the literature around autism diagnosis and hearing from autistic individuals who have been through the process of formalized autism diagnosis, my view has changed. I was moved hearing the accounts of the participants in the present study who have been through the mental health system for much of their lives seeking answers for why they were struggling and had faced many challenges. They spoke about feeling as though they never fit in right from childhood, and faced multiple incorrect diagnoses of mental health conditions such as borderline personality disorder, which carry with them their own stigma. It was powerful to hear from many of the participants that the autism label gave them a name and reason for their struggles and explained why they had felt othered by society. The autism label enabled them to access formal support services and gave them a method to find a community and connect with others who had similar experiences to them, which became healing for many. While this wasn't universal for all participants, these findings replicated themes found in other qualitative studies in the literature around experience of autism diagnosis. This shifted my view on diagnosis to understand that while autism may be a label created by our Western society, the power the autism label holds for many cannot be underestimated. This research showed me that receiving a diagnosis of autism was important and needed, but it is perhaps *how* this is done which is also important.

While working clinically with autistic individuals with eating disorders alongside this research, I noticed another discussion around diagnosis. Many clinicians I worked with argued that it wasn't ethical to diagnose an individual with autism while they are so acutely unwell with and eating disorder and whether this should be the priority. While we have a duty to make clinical decisions in the best interests of the individual, after completing this research I would argue that withholding an autism diagnosis until someone has recovered is

to withhold important information not only about themselves, but also information which can guide eating disorder treatment and adaptions to support them, such as the use of The Pathway for EDs and Autism developed from Clinical Experience (PEACE), which provides treatment resources and advice for patients and clinicians (Tchanturia et al., 2020). This research therefore challenged my assumptions around diagnosis which I could then directly apply to clinical work to help autistic individuals with eating disorder.

Impact of the Research

Recently, I presented the preliminary data from this research in a department wide meeting at my placement in a national children's hospital. The response was overwhelmingly positive and all the clinicians who attended were keen to think about how my research could improve treatment and reduce barriers to the autistic children they see within the service. Being able to have an estimated prevalence rate of autism in eating disorder populations from my systematic review led to discussion of whether they should include a measure of autism traits such as the AQ-10 in their service as standard, to ensure anyone with undiagnosed autism has the opportunity for their traits to be recognized. We also discussed whether a Quality Improvement (QI) project could be started to create an autism-friendly environment on the inpatient ward to further reduce barriers to treatment and meeting everyone's needs. In addition, the findings of my empirical paper challenged their long-held assumptions and clinical practice that autism should be diagnosed in the community upon recovery from eating disorder. This led them to question whether they could review their protocol around this and consider autism more centrally in the formulation of the children on the ward.

While this was only one conversation with one eating disorder inpatient unit, I was very encouraged that this felt like the beginning of an important dialogue. I am keen to continue disseminating the findings through both meetings, presentations and publications

and will consider how I can ensure this conversation is facilitated in to other eating disorder units too.

Holding in mind Chown et al's (2017) important discussion of how imperative it is that autism research involves autistic individuals as it is fundamentally for them, it is important to consider how I can also disseminate the findings to the autism community. The original research was funded by the charity Autistica and both Brede et al (2020) and Babb et al (2021) created sections on the charity's website to disseminate the findings of the research. It would therefore be important for me to contact the charity to update them on the ongoing work with the participant's narratives around diagnosis and to communicate this within their community. I also plan to develop an accessible version of the research upon publication to engage autistic individuals who are outside of the academic and professional sphere to ensure the research is discussed with those whom it focusses on.

Conclusion

While this wasn't the project that I had originally planned for at the beginning of the research process, I am very grateful to have been a part of it and to have been a witness to the participant's narratives. I have been moved by the autistic women's experiences of autism diagnosis and even though I didn't meet them in person, I felt a responsibility to do justice to their stories. This combined with my clinical work alongside has forged a passion to advocate for autistic individuals within the mental health system. I am excited to see where this research may go and what change can be made within eating disorder services for autistic people.

References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

Babb, C., Brede, J., Jones, C.R., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Mandy, W. & Fox, J.R., (2021). 'It's not that they don't want to access the support... it's the impact of the autism': The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals. *Autism, 25(5),* 1409-1421. https://doi.org/https://dx.doi.org/10.1177/1362361321991257

Barker, K. K. (2010). The social construction of illness. *Handbook of medical sociology*, 147-162.

Braun, V. & Clark. V. (2021). Thematic analysis: a practical guide. London:SAGE Publications Ltd.

Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be (com)ing a knowing researcher. *International Journal of Transgender Health*, *24*(1), 1-6. https://doi.org/10.1080/26895269.2022.2129597

Brede, J., Babb, C., Jones, C., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Fox, J. & Mandy, W., (2020). "For me, the anorexia is just a symptom, and the cause is the autism": Investigating restrictive eating disorders in autistic women. *Journal of Autism and Developmental Disorders, 50(12),* 4280-4296. https://doi.org/10.1007/s10803-020-04479-3

Castle, J. E. (2003). Maximizing research opportunities: Secondary data analysis. *Journal of Neuroscience Nursing*, *35*(5), 287-290.

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., ... & MacGregor, D. (2017). Improving research about us, with us: A draft framework for

inclusive autism research. *Disability & society*, *32*(5), 720-734. https://doi.org/10.1080/09687599.2017.1320273

Eshraghi, A. A., Li, C., Alessandri, M., Messinger, D. S., Eshraghi, R. S., Mittal, R., & Armstrong, F. D. (2020). COVID-19: Overcoming the challenges faced by individuals with autism and their families. *The Lancet. Psychiatry,* 7(5), 481–483. https://doi.org/10.1016/S2215-0366(20)30197-8

Foote, M. Q., & Bartell, T. G. (2011). Pathways to equity in mathematics education: How life experiences impact researcher positionality. *Educational studies in mathematics*, *78*, 45-68. https://doi.org/10.1007/s10649-011-9309-2

Health Education England (2022). *Allied Health Professions' Research and Innovation Strategy for England.* https://www.hee.nhs.uk/our-work/allied-health-professions/enable-workforce/allied-health-professions%E2%80%99-research-innovation-strategy-england

Hiller, R., & Pellicano, L. (2013). Anorexia and autism: a cautionary note . *Psychologist*, *26*(11), 780. https://thepsychologist.bps.org.uk/volume-26/edition-11/letters

Keys, A., Brožek, J., Henschel, A., Mickelsen, O., & Taylor, H. L. (1950). *The biology of human starvation. (2 Vols.).* Univ. of Minnesota Press.

Oakley, B., Tillmann, J., Ruigrok, A., Baranger, A., Takow, C., Charman, T., ... & Murphy, D. G. (2021). COVID-19 health and social care access for autistic people: European policy review. *Bmj Open*, *11*(6), e045341. https://doi.org/10.1136/bmjopen-2020-045341

Tchanturia, K., Smith, K., Glennon, D., & Burhouse, A. (2020). Towards an improved understanding of the anorexia nervosa and autism spectrum comorbidity: PEACE

pathway implementation. *Frontiers in Psychiatry*, *11*, 640. https://doi.org/10.3389/fpsyt.2020.00640

Molloy, H., & Vasil, L. (2002). The Social Construction of Asperger Syndrome: The pathologising of difference?, *Disability & Society,* 17:6, 659-669, https://doi.org/10.1080/0968759022000010434

Appendices

Appendix 1: PRISMA-P Checklist (2015)

This appendix details the PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) checklist which contains recommended items to address in a systematic review protocol (Shamseer et al., 2015).

Section and topic	Item No	Checklist item
ADMINISTRATIVE INFORMATION		
Title:		
Identification	1a	Identify the report as a protocol of a systematic review
Update	1b	If the protocol is for an update of a previous systematic review, identify as such
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number
Authors:		
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
Support:		
Sources	5a	Indicate sources of financial or other support for the review
Sponsor	5b	Provide name for the review funder and/or sponsor
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
INTRODUCTION		
Rationale	6	Describe the rationale for the review in the context of what is already known
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
METHODS		
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
Study records:		

Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2, Kendall's τ)
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)

*** It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated. The copyright for PRISMA-P (including checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution Licence 4.0.**

From: Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart L, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015 Jan 2;349(jan02 1):g7647.

Appendix 2: JBI Critical Appraisal Check for Studies Reporting Prevalence Data

This appendix details the quality appraisal tool developed by the Joanna Briggs Institute (JBI) to determine the risk of bias in studies reporting prevalence data.

	Yes	No	Unclear	Not applicable
1. Was the sample frame appropriate to address the target population?	☐	☐	☐	☐
2. Were study participants sampled in an appropriate way?	☐	☐	☐	☐
3. Was the sample size adequate?	☐	☐	☐	☐
4. Were the study subjects and the setting described in detail?	☐	☐	☐	☐
5. Was the data analysis conducted with sufficient coverage of the identified sample?	☐	☐	☐	☐
6. Were valid methods used for the identification of the condition?	☐	☐	☐	☐
7. Was the condition measured in a standard, reliable way for all participants?	☐	☐	☐	☐
8. Was there appropriate statistical analysis?	☐	☐	☐	☐
9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Appendix 3: UCL Ethical Approval

This appendix details the confirmation of ethical approval for the original data collection.

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

20th April 2018

Dr Will Mandy
Research Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Mandy

Notification of Ethics Approval
Project ID/Title: 12973/001: Study of eating disorder in autistic females

I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that the data collection element of your study has been approved by the UCL REC until **24th April 2019**.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Dr Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Janina Brede & Charlotte Babb

Appendix 4: Interview Schedule

This appendix details the questions that were asked in the original interviews and used for secondary analysis around the topic of experience of autism diagnosis.

Interview Schedule for Autistic Women

Hello, thank you so much for agreeing to take part in our study, we really appreciate it.

- That there are no right or wrong answers, we are just interested in your views and experience.
- Please let me know if you would like me to repeat any questions or ask it in a different or more specific way.
- It is important for you to know that you don't need to answer any questions that you don't feel comfortable with, we can skip them, or go back to them later.
- Don't worry if you feel like you have forgotten to include anything. At the end I will check with you if you would like to add anything and if there are any topics you think we have missed that you might like to tell me about.
-

Note for interviewer: General prompts that can be used throughout the interview

- *What/why/who/how?*
- *Can you give me an example, or describe a situation where this was the case?*
- *Could you talk me through this experience/situations?*

Experience and diagnosis of autism

To start off, could you tell me about your autism?

1. What is autism like for you in your day to day life?
    - 1.1 Are there ways in which autism makes your life more difficult?
    - 1.2 Are there things that you're better at than others?
    - 1.3 When did you first notice ____?
2. Has this changed with time/as you have grown up?
3. What was it like to receive your autism diagnosis?
    - 3.1 When were you diagnosed with autism?
    - 3.2 Could you describe how you received your diagnosis? *(reason and process, e.g. school initiated assessment, seeking referral from GP, referral from other MH services)*
4. What did you think of the diagnosis?
    - 4.1 Did you think/suspect you might be on the autism spectrum prior to receiving a diagnosis, or was this something new to you?
    - 4.2 How did you react when you received the diagnosis?
    - 4.3 How did other people around you react when you received the diagnosis? (Think about family, friends, teachers/employers reactions)
5. What, if anything, changed as a result of being diagnosed?

Appendix 5: Candidate Codes, Sub-Themes and Themes

This appendix details the candidate codes which were combined into the sub-themes. The sub-themes were combined into broader themes and presented in the empirical paper.

Candidate Themes	Sub Themes	Themes
Always felt different Never felt like I fit in Could finally fit in somewhere Autism makes sense and fits me Didn't feel supported by friends and family post-diagnosis Recognised autistic traits in family post-diagnosis Autism needs to be diagnosed	1. Searching For A Place to Fit	1. The Search for Understanding and Support
Lack of understanding of the female autistic experience Misdiagnosis pre-autism diagnosis Diagnosis came later in life Autism had been suggested before in childhood but never diagnosed Family didn't know what autism was before diagnosis Experience of judgements/assumptions from others pre-diagnosis Autism came after ED Looking back on life now Long process to autism diagnosis Sought out a diagnosis myself Suspected autism before the diagnosis Earlier diagnosis would have made a difference	2. Mis(sed) Diagnosis and Misunderstanding	
Diagnosis came after the point of breakdown/burnout Thought I was going mad pre-diagnosis Experienced difficulties in life since childhood How the diagnosis was made was varied	3. Journey to Crisis Point	
Offered either ED or autism service, not both Addressing both ED and autism in treatment was most helpful Lack of post-diagnosis support Passed around and refused services post-diagnosis Variation in available autism services Lack of understanding from ED services about autism Some support post-diagnosis has been helpful Lack of transparency from service during assessment	4. Passed From Service to Service Post-Diagnosis	
Diagnosis brought understanding of self and acceptance ED didn't explain all the difficulties Always knew there was "something" but couldn't name it Autism gave a name, reason and answers to problems and struggles Relief after diagnosis was discovered Diagnosis meant I could connect mental health difficulties and autism Autism makes sense and fits me Could make the links between ED and autism Friends and family thought autism made sense Family and friends were supportive after diagnosis	1. Everything Makes Sense	2. A Shifting Moment
How do I tell my friends and family about autism? Autism didn't fit me Never considered autism before Period of processing and adjusting to the diagnosis	2. Shock and Upset	

Initial shock and upset at receiving the diagnosis		
Diagnosis brought confusing feelings		
Parents found me receiving the diagnosis difficult		
Experience the negatives of autism		
Don't know how autism affects me	3. What Difference Does This Make?	
I didn't know anything about autism before diagnosis		
Wait for an assessment and diagnosis was minimal		
Ambivilance to the diagnosis		
Some people don't believe the autism diagnosis		
Difficulties didn't automatically improve post-diagnosis		
Reluctant to go for assessment		
Didn't tell family about the diagnosis		
I've always been like this		
Had to find a way to function pre-diagnosis		

Family and friends understand me better now	1. A Communication Tool	3. Taking Control
Able to communicate my needs better now		
Had something to tell people to explain my struggles		
ED service understood my needs		
The diagnostic label itself was helpful		
Autism service helped plan my ED treatment		
Positive experiences of therapy post-diagnosis		
Adaptions could be made (in treatment, in work and in life)	2. Forging My Own Path Post-Diagnosis	
Found own support post-diagnosis		
View autism as a strength		
Diagnosis brought self-compassion and confidence		
Able to move forward now		
Did own research post-diagnosis		
Learned to manage better post-diagnosis		
The label meant I could research it		