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A comparison of the eating disorder service experiences of autistic and non-autistic women in the UK

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Autistica

Abstract

Objective: Qualitative studies report that autistic women have poor experiences when being treated for an eating disorder (ED) and express that ED services are not appropriately tailored to meet their needs. It is unclear whether their experience differs to other women accessing ED services. The aim of the current study was to compare autistic and non-autistic women's ED illness history and experiences in ED services.

Method: An online survey about ED illness history and their experience with ED treatment was completed by 46 autistic women with a restrictive ED and 110 non-autistic women with a restrictive ED.

Results: Despite some similarities, there were three key differences in the experiences reported by autistic and non-autistic women. First, autistic women reported a longer duration of ED and being diagnosed with an ED at a younger age than non-autistic women. Second, autistic women reported accessing a broader range of healthcare settings and ED treatments than non-autistic women when being treated for an ED. Finally, autistic women rated their experiences of inpatient care, dietetic input, and cognitive behavioural therapy (CBT) as significantly less beneficial than non-autistic women when being treated for an ED.

Conclusion: These findings increase understanding of autistic women's ED experience and can help to shape ED services and treatments to better accommodate the needs of their autistic clients.

KEYWORDS

anorexia nervosa, ARFID, autism, eating disorders, mental health services

Abbreviations: AN, Anorexia Nervosa; ARFID, Avoidant and Restrictive Food Intake Disorder; BMI, Body Mass Index; CAMHS, Child and Adolescent Mental Health Service; CBT, Cognitive Behavioural Therapy; DBT, Dialectical Behaviour Therapy; DSM, Diagnostic and Statistical Manual of Mental Disorders; ED, Eating disorder; EDE-Q, Eating Disorder Examination Questionnaire; GP, General Practitioner; HCRW, Health and Care Research Wales; HRA, Health Research Authority; ICD, International Classification of Diseases; MANTRA, Maudsley Anorexia Nervosa Treatment for Adults; NHS, National Health Service; NICE, National Institute for Health and Care Excellence; OCD, Obsessive Compulsive Disorder; OT, Occupational Therapy; RAADS, Ritvo Autism Asperger Diagnostic Scale; RED, Restrictive Eating Disorder; SD, Standard deviation; SSCM, Specialist Supportive Clinical Management; SWEAA, Swedish Eating Assessment for Autism spectrum disorders.

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Highlights

- The current study is the first to compare the eating disorder (ED) illness history and treatment experiences of autistic and non-autistic women.
- Autistic women with EDs are diagnosed at a younger age and report longer illness duration than non-autistic women.
- Autistic women with EDs tend to access a broader range of healthcare settings and ED treatments than non-autistic women, but report these to be less beneficial.

1 | INTRODUCTION

Autistic women are overrepresented in eating disorder (ED) populations (Postorino et al., 2017; Westwood, Mandy, et al., 2017), with studies estimating that 20%–35% of women with AN will also meet the diagnostic criteria for autism (for review, see Westwood & Tchanturia, 2017). Importantly, autistic women report that their experiences of an ED, specifically anorexia nervosa (AN), is closely intertwined with their autistic traits (Brede et al., 2020; Kinnaird et al., 2019). For example, autistic women related their eating difficulties to sensory sensitivities, thinking styles, sense of identity, and emotional and social processing (Brede et al., 2020). Due to the distinct experiences reported by autistic women with an ED, it could be theorised that their ED treatment experiences would also differ from non-autistic women's experiences.

Previous research has explored the relationship between levels of autistic traits and ED treatment outcomes. For example, those with AN presenting with higher levels of autistic traits tend to experience poorer clinical outcomes (Nielsen et al., 2015), fewer improvements following ED intervention and a need for more treatment augmentation (Stewart et al., 2017; Tchanturia et al., 2016), and longer, more frequent inpatient stays (Nazar et al., 2018). Moreover, the presence of autistic traits has been related to a longer duration of AN (Saure et al., 2020). Autistic traits in these studies are determined using a variety of measures, including self and parent reports, observational and interview measures, and measures of neuropsychological characteristics related to autism. Taken together, these findings suggest that higher levels of autistic traits are associated with overall worse ED outcomes.

Evidence from a stage of illness-based model indicates that the longer the duration of the ED, the more entrenched, habitual and chronic the ED presentation becomes (Treasure et al., 2015). The model, supported by neurobiological studies (Fonville et al., 2014) and developmental epidemiological studies of AN (Herzog et al., 1993), stresses that the first 3 years of onset is a

particularly crucial stage for the potential of full recovery (Treasure et al., 2015). Given evidence that elevated autistic traits are associated with poorer ED treatment outcomes and longer duration of AN, autistic individuals could be at greater risk of a chronic and enduring ED.

Autism is a dimensional condition, representing high autistic traits that are continuously distributed throughout the population (Happé & Frith, 2020). However, the validity of findings concerning autistic traits in ED samples may be compromised by measurement challenges. Specifically, characteristics that superficially resemble autistic traits occur in individuals with AN when in a state of semi-starvation, and this effect can be compounded by other aspects of their clinical presentation, such as co-occurring anxiety and perfectionism (Calugi et al., 2018; Keys et al., 1950). Moreover, having a diagnostic label of autism may affect a person's experience of ED services (Babb et al., 2021). Thus, it is unclear to what extent findings using measures of autistic traits reflect the experiences of women with a formal diagnosis of autism, as opposed to representing the experience of women with EDs more widely.

Previous qualitative research indicates that autistic women's needs are commonly not met when treated for an ED (Adamson et al., 2020; Kinnaird et al., 2019; Kinnaird et al., 2017). Babb et al. (2021) triangulated the views of autistic women with experience of AN, parents of autistic women with experience of AN and healthcare professionals. Participants reported that women's autistic traits were often misconstrued by healthcare professionals, sometimes being labelled as reflecting resistance and disengagement from treatment. A lack of knowledge about autism in ED services made it difficult for these women to feel understood, with some healthcare professionals labelling autistic service users as too complex for ED services. Moreover, the standardised treatments offered were often deemed inappropriate or ineffective by the autistic women. For example, participants suggested that commonly used models, such as cognitive behavioural therapy (CBT), may be less accessible for autistic individuals due to its perceived one-size-fits-all approach and the underlying assumptions of skills

needed to benefit from the intervention. Other approaches such as dialectical behaviour therapy (DBT) and occupational therapy (OT) were thought to be more helpful due to their practical and skills-based approach. Finally, autistic women highlighted the importance of services being flexible to meet their communication and environmental needs, and these were particularly salient in inpatient environments. Due to the perceived mismatch between offered treatment options and autistic individuals' needs (Babb et al., 2021), and the need for treatment augmentation, for example, via more intensive service provision, reported in other studies (Stewart et al., 2017), autistic women may experience a broader range of treatment options due to the lack of autism-informed treatments or treatments modified for autistic individuals.

Together, previous research suggests that ED services are currently not meeting the needs of service users that are autistic. However, this research has been limited by only exploring the impact of autistic traits or by only focussing on the experiences of autistic people. The current study extends this previous work by directly assessing whether there are differences in ED treatment experience between those with and without an autism diagnosis.

2 | AIMS

The aim of the current study is to compare the ED illness history and ED service experiences of women with and without an autism diagnosis. Although previous research was primarily conducted with women with AN, the current study considered women with a variety of restrictive ED (RED) diagnoses, including AN, Atypical Anorexia, and Avoidant and Restrictive Food Intake Disorder (ARFID). This was designed to reflect the complexities of real-world clinical practice, in the light of recent evidence that suggests that autistic women's RED presentations might not primarily and/or overtly be driven by weight and shape concerns (Brede et al., 2020). Thus, only focussing on those with AN might not result in a representative sample of autistic women accessing adult ED services for help with a RED.

Based on previous literature, our first hypothesis was that autistic women with a RED would report a longer duration of ED than non-autistic women with a RED. Our remaining hypotheses focussed on ED service experience. The second hypothesis predicted that autistic women with a RED would experience a broader range of treatment for their ED. Our third hypothesis was that autistic women would rate ED treatments as less beneficial. Based on previous work, we expected this to be particularly the case for CBT (Babb et al., 2021).

3 | METHOD

3.1 | Participants

Participants in this study were part of a wider study conducted by the SEDAF research group in the UK. This study obtained ethical approval from a National Health Service (NHS) ethics committee in accordance with Health Research Authority (HRA) and Health and Care Research Wales (HCRW) guidance. Ethical approval was also obtained from the ethics committee at UCL.

For the current study, there were two distinct groups: those who were formally diagnosed autistic (i.e., with an official autism spectrum disorder diagnosis) with a RED (Autism + REDs); and those with a RED without a formal autism diagnosis (REDs only). For both groups, the inclusion criteria required them to be: (1) a woman; (2) aged 18+; (3) living in the United Kingdom (UK); (4) clinically diagnosed and currently living with a RED (including AN, atypical anorexia and ARFID). The current study did not recruit men, as they are rare in RED populations (Raevuori et al., 2014), so we would have been unable within the scope of the current study to recruit sufficient numbers to allow us to model sex/gender effects with sufficient power. BMI was not used to determine eligibility to participate, due to the inclusion of EDs such as atypical AN that do not use weight parameters, and due to participants being at different stages of illness/recovery.

We used secondary criteria post-data collection to confirm the presence of ED behaviours and cognitions. Participants were required to score above a pre-defined, clinically meaningful cut-off on at least one of three disordered eating measure sub-scores, which were collected as part of the larger study. We considered scores on a combination of measures, which focus on different mechanisms underlying disordered eating behaviours and/or cognitions, to prevent exclusion of participants with less traditional RED presentations, that is, those with fewer weight and shape concerns. Scores on the Eating Disorder Examination-Questionnaire (EDE-Q; Fairburn & Beglin, 1994) global scale, the SWedish Eating Assessment for Autism spectrum disorders (SWEAA; Karlsson et al., 2013) eating behaviour subscale and SWEAA other behaviour associated with disturbed eating subscale were considered. Participants must have scored above a cut-off of 2.5 on their EDE-Q global score (Mond et al., 2004; Rø et al., 2015) and/or score +1 standard deviation above the means of an autism (clinical) group on one of the SWEAA subscales (Karlsson et al., 2013).

For the Autism + REDs group, participants were required to have an independent clinical autism diagnosis (including autism spectrum disorder, autism, Asperger's

syndrome, high functioning autism, and pervasive developmental disorder) by a qualified healthcare professional or multi-disciplinary team in line with latest International Classification of Diseases (ICD; World Health Organization, 2019) or Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2013) criteria at the time of their assessment. This was either confirmed by the NHS service that recruited the participant or was confirmed by the participant as part of the information collected during the study.

Participants were recruited via social media (Twitter, Facebook) our project blog, relevant charity networks, one NHS Autism service and six NHS Eating Disorder services across England and Wales.

The current study included 46 participants in the Autism + REDs group and 110 participants in the REDs

only group. Demographics relating to age, BMI and a self-report autism and ED measures for these groups can be found in Table 1. *T*-tests revealed that there were no significant differences in age, current BMI and lowest ever BMI between the two groups.

Frequency of ED diagnoses reported for the Autism + REDs and REDs only groups and their mean current BMIs can be found in Supplementary Material 1.

3.2 | Materials

Materials were presented in an online survey. This included a self-report measure of ED psychopathology, a self-report measure of autistic traits, and a clinical background questionnaire.

TABLE 1 Participant demographics

		Autism + REDs (<i>n</i> = 46)	REDs only (<i>n</i> = 110)	<i>t</i> -test
Age (years)	Mean	30.41	29.99	$t(154) = 0.245, p > 0.05, 95\%$ CI [-2.98, 3.83]
	Standard deviation	11.02	9.28	
	Range	18–61	18–63	
Current BMI	Mean	17.89	17.35	$t(142) = 1.141, p > 0.05, 95\%$ CI [-0.4, 1.49]
	Standard deviation	2.27	2.72	
	Range	13.11–22.34	11.76–26.2	
Lowest ever BMI (<18 years)	Mean	13.25	14.09	$t(29) = -1.164, p > 0.05, 95\%$ CI [-2.34, 0.64]
	Standard deviation	1.9	2.1	
	Range	10.1–16.61	10.94–18.66	
Lowest ever BMI (18+ years)	Mean	14.03	14.34	$t(110) = -0.586, p > 0.05, 95\%$ CI [-1.33, 0.72]
	Standard deviation	2	2.39	
	Range	10.3–19.76	10.16–23.05	
EDE-Q score	Mean	3.57	4.27	$t(154) = -3.3, p < 0.05, 95\%$ CI [-1.13, -0.28]
	Standard deviation	1.37	1.15	
	Range	0.74–5.7	1.14–6	
RAADS-14 score	Mean	34.98	17.2	$t(154) = 10.425, p < 0.05, 95\%$ CI [14.41, 21.15]
	Standard deviation	6.01	10.88	
	Range	17–42	0–42	
SWEAA eating behaviour	Mean	62.14	53.36	$t(154) = 2.4, p < 0.05, 95\%$ CI [1.51, 15.65]
	Standard deviation	17.61	21.42	
	Range	20.83–100	0–100	
SWEAA other behaviour associated with disturbed eating	Mean	32.88	33.58	$t(154) = -0.26, p > 0.05, 95\%$ CI [-6, 4.6]
	Standard deviation	12.86	16.19	
	Range	6.25–62.5	0–96.88	

Abbreviations: BMI, Body Mass Index; ED, eating disorder; EDE-Q, Eating Disorder Examination Questionnaire; RAADS, Ritvo Autism Asperger Diagnostic Scale; RED, restrictive eating disorder; SWEAA, Swedish Eating Assessment for Autism spectrum disorders.

3.2.1 | Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994)

The EDE-Q is a 32-item self-report questionnaire used to assess the core behavioural and cognitive symptoms of disordered eating over the past 28 days. The questionnaire comprises four subscales each with five to eight items: 'Restraint', 'Eating concerns', 'Weight concerns', and 'Shape concerns'. Scores are averaged to gain an overall global score, which ranges from 0 to 6. The measure boasts good internal consistency ($\alpha = 0.70\text{--}0.93$; Berg et al., 2012), discriminative validity (Mond et al., 2004) and convergent validity (Berg et al., 2011).

3.2.2 | Ritvo Autism Asperger Diagnostic Scale (RAADS-14; Eriksson et al., 2013)

The RAADS-14 is a 14-item screening tool which reflects autism diagnostic criteria, developed to screen for autism in psychiatric populations. Scores from 0 to 3 for each item are summed to achieve a total score, ranging from 0 to 42, with higher scores indicating greater endorsement of autistic traits. A cut-off score of 14 reached a sensitivity of 97% and a specificity of 95% for non-psychiatric controls and 64% for those with psychiatric disorders, including psychotic disorder, mood disorder, anxiety disorder, obsessive-compulsive disorder and borderline personality disorder (Eriksson et al., 2013). The measure has good internal consistency (Cronbach's Alpha (α) > 0.7), and adequate construct and convergent validity (Eriksson et al., 2013).

3.2.3 | Swedish Eating Assessment for Autism spectrum disorders (SWEAA; Karlsson et al., 2013)

The SWEAA is a 60-item self-report questionnaire developed to measure eating disturbances in autistic individuals. This measure identifies autism-specific eating difficulties that may not be picked up by standard ED measures such as the EDE-Q, for example, relating to sensory sensitivities to food items. The subscales of interest for the current study are 'Eating behaviours' and 'Other behaviour associated with disturbed eating', as these are the most associated with disordered eating behaviours. The means of the items for each subscale are calculated and transformed into a scale from 0 to 100 to create a more easily interpretable scale. The measure and its individual subscales show good reliability ($\alpha = 0.73\text{--}0.92$), good test-retest reliability (intra-class correlation

coefficient (ICC) = 0.86), and good convergent validity (0.34–0.62) (Karlsson et al., 2013).

3.2.4 | Clinical background questionnaire

The clinical background questionnaire collected information relating to participant demographics, ED diagnostic category, illness duration and experiences in ED services. Questions to gather information about ED illness history and service experiences were as follows:

- How old were you when you received this diagnosis? (In years)
- How old were you when your eating disorder symptoms first started? (In years)
- Have you been in treatment for your eating disorder? If so, for how long (roughly) have you had treatment for your eating disorder (in years and months)?
- Which type of healthcare service have you used for your eating disorder? Select all that apply. (Multiple choice options: Specialist eating disorder service, general mental health service, Child and Adolescent Mental Health Service (CAMHS), GP, Other).
- In treatment for your eating disorder, were you under any of the following? Select all that apply. (Multiple choice options: Inpatient care, Outpatient care, Day patient care, Community-based care, Other, Not sure).
- Did you have any of the following treatments? Select all that apply. (Multiple choice options: Medication, Dietitian input, Occupational therapy, Psychological therapy, Other, Not sure).
- If you had psychological therapy, which approach(es) did you receive? Select all that apply. (Multiple choice options: Cognitive Behavioural Therapy (CBT), Family Therapy, Maudsley Anorexia Nervosa Treatment for Adults (MANTRA), Specialist Supportive Clinical Management (SSCM), Dialectical Behaviour Therapy (DBT), Other, Not sure).

For questions five to seven, for each selected answer, participants were asked to rate their experience on a scale from 1 to 7 (1 = not beneficial at all, 7 = extremely beneficial).

3.3 | Procedure

Potential participants were asked a number of screening questions to confirm eligibility either via phone or email. They were provided with a participant information sheet and completed a consent form if suitable for the study. Participants completed an online survey as part of larger

study, which included the measures reported here. Participants completed the clinical background questionnaire first, followed by the remaining measures presented in a randomised order. Overall, completion of the online survey took approximately 1–1.5 h. Participants were encouraged to take regular breaks and could complete the online measures in their own time over a 2-week period. Participants were encouraged to ask for clarification either in-person or via email, if they had any questions. After participation they were electronically debriefed and were offered a £15 or £30 voucher to thank them for their time, depending on whether participants only completed the online survey or also the in-person measures. The study was conducted during the COVID-19 pandemic. A subset of participants ($n = 17$) had been seen in-person prior to the pandemic and completed additional experimental measures. Two autistic women with experience of AN had reviewed the study protocol and advised on how to make the study as accessible as possible for potential participants.

3.4 | Data analysis

Distribution of data was assessed using the Kolmogorov-Smirnov test and by calculating z-scores to detect skewness and kurtosis. For non-normally distributed variables, logarithmic transformations and square root transformations were considered to improve distribution. However, neither transformation improved the distribution of data across groups and therefore these were not

applied, and the original data was used. When analysing the data, statistical tests were run with and without outlier corrections. We found no differences in the outcome of the analysis when using either, and so the original data with outliers has been reported. Moreover, where parametric tests were run with non-normal data, a non-parametric alternative was also conducted. There were few differences between the parametric and non-parametric outputs, so parametric tests are reported to preserve statistical power.

Statistical analyses were carried out using IBM SPSS Statistics for Windows, Version 26.0. *T*-tests and chi-squared tests were performed to compare continuous variables and frequencies, respectively, between the two groups. Hedges' *g* is reported for pairwise standardised effect sizes.

4 | RESULTS

4.1 | Hypothesis 1: ED illness history

Independent samples *t*-tests were carried out to examine differences between the two groups for: (1) the age at which ED symptoms were reported to have started; (2) the age of ED diagnosis; (3) the duration of ED (in years); and (4) ED treatment duration (in months). *T*-test results can be seen in Table 2. The Autism + REDs group had a significantly lower reported age at which ED symptoms started and at which they reported receiving their ED diagnosis. The Autism + REDs group also had a

TABLE 2 Means, standard deviations (SD's), range, and *t*-test results for the ED history variables

		Autism + REDs ($n = 46$)	REDs only ($n = 110$)	<i>t</i> -test
Age that ED symptoms started	Mean	14.87	16.97	$t(152) = -2.079, p < 0.05, 95\% \text{ CI } [-0.11, -0.002],$ Hedges' $g_s = 0.32$
	SD	5.74	6.84	
	Range	5–34	6–46	
Age at ED diagnosis	Mean	18.13	22.06	$t(153) = -2.845, p < 0.01, 95\% \text{ CI } [-0.13, -0.03],$ Hedges' $g_s = 0.47$
	SD	5.85	9.22	
	Range	9–35	11–59	
ED duration (years)	Mean	12.28	8	$t(153) = 2.117, p < 0.05, 95\% \text{ CI } [0.01, 0.29],$ Hedges' $g_s = 0.45$
	SD	12.36	7.83	
	Range	1–52	0–33	
Total ED treatment duration (months)	Mean	74.63	61.66	$t(148) = 0.936, p > 0.05, 95\% \text{ CI } [-0.1, 0.28],$ Hedges' $g_s = 0.17$
	SD	80.88	72.13	
	Range	1–312	1–336	

Note: Significant *t*-tests are highlighted in bold.

Abbreviations: ED, eating disorder; RED, restrictive eating disorder.

significantly longer total duration of ED. There was no significant difference in reported duration of ED treatment between the two groups.

4.2 | Hypothesis 2: ED services and treatments accessed

A chi-squared test of independence was conducted to examine any differences in the percentages of reported ED care settings, treatment types and psychological treatment types accessed across the two groups. Table 3 depicts the percentage and number of ED services and treatments the participants in each group received.

There were no significant differences across any specific reported treatment settings or types accessed, with the exception of Child and Adolescent Mental Health Service (CAMHS). A significantly higher percentage of the Autism + REDs group reported having accessed this type of service, in comparison to the REDs only group. This suggests that, overall, a similar number of participants across both groups had accessed and received different types of treatment settings, services, and treatments.

Within each of the different categories of care settings and treatment types were several different options that the participants could endorse. To explore this further, we totalled the number of experiences in each of the four categories (care setting, ED service setting, ED treatment and psychological therapies) that each participant reported accessing (see Table 4).

The Autism + REDs group reported accessing significantly more care settings (e.g., CAMHS, GP, general MH, specialist ED) and significantly more ED treatments (e.g., dietitian, psychological therapy, medication, OT) than the REDs only group. There were no significant differences in the number of ED service settings or psychological therapies reported being accessed by the two groups.

4.3 | Hypothesis 3: ED service and treatment ratings

Participants rated the ED service experiences they reported accessing (with the exception of care settings, due to the broader nature of this category) on a scale from 1 to 7, where 1 = not beneficial at all, and 7 = extremely beneficial. Ratings for each service/treatment type were averaged across their categories (ED service setting, ED treatment and psychological therapies). Table 5 shows the mean ratings, standard deviations, and *t*-test results for each category.

When averaging ratings across categories, the Autism + REDs group rated all three categories (ED service setting, ED treatment and psychological therapies) as significantly less beneficial than the REDs only group.

To understand each category further, individual *t*-tests were conducted for mean ratings for each type of service/treatment. Bonferroni corrections were applied for each category to decrease the risk of Type I errors when carrying out multiple *t*-tests. The mean ratings from 1 to 7, standard deviations and *t*-test results for the ED service settings, treatments and psychological therapies received for their ED can be found in Supplementary Material 2. Specialist Supportive Clinical Management (SSCM) was not included in the *t*-test comparisons due to the small number of participants that reported receiving this intervention.

The pattern of data shows that the Autism + REDs group rated most types of services and treatments as less beneficial than the REDs only group. This pattern was significant for inpatient care, dietetic input, and CBT.

5 | DISCUSSION

The current study aimed to investigate any differences in the ED illness histories and service experiences of autistic and non-autistic women with a RED. Forty-six autistic women and 110 non-autistic women completed online questionnaires about their illness history and ED treatment experiences as part of a wider study.

5.1 | ED illness history

Autistic women reported: (i) being younger when their ED symptoms began; (ii) receiving their ED diagnosis at a younger age and; (iii) having a longer overall ED duration. There was no significant difference between the two groups for the reported length of time in treatment for an ED. These findings broadly support previous studies that have found that more autistic traits were related to a longer illness duration (Saure et al., 2020). Given that a longer ED duration is also associated with a more chronic ED presentation (Treasure et al., 2015), it is possible that autistic women are at a higher risk of developing this presentation than non-autistic women, meaning that effective, tailored and early treatment is fundamental for this population. Furthermore, the longer ED duration reported by autistic women could reflect reduced treatment efficacy in these individuals (Nazar et al., 2018; Stewart et al., 2017; Tchanturia et al., 2016). Longer illness duration is associated with perpetuating factors,

TABLE 3 Types of services and treatments accessed for an eating disorder reported by Autism + REDs and REDs only participant groups

Question	Answer	Autism + REDs (<i>n</i> = 46)	REDs only (<i>n</i> = 110)	Chi-squared
Have you been in treatment for your eating disorder?	Yes	93.5% (<i>n</i> = 43)	97.3% (<i>n</i> = 107)	$X^2(1) = 1.26, p > 0.05$
	No	6.5% (<i>n</i> = 3)	2.7% (<i>n</i> = 3)	
Type of care setting accessed	Specialist eating disorder service	90% (<i>n</i> = 40)	90% (<i>n</i> = 99)	$X^2(1) = 0.31, p > 0.05$
	General mental health service	52.2% (<i>n</i> = 24)	40% (<i>n</i> = 44)	$X^2(1) = 1.96, p > 0.05$
	CAMHS	54.3% (<i>n</i> = 25)	28.2% (<i>n</i> = 31)	$X^2(1) = 9.65, p < 0.01$
	GP	60.9% (<i>n</i> = 28)	66.4% (<i>n</i> = 73)	$X^2(1) = 0.43, p > 0.05$
Type of eating disorder service setting accessed	Inpatient	60.9% (<i>n</i> = 28)	56.4% (<i>n</i> = 62)	$X^2(1) = 0.27, p > 0.05$
	Outpatient	76.1% (<i>n</i> = 35)	68.2% (<i>n</i> = 75)	$X^2(1) = 0.97, p > 0.05$
	Day patient	32.6% (<i>n</i> = 15)	35.5% (<i>n</i> = 39)	$X^2(1) = 0.12, p > 0.05$
	Community-based	37% (<i>n</i> = 17)	38.2% (<i>n</i> = 42)	$X^2(1) = 0.02, p > 0.05$
Type of treatment received for an eating disorder	Medication	78.3% (<i>n</i> = 36)	69.1% (<i>n</i> = 76)	$X^2(1) = 1.35, p > 0.05$
	Dietitian	91.3% (<i>n</i> = 42)	81.8% (<i>n</i> = 90)	$X^2(1) = 2.24, p > 0.05$
	Occupational therapy	37% (<i>n</i> = 17)	50% (<i>n</i> = 55)	$X^2(1) = 2.2, p > 0.05$
	Psychological therapy	90% (<i>n</i> = 40)	78.2% (<i>n</i> = 86)	$X^2(1) = 1.6, p > 0.05$
Types of psychological treatment received for an eating disorder	CBT	65.2% (<i>n</i> = 36)	67.3% (<i>n</i> = 74)	$X^2(1) = 1.88, p > 0.05$
	Family therapy	32.6% (<i>n</i> = 15)	31.8% (<i>n</i> = 35)	$X^2(1) = 0.01, p > 0.05$
	MANTRA	17.4% (<i>n</i> = 8)	23.6% (<i>n</i> = 26)	$X^2(1) = 0.74, p > 0.05$
	SSCM	8.7% (<i>n</i> = 4)	8.2% (<i>n</i> = 9)	$X^2(1) = 0.01, p > 0.05$
	DBT	32.6% (<i>n</i> = 15)	21.8% (<i>n</i> = 24)	$X^2(1) = 2.01, p > 0.05$

Note: Significant chi-squared tests are highlighted in bold.

Abbreviations: CAMHS, Child and Adolescent Mental Health Services; CBT, Cognitive Behavioural Therapy; DBT, Dialectical Behaviour Therapy; GP, General Practitioner; MANTRA, Maudsley Anorexia Nervosa Treatment for Adults; RED, restrictive eating disorder; SSCM, Specialist Supportive Clinical Management.

such as consequent isolation, secondary mental health problems and chronic stress (Treasure et al., 2020), which might affect autistic women with EDs disproportionately and should be considered when supporting these individuals.

The current findings add to the emerging evidence that autistic individuals tend to develop ED symptoms at a younger age. Previous research consistently reports atypical eating behaviours and food selectivity in autistic children (Baraskewich et al., 2021; Cermak et al., 2010; Kral et al., 2013). The current findings support qualitative interviews with autistic women with a RED who reported eating difficulties in childhood that they believe contributed to the development of an ED (Brede et al., 2020). Interventions to address atypical eating behaviours may help to reduce some of these initial eating difficulties that lead to more disordered eating in adolescence and adulthood, but interventions that are

currently available have high variability in their success rates and overall a relatively low rate of success across interventions (Ledford et al., 2018).

5.2 | Services and treatments accessed

With the exception of CAMHS, which may reflect the younger age at which autistic women received their ED diagnosis, a similar number of autistic and non-autistic women reported accessing different types of treatment settings, services, and treatments for their ED. However, across all settings accessed, autistic women reported accessing significantly more healthcare settings and ED treatments than non-autistic women in the treatment of their ED. At face value, access to a wider range of treatment options for autistic women with an ED could be viewed as better treatment provision. This

TABLE 4 Means, standard deviations (SD's), and *t*-tests for totalled experiences across the four service and treatment categories

Eating disorder service/treatment categories	Mean (SD)		<i>t</i> -test
	Autism + REDs	Autism only	
Care settings	2.98 (1.17)	2.44 (1.07)	<i>t</i>(148) = 2.704, <i>p</i> < 0.01, 95% CI [0.15, 0.93], Hedges' <i>g</i>_s = 0.49
Eating disorder service settings	2.35 (1.0)	2.13 (1.04)	<i>t</i> (148) = 2.499, <i>p</i> > 0.05, 95% CI [0.11, 0.93], Hedges' <i>g</i> _s = 0.21
Eating disorder treatments	3.44 (1.08)	2.93 (1.17)	<i>t</i>(148) = 1.176, <i>p</i> < 0.05, 95% CI [-0.15, 0.58], Hedges' <i>g</i>_s = 0.44
Psychological therapies	2.26 (1.68)	1.82 (1.43)	<i>t</i> (148) = 1.598, <i>p</i> > 0.05, 95% CI [-0.1, 0.97], Hedges' <i>g</i> _s = 0.29

Notes: Significant *t*-tests are highlighted in bold.

Abbreviations: CAMHS, Child and Adolescent Mental Health Services; GP, General Practitioner; RED, restrictive eating disorder.

TABLE 5 Means, standard deviations (SD's), and *t*-tests for overall ratings of perceived benefit for eating disorder services, treatments and psychological therapies received for the Autism + REDs and REDs only groups

	Rating mean (SD)		<i>t</i> -test
	Autism + REDs	REDs only	
Eating disorder service settings accessed	3.76 (1.22)	4.3 (1.47)	<i>t</i>(136) = -2.062, <i>p</i> < 0.05, 95% CI [-1.05, -0.02], Hedges' <i>g</i>_s = 0.38
Eating disorder treatments received	3.78 (1.33)	4.41 (1.38)	<i>t</i>(146) = -2.53, <i>p</i> < 0.05, 95% CI [-1.12, -0.14], Hedges' <i>g</i>_s = 0.46
Psychological therapies received	3.41 (1.42)	4.12 (1.62)	<i>t</i>(116) = -2.261, <i>p</i> < 0.05, 95% CI [-1.33, -0.09], Hedges' <i>g</i>_s = 0.45

Note: Significant *t*-tests are highlighted in bold.

Abbreviation: RED, restrictive eating disorder.

is particularly as a holistic approach and collaboration across services has been reported to being positively received by autistic individuals in ED and other mental health settings (Babb et al., 2021; Brede et al., 2022). However, it could also reflect the narrative reported by autistic individuals with EDs and those supporting them (Babb et al., 2021) that autistic individuals are 'too complex', resulting in these individuals being passed around different healthcare settings and ED treatment types. Others support this perspective, providing evidence that clinicians working in healthcare services view autistic service users as complex and requiring additional service input beyond their usual role (Morris et al., 2019). Indeed, females with high autistic traits in treatment for AN required greater treatment augmentation than those with lower levels of autistic traits (Stewart et al., 2017), suggesting there may be a need for further or more intensive treatment approaches for autistic individuals. This can be particularly challenging for autistic individuals, given their difficulties to adapt to change and need for consistency in their care (Babb et al., 2021).

5.3 | Perceived benefit of different types of ED treatment

Across the three ED service experience categories (ED service settings, ED treatments and psychological therapies), autistic women's ratings reflected that they felt these to be significantly less beneficial in regard to their recovery than non-autistic women. Participant ratings of individual ED settings and treatments that they had accessed were, on the whole, similar across both groups. Where ratings did differ, autistic women rated inpatient care, dietetic input, and CBT as significantly less beneficial than non-autistic women.

ED inpatient environments have been reported to be a particularly challenging environment by autistic women in previous research (Babb et al., 2021). In their autism strategy, the UK government acknowledged the unaccommodating nature of inpatient environments for autistic people, pledging to put in better supports for these individuals (Department of Health, 2016). This highlights the importance of tailoring inpatient settings to be suitable to autistic service users who may need to use them.

We also found that autistic women rated dietetic input as less beneficial than non-autistic women. This could relate to a lack of understanding about autism amongst healthcare professionals working in ED services (Babb et al., 2021; Kinnaird et al., 2017). For dietitians specifically, this may include having a knowledge of sensory sensitivities to different food items for autistic people (Kuschner et al., 2015) and incorporating this into their dietary advice. These implications for clinical environments can be implemented with the inclusion of adequate autism training more broadly within ED services. Such training is being developed and rolled out in some ED services in the UK where the need has been identified, and an autism-specific pathway has been developed as part of this (Tchanturia et al., 2020). This model could be used as a foundation for other services to base their own provisions on to support their autistic clients.

Our finding that autistic women rated CBT as significantly less beneficial than non-autistic women supports previous qualitative research (Babb et al., 2021). Autistic women reported that in its traditional form, CBT was challenging and often ineffective as they felt that they did not possess the foundational skills needed to fully engage with the therapy, for example, generalising information from CBT into everyday situations. CBT has been adapted to treat EDs (i.e., CBT-ED; Fairburn, 2008) but this adaptation does not take into account neurodivergence and that many people in ED treatment may be autistic. Furthermore, CBT-ED assumes that ED difficulties are predominantly driven by weight and shape concerns, which might be less relevant for autistic individuals (Brede et al., 2020). Studies have found that some characteristics related to autism, such as rigid thinking and emotion recognition, may reduce the efficacy of using a cognitive-behavioural approach when treating psychiatric conditions, for example, anxiety and depression, in young autistic people (Lickel et al., 2012; Puleo & Kendall, 2011). Consequently, modifications to CBT have been recommended for autistic individuals when treating common mental health conditions, and these are outlined in the National Institute for Health and Care Excellence (NICE) guidelines (National Institute for Health and Care Excellence, 2012). Suggested adaptations may include using a more structured and concrete approach, placing a greater emphasis on behaviour change as opposed to cognitions, incorporating special interests into therapy and limiting the use of metaphors and hypothetical situations (National Institute for Health and Care Excellence, 2012). So far, research on modifying CBT for autistic people focuses on conditions such as anxiety, OCD and depression (Walters et al., 2016), but not yet EDs. The findings in this study emphasise the

need to make specific adaptations to therapeutic approaches commonly used in ED treatment, such as CBT-ED (Fairburn, 2008), for autistic people.

5.4 | Limitations

This research relied upon on self-report data. Whilst this has its advantages, for example, ease of access to a broad range of personal information (Paulhus & Vazire, 2007), there are also disadvantages. For example, the way in which the questions are posed may be interpreted differently across participants, subsequently reducing internal validity. There was high variability across the length of time in treatment for an ED, and while this could be indicative of the wide range of participants' experiences, it could also reflect differences in the interpretation or reporting of ED treatment duration. Some may give an overall estimate from when they were first diagnosed, whereas others may have more meticulously calculated month by month their time in treatment. A more accurate way to measure these variables would have been via access to individual health records, which were not accessible for all participants in the current study. We also relied on self-reported ED diagnoses for participants recruited outside of NHS services. Nevertheless, these were validated and confirmed via self-report measures of ED psychopathology.

Although RED illness duration was significantly longer in the Autism + REDs group, many individuals across the two groups would be considered to have an enduring or chronic presentation, that is, illness duration longer than 7 years (Tierney & Fox, 2009). This may reflect a bias in individuals with REDs who tend to volunteer for research, in that those with shorter illness durations, and potentially more positive service experience, tend to be underrepresented.

Also, we only included women in this study, as we lacked the resources to recruit sufficient numbers of men to enable adequately powered modelling of gender differences. Future work is needed to investigate REDs of autistic men.

6 | CONCLUSION

The current study broadens our understanding of autistic and non-autistic women's experiences of ED services. We hypothesised that autistic women with a restrictive ED would report different experiences of ED services than non-autistic women. The findings within this study support previous studies (e.g., Nazar et al., 2018; Nielsen et al., 2015; Saure et al., 2020) suggesting that across some

aspects of ED services, autistic people experience poor service provision in comparison to their non-autistic counterparts. It highlights the need for earlier intervention and adaptations to be made for autistic people using ED services. This will also require greater awareness and knowledge of autism and how being autistic might affect ED presentations (Brede et al., 2020), within these services. In our sample, duration of ED was significantly longer for autistic women than non-autistic women, and it could be speculated that this may be partly due to the poorer service experiences they reported. Recommendations for models of autism training and pathways are given.

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DATA AVAILABILITY STATEMENT

Research data are not shared.

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