Towards better outcomes for autistic individuals with Eating Disorders

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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.

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Overview

Evidence suggests that autistic individuals with an Eating Disorder (ED) respond to current interventions differently compared to neurotypical individuals. Furthermore, many are undiagnosed until they reach mental health services with mainly women being missed with current bias in the assessment process. Once they reach mental health services clinicians struggle to identify who might benefit from a full assessment and potential treatment adaptations. This thesis aims to firstly evaluate how autistic individuals respond to standard ED interventions utilising a systematic search to evaluate all available literature on the topic. By evaluating the current literature clinicians can make more informed clinical pathway decisions. Secondly, to evaluate an improved screening measure for use in ED services to help guide clinicians to make accurate referrals and appropriate adaptations for those that might benefit from an autism assessment. Participants were recruited as part of a larger study examining eating difficulties in autistic individuals, but the data was utilised in a novel way to develop a predictive model for screening autistic individuals with an ED. Finally, my reflections on the process of completing a thesis in this area for the benefit of fellow researchers and clinicians working in this field.

Impact Statement

How autistic individuals respond to Eating Disorder (ED) interventions is critically important to guide clinical pathway decisions and future research, especially around adapting existing treatments for better outcomes. Between 17 and 35% of individuals who present to ED services score high on autism screening measures and many go on to receive an autism diagnosis. Furthermore, these individuals are overrepresented in inpatient settings and generally have worse clinical outcomes compared to those without autism. Despite this, there is still very little research to evaluate what aspects of treatment autistic individuals respond positively to and what aspects might need adaptations. Without a clear and consistent evidence base, clinicians are using their instinct and experience which leads to an inconsistent approach and limits dissemination of any findings. This review is the first systematic search to pull together all the relevant research on how autistic individuals or those that score high on autism screening measures respond to standard ED treatment. Although the findings are limited due to methodological issues within the research base and a limited number of studies in this area, results suggest that clinicians should concentrate on individual format psychological interventions with group interventions limited to only more direct, skills-based interventions. Despite the limited number of studies, the review helps to guide future research by highlighting the gaps and issues with the existing literature and clearly outlining future directions. With more robust research, following the suggestions outlined in the review, researchers and clinicians will be able to offer more effective treatment to autistic individuals presenting with an ED globally.

However, to decide who might benefit from a modified treatment pathway or an adapted intervention we first need to accurately identify them as likely autistic. As many autistic women are missed until much later in life, often after presenting to mental health services, accurate screening measures that are valid within ED populations are vitally needed by clinicians. Clinicians currently rely on a screening measure that is not validated in ED populations and is less sensitive, potentially due to its narrow focus. The findings from the empirical paper lay the foundations for an improved screening measure that accurately identifies women who might be autistic in an ED population. This can lead to more accurate referrals to the autism diagnostic pathway and the application of appropriate treatments. Importantly, an accurate autism screening measure can support clinicians in understanding the profile of autistic traits in their patients with EDs, so that treatment adaptations can be considered regardless of diagnostic status. Future research is needed to test the model we generated in a larger sample where all participants are given full autism diagnostic assessments to confirm group eligibility. With further validation, the model we developed has the potential to be the standard screening tool used in all ED services across the country and internationally, once further cultural validation studies are completed.

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Part 1: Literature Review

Title: How effective is psychological therapy for Autistic individuals with an Eating Disorder? a systematic review.

Abstract

Objective

It is now widely accepted that autistic individuals are overrepresented in Eating Disorder (ED) populations, particularly in inpatient settings where around 24% of patients might be autistic. Evidence suggests that autistic individuals respond to standard ED treatment differently to those without an autism diagnosis. However, currently there are no reviews pulling together all the literature on how autistic individuals respond to different ED interventions.

Method

A systematic search of major databases from inception to 12/2021 was undertaken investigating how autistic individuals respond to ED interventions. Data quality was assessed, and key findings summarised.

Results

Of the four studies that were identified, all were based in inpatient services in the United Kingdom and included only participants with a diagnosis of AN. No studies utilised gold standard diagnostic testing or confirmed diagnosis of autism, instead categorising participants into high and low autistic traits using autism screening measures. Findings suggest that those with high autistic traits benefit more from individual than group interventions.

Conclusions

Despite the few studies that have been conducted in this area, there appears to be an association between high levels of autistic traits and a different response to standard ED interventions. Future research is needed in outpatient services and with

participants who have undergone full autism assessments, before any conclusive findings can be drawn.

Introduction

There is a growing interest in the overlap between Anorexia Nervosa (AN) and autism including how autistic individuals respond to standard Eating Disorder (ED) treatment and whether they would benefit from adaptions (Tchanturia et al., 2020). Prevalence rates for those with diagnosed autism and those who score above clinical cut-offs on autism screening tools range from 17 to 35% depending on the measure used and the clinical setting (Boltri & Sapuppo, 2021; Huke et al., 2013; Westwood & Tchanturia, 2017). AN has been suggested to be the female version of Autism (Oldershaw et al., 2011) and is therefore the most studied when evaluating the links between EDs and autism. AN is an ED that is typically characterised by extreme shape and weight concerns and an intense fear of gaining weight and often results in individuals becoming significantly underweight (American Psychiatric Association, 2013). Autism is a neurodevelopmental condition that is associated with social-emotional and communication differences and restricted and repetitive patterns of behaviour (American Psychiatric Association, 2013). Although diagnostically autism is a term used to refer to autism spectrum disorder, in line with individuals with autism preferences for being referred to we will henceforth use the terms ‘autism’ and ‘autistic individual’ (Bury et al., 2020; Kenny et al., 2016). AN is a mental health condition that with effective treatment can be overcome whereas autism is a neurodevelopmental condition that will affect individuals in different ways throughout their life.

A high proportion of autistic individuals with AN are women who were undiagnosed until they accessed mental health services for their eating difficulties (Kinnaird et al.,

2017; Solmi et al., 2021). Many women go undiagnosed potentially due to bias in autism assessments not picking up more female traits (Gould & Ashton-Smith, 2011; Sedgewick et al., 2019). Furthermore, autistic women are more likely to mask their social communication difficulties in social settings than men, known as social camouflaging (Cook et al., 2021; Mandy, 2019). Autism can often be overshadowed by mental health difficulties with many women receiving a mental health diagnosis long before being referred for an autism assessment leading to a diagnosis much later in life than males (Leedham et al., 2020). Furthermore, evidence suggests that when presented with identical descriptions of girls and boys with autism, educators are less likely to recognise the autistic girls, suggesting a stereotype bias (Whitlock et al., 2020). All these factors lead to autistic girls and women not being picked up until later in life and often only after they reach mental health services. Because of this, studies examining how autistic women respond to ED treatment often use screening measures to indicate high autistic traits when diagnostic assessments are unavailable (Tchanturia et al., 2019).

There are significant overlaps in clinical presentations of AN and autism, especially when effects of starvation are present (Kinnaird et al., 2019; Tchanturia et al., 2013). For example, cognitive rigidity, attention to details, atypical eating behaviours and social difficulties are psychological effects of starvation, as well as being features of autism (Kinnaird et al., 2019). However, aspects such as food, weight, and body image, seem to play less of a role in autistic women with AN (Brede et al., 2020) suggesting that the mechanisms for developing and maintaining the ED might be different. As many studies rely on autism screening measures as a proxy for a diagnostic assessment for the purpose of evaluating outcomes, one concern was

that the effects of starvation in AN mimic autistic traits (Westwood & Tchanturia, 2017) . However, autism screening scores appear to be stable over the course of an inpatient admission for an ED and post-recovery (Boltri & Sapuppo, 2021; Tchanturia et al., 2019).

Individuals with autism, either diagnosed or scoring highly on screening measures, are more likely to have more severe AN symptoms and have poorer outcomes than those without autism or scoring below cut-off on screening measures (Tchanturia et al., 2019). AN severity appears to be related to high autism scores on screening measures, suggesting that those that score above cut-off might represent the more severe ED patients and therefore the ones where clinical change takes longer and is more difficult (Fornaro et al., 2020). These individuals are also overrepresented in inpatient settings, i.e., most severe, and likely have not responded to outpatient treatment, the first line intervention (Westwood et al., 2016). This suggests that autistic individuals with an ED are not responding to first line treatment approaches, such as Cognitive Behavioural Therapy for Eating Disorders (CBT-ED) or the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA), both National Institute for Health and Care Excellence (NICE) recommended first line treatments (NICE, 2017). However, we are not aware of an evaluation of these interventions for autistic individuals and as such we cannot be sure how effective they are for this group of individuals.

From qualitative studies we know that clinicians lack experience and confidence in treating individuals with both autism and AN where specific modifications are often required (Kinnaird et al., 2017). Kinnaird et al. (2017) suggest that current adaptions

to treatment are based on individual clinicians' prior experience rather than a systemic approach born from an evidence base of what works for these individuals in ED services. Families feel that existing services do not adapt standard ED treatment for autistic individuals, leaving families feeling frustrated often having to advocate for their loved one to get appropriate treatment (Adamson et al., 2020). Autistic individuals with an ED mirror the frustration of a lack of adaption in ED services and little input in their treatment, including support for traits related to their autism such as sensory sensitivities that are often overlooked and not considered (Kinnaird et al., 2019). Interestingly, autistic individuals describe a difficulty in communication in the therapist patient relationship including feeling not listened to or believed. This highlights the didactic element of communication otherwise known as the 'double empathy' problem in autism, where clinician and patient have very different experiences in interacting (Mitchell et al., 2021).

The issue of double empathy will inevitably have implications for psychological interventions that largely rely on communication as the method of delivery. For example, a recent qualitative study found that most autistic women experienced CBT-ED negatively, describing difficulties with engaging in the theory and applying the skills they learned (Babb et al., 2021). Furthermore, autistic individuals found managing social demands in group therapy interventions challenging, negatively impacting their ability to engage and therefore benefit from the interventions (Babb et al., 2021). On the other hand, highly structured group therapy namely Dialectical behaviour therapy (DBT), was found to be more helpful, perhaps due to its more directive, skills-based approach with less reliance on group processes and communication with the therapist.

Recent attempts to modify standard ED treatment for better outcomes for autistic individuals are largely investigational as there is not yet a consistent evidence base on what aspects of treatment autistic individuals respond to and which adaptations may or may not be helpful (Tchanturia et al., 2020). The PEACE pathway uses a quality improvement methodology to explore whether adaptations to typical ED treatment pathways foster improved outcomes for autistic individuals. These type of intervention studies are helpful to test hypotheses in short periods of time and inspire future direction for this area of research however, it is hard to ascertain what elements of the pathway are having a significant effect on the outcomes for these individuals and what might be confounding factors. Furthermore, large elements of treatment pathways are still unstudied within autistic populations, with most of the research focusing on two psychological therapy interventions for inpatients (Adamson et al., 2018; Dandil, Smith, Adamson, et al., 2020; Tchanturia et al., 2016a). For example, in inpatient settings where we see a different response between those with high and low autistic traits (Tchanturia et al., 2019), typical treatment involves a MDT approach utilising many different interventions from different professional groups and therefore makes it almost impossible to standardise.

Current systematic reviews looking at autistic individuals with EDs focus on prevalence rates which was initially studied using predominantly cross-sectional research with various assessment tools (Westwood & Tchanturia, 2017) and updates more recently with some longitudinal studies allowing us to evaluate the stability over time of self-report measures (Boltri & Sapuppo, 2021). However, neither review

investigated the efficacy of interventions for autistic individuals with EDs and to our knowledge no review yet systematically brings current understanding together across all ages. There has been one recent review that included some intervention studies but focused only on Cognitive Remediation Therapy (CRT) and Oxytocin in adolescents (Tololeski et al., 2021). The aim of this review was to systematically evaluate all intervention studies in EDs that include autistic individuals or use an autism screening measure to help guide clinicians in making appropriate treatment adaptations and guide clinical pathways.

Methods

This systematic review was conducted following the PRISMA guidelines (Page et al., 2021).

Inclusion criteria

Considering the anticipated sparseness of the literature, we set the inclusion criteria to be as broad as possible to build a holistic view of all available literature pertaining to intervention studies in EDs that include autistic individuals or use an autism screening measure. For the same reasons, we also allowed for any methodological design that has some level of comparison, i.e., compares between or within participants. The inclusion criteria were; studies that included patients with a diagnosis of an Eating Disorder, at any age and gender, and included patients with an autism diagnosis or an autism screening measure was used. Furthermore, the study examined Psychological or Behavioural interventions within this population.

Exclusion criteria

Studies using pharmacological interventions were excluded from the study furthermore other exclusion criteria were; animal studies, case studies, conference abstracts, qualitative studies, treatment programmes as defined as a service or programme involving multiple interventions where results are described together, as in such instances the impact of any one intervention cannot be ascertained.

Search Strategy

The search strategy was designed to be as broad as possible, to ensure all relevant studies were included. Furthermore, an exhaustive list of databases was utilised including;
Medline, Embase, PsycINFO, Web of Science, CINAHL, Scopus and Cochrane Library. Search terms were an exhaustive combination of relevant Medical Subject Headings (MESH terms) with an exclusion for animal studies: (Anorexia* OR Bulimia* OR Eating Disorder* OR Avoidant Restrictive Food Intake Disorder OR Purging Disorder OR Binge Eating Disorder) AND (Autism* OR Autistic* OR Asperger* OR Pervasive Developmental Disorder) AND NOT (Animal* NOT (Animal* AND Human*)). Databases were searched from inception until December 2021.

Study Selection

After removing duplicates using reference management software, titles and abstracts were screened for potential eligibility. Ten percent of the indicated studies were then double-checked by an independent researcher to confirm that the eligibility criteria were adhered to. A list of full text articles was then screened by both researchers until a consensus was achieved. Any disagreements were discussed with a third independent researcher with the majority decision being final. There was 90% agreement between the first two authors with only four studies that needed further discussion. Data was then extracted from each included study manually, with the outcomes of interest being any measure of psychological and/or behavioural change related to ED symptoms following the intervention.

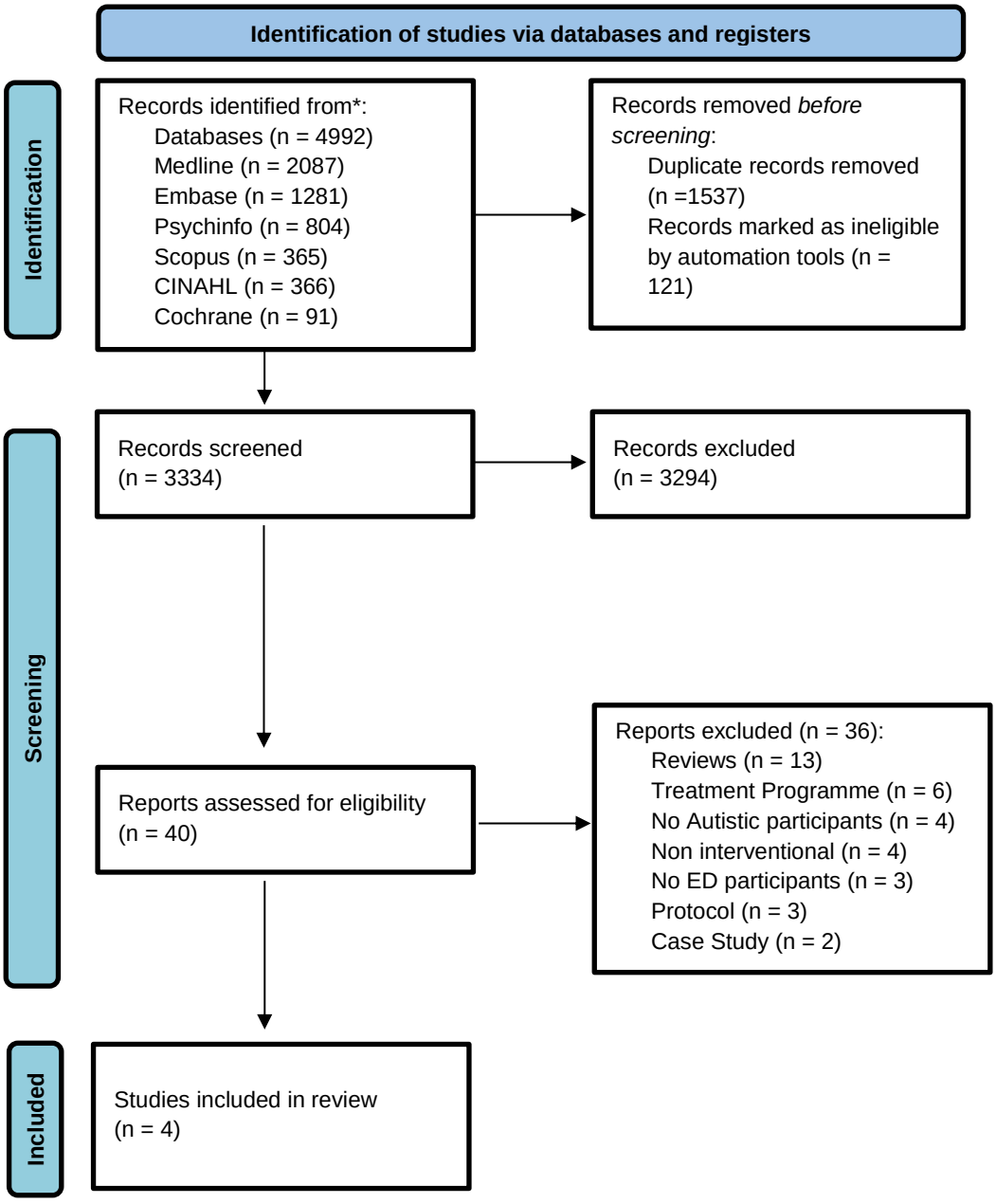
Quality of included studies

Methodological quality was assessed using the Newcastle-Ottawa Scale (NOS) (Wells et al., 2000). It was chosen because it was designed to appraise both case controlled, and cohort studies and allows for comparability between study design. Furthermore, it has good content validity and inter-rated reliability (Wells et al., 2000). The scale includes three main areas 1) Participant selection 2) comparability of the groups 3) Outcomes. Each study can score up to nine points with a higher score indicating better methodological quality.

Results

Initial search yielded 4992 hits with 1537 duplicates. Once duplicates and animal studies were removed automatically, there were 3334 abstracts and titles to screen.

Forty articles were considered at the full text stage and 36 were subsequently excluded, see Figure 1 below. At the full text stage, both reviewers agreed on 100% of the included articles.



Abbreviations: ED, Eating Disorder

Figure 1: PRISMA flow diagram.

Quality Appraisal

The methodological quality of the included studies were assessed using the NOS with individual scores depicted in Table 1. The quality scores of all studies were constrained by several shared methodological limitations that resulted in none scoring above a four out of the potential nine, indicating low to moderate quality. Firstly, all studies used self-report screening measures to categorise individuals into high and low autistic traits categories with the low autistic trait groups becoming the comparison group. Secondly, none of the studies controlled for any extraneous variables in the analysis except for Adamson et al. (2018) that used BMI as a covariate in both individual and group analyses to rule out the influence of a change in BMI in intervention outcome. This was the only methodological variability between the cohort studies that resulted in an extra point on the NOS. However, Giombini et al. (2022) used a randomized controlled trial (RCT) design which limits the impact of extraneous variables using a control group that received treatment as usual as a comparison. However, the NOS does not award more points for more robust study designs, which is a limitation of the scale.

Thirdly, In all studies, outcomes relied on self-reported measures at all time points, and none had a follow-up longer than the end of the intervention, making it difficult to see if any changes seen are lasting. Finally, drop-out rates varied from 28-38% across all studies where they utilised a naturalistic design and none included a drop out analysis. The evaluation of Cognitive Remediation and Emotional Skills Training (CREST) (Adamson et al., 2018) used an intend to treat analysis and therefore only included participants that had complete data, therefore excluding dropouts. However, there was no description or comparison between those with incomplete data and

those that made it into the study. One methodological strength is that all studies used individuals from the same service and used the same screening measure which negates the need to control for most sampling biases.

Interventions

Three of the included studies evaluated the efficacy of CRT in both individual and group formats for patients with a diagnosis of AN (Dandil, Smith, Adamson, et al., 2020; Giombini et al., 2022; Tchanturia et al., 2016b) whilst the remaining study evaluated CREST within the same sample and formats (Adamson et al., 2018). CRT attempts to target both cognitive flexibility and visuospatial abilities, known to be maintaining factors in EDs (Tchanturia et al., 2007). It is typically delivered at the start of inpatient treatment for EDs in both individual and group formats. CREST is an intervention developed to target emotional processes that are common in EDs including addressing alexithymia and social anhedonia (Davies et al., 2012; Tchanturia et al., 2014; Tchanturia et al., 2015). It is also typically delivered in inpatient settings in both individual and group formats and often following CRT.

Included Studies

All four included studies come from the same research group in the United Kingdom, with the same senior author present in each. An overview of the included studies and relevant information is included in Table 1. Three of the studies used an adult patient sample with one evaluating CRT in a child and adolescent service where they also grouped individuals by age. Three were cohort studies, using the AQ-10 as a cut-off

to compare between participants who received the intervention within the same time period. Giombini et al. (2022) utilised a feasibility RCT approach to compare consecutive admissions to an inpatient unit with the intervention being delivered at different time points. All four studies were based in inpatient ED services where participants also received treatment as usual (TAU) during the time of the intervention being evaluated.

Tchanturia et al. (2016) conducted an evaluation of group CRT in an inpatient ED service, with participants receiving five to six weekly sessions and evaluation completed at the start and end of the group programme. Although the study took place in a general ED service, AN was the only diagnosis represented in the study. Thirty-five female participants were categorised in to high and low scorers based on the cut-off of 6 on the AQ-10 (Allison et al., 2012) although AQ and ADOS were also mentioned without clarification as to which was used and with whom. Participants scoring above the cut-off on the AQ-10 were seen to have high levels of autistic traits with 14 individuals meeting this threshold. Dropout rate was 28% suggesting that many individuals do not complete the group but the ratio of which group they were categorised in was not reported so we are unable to tell if the group is less tolerated by either high or low autistic trait scorers. The high autistic traits group did not see any significant changes in any measure following the CRT group, suggesting they did not benefit from the intervention. The low autistic traits group did see a significant change in cognitive flexibility and motivation after the group, suggesting the those with high autistic traits respond differently to the group intervention.

Dandil et al. (2020) conducted an evaluation in the same ED service as the Group evaluation but instead evaluated outcomes from Individual CRT. Individual CRT was delivered twice a week for eight to 10 sessions. The same methodology for categorising the 99 female patients with AN into high and low autistic trait groups was used resulting in 25 in the high autistic trait group and 36 in the low autistic trait group, once dropouts were considered. The dropout rate for this study was 38%, meaning that that over a third of individuals did not complete individual CRT, for a variety of reasons. In individual format CRT, both high- and low-autism-trait groups showed significant improvements in set shifting and central coherence. This suggests that the method of delivery might impact the way the intervention is received and perhaps is more suitable for those with high autistic traits than CRT in group format.

There was one included study evaluating psychological interventions in children and young people (CYP). Giombini et al. (2021) evaluated individual CRT administered at different time points during an inpatient stay, using a RCT design. Individual CRT was compared with Treatment as Usual (TAU) with the control group going on to receive CRT with a delay. Autism was measured using the Social Responsiveness Scale, version 2 (SRS-2), parent version (Constantino et al., 2003) which uses a cut-off of 59 to indicate the possible presence of Autism, mild-severe range. The SRS-2 has been shown to be a useful and reliable tool for screening autism in adult females with AN (Kerr-Gaffney et al., 2020) but this is yet to be replicated in CYP. Eighty participants were consecutively recruited into the study with 18 (23%) scoring above cut-off and therefore being classified as having high autistic traits. Five males (6.3%) were included in the study although the group split on gender was not reported.

Patients with either AN or Atypical AN were included although how many with each diagnosis was not reported. Treatment as usual consisted of a re-feeding programme, MDT treatment including nursing, dietetics, and other psychological interventions i.e., CBT-ED, fortnightly Family Therapy (FT) and Psychological Groups. Both categorised autistic trait groups showed significant improvements in cognitive flexibility and spatial anticipation (executive functioning) but the low autistic trait group showed the largest change. The high autistic traits group did not significantly improve on either bigger picture thinking or set shifting, suggesting that they are responding to some elements of the CRT intervention but not others.

The final included study evaluated both group and individual cognitive remediation and emotional skills training (CREST) in the same inpatient treatment programme as the adult CRT studies (Adamson et al., 2018). The group CREST evaluation consisted of 62 females with AN and the individual CREST evaluation consisted of 66 females with AN. The same categorising method using the AQ-10 was utilised for this study with 21 individuals scoring above cut-off in both formats. In the group intervention high autistic traits were associated with higher alexithymia scores at baseline. Both high and low scorers significantly improved on motivation ability scores but neither group had significant changes in alexithymia or social anhedonia measures following group CREST. This suggests that in this cohort, group CREST was not an effective intervention for reducing alexithymia or social anhedonia, the two areas it is designed to target. In individual format, high autistic traits were associated with both high alexithymia and social anhedonia scores. There was a significant reduction in alexithymia for both groups following individual CREST and an increase in motivation ability subscale but no change for either group on social

anhedonia measures. This suggests that similarly to CRT, there is a better response to individual format interventions that those delivered in a group.

Table 1

Data extracted from included studies

Study	Design	Aims	Participants	Autism Assessment	Intervention	Outcome Measures	Results	NOS
Tchanturia et al., 2016	Cohort	Evaluation of group CRT for AN, comparing patients with high and low autistic traits	N = 35, Female (100%), Mean Age = 26.2 (SD = 7.7), ED Diagnosis = AN	AQ, AQ-10 & ADOS	Group CRT	DFlex, Motivational Ruler, CFS	• Low autistic traits are associated with a greater change in motivation ability to change subscale. • Greater improvement in cognitive flexibility after the CRT group compared to high autistic trait group. • High autistic traits associated with no significant changes in any measure post CRT group.	3
Adamson et al., 2018	Cohort	Evaluation of group and individual CREST for AN, comparing patients with high and low autistic traits	CREST Individual N = 66, Mean Age = 25.8 (8.75), ED Diagnosis = AN. CREST Group N = 62, Mean Age = 25.5 (11.25)	AQ-10	Group and Individual CREST	SAS, TAS, Motivational Ruler	Group: • High autistic traits are associated with high alexithymia scores. • Both groups motivation ability scores increase after group CREST. • No significant changes in TAS or SAS for either group. Individual: • High autistic traits associated with high alexithymia and anhedonia scores. • Significant reduction in alexithymia for both groups and increase in motivation ability subscale	4
Dandil, Smith, Adamson, et al., 2020	Cohort	Evaluation of individual CRT for AN, comparing patients with high and low autistic traits	N = 99, Female (100%), Mean Age = 23.9 (6.2), ED Diagnosis = AN	AQ-10	Individual CRT	DFlex, ROCF, Brixton	• Both groups showed significant improvements in Brixton, set shifting and ROCF central coherence after CRT	3
Giombini et al., 2022	RCT	Evaluation of individual CRT for children and young people with AN or Atypical AN	N = 80, Female (93.8%), Mean Age = 14.49 (1.75), ED Diagnosis = An & Atypical AN	SRS-2	Individual CRT	DFlex, WCST, Brixton, ROCF	• Both groups showed significant improvements in Brixton and Dflex with the low autism trait group showing a greater change • The High Autism traits group did not significantly improve in ROCF or WCST	3

Abbreviations: NOS, Newcastle Ottowa Quality Assessment Scale, RCT, Randomised Controlled Trial; CFS, Cognitive Flexibility Scale; SAS, Social Anhedonia Scale; TAS, Toronto Alexithymia Scale; Brixton, Brixton Spatial Anticipation Test; ROCF, Rey–Osterrieth Complex Figure; AQ-10, Autism Quotient 10-Item; AQ, Autism Quotient, ADOS, Adult Diagnostic Observational Schedule; DFlex, Detail and Flexibility Questionnaire; CRT, Cognitive Remediation Therapy; CREST, Cognitive remediation and emotional skills training; AN, Anorexia Nervosa; WCST, Wisconsin Card Sorting Test; SRS, Social Responsiveness Scale.

Discussion

This review aimed to pull together all available literature on how autistic individuals respond to standard ED interventions to help guide clinical decisions and adaptions to treatment pathways. Only four studies were identified in this broad review highlighting the lack of research in this area. All available literature focused exclusively on inpatients with AN, but early patterns are emerging, and future research is indicated. The two interventions highlighted in the review were CRT and CREST, both designed for inpatients with AN and delivered in both adult and CYP services. In both interventions, group format was not found to be helpful for individuals who score above cut-off on the AQ-10, indicating high levels of autistic traits. Whereas all studies suggest that both adults and CYP with high levels of autistic traits significantly improve on relevant outcome measures with the same intervention delivered in an individual format. This is in line with qualitative studies where autistic individuals note difficulties with managing the social aspects of a group, negatively impacting their ability to engage and therefore benefit from the interventions (Babb et al., 2021). However, qualitative data from the same study suggests that DBT group therapy was perceived as helpful, although this is perhaps due to its more directive, skills-based approach.

Individual cognitive remediation interventions have been shown to potentially be effective in improving cognitive functioning and social cognition in autistic women with AN (Dandil, Smith, Kinnaird, et al., 2020). Both adults and CYP saw significant improvements in outcomes over the course of the intervention. This is perhaps for a

variety of reasons related to the format of delivery. Firstly, CRT in an individual format is a semi-manualised approach that allows the clinician to be flexible, especially when not delivered in an RCT format where clinician adherence to the model and protocol is monitored (Tchanturia et al., 2007). The flexibility in the deliver allows for clinicians to make minor adjustments to suit an individual's needs, although these are often based on past experiences and not agreed adaptations supported with clinical evidence (Kinnaird et al., 2017). Furthermore, CRT in individual format is designed to be between 10 and 12 sessions, double the group format where patients receive five to six sessions. Perhaps the length of intervention had a significant influence on intervention outcomes however, as outcomes were only measured at the beginning and end of the intervention, we do not know whether the length of intervention has a significant effect on outcomes. However, the consistency in outcome measures across all included studies, perhaps due to the same senior author being involved in each study, means future studies can be easily compared to the outcomes seen in this research group.

However, there are many methodological flaws that limit the generalisability of the findings and need addressing in future intervention studies. All included studies except for the evaluation of CREST (Adamson et al., 2018) reported participant dropout rates or it could be ascertained from the data. There was a 28-38% drop-out rate across all three studies that reported it suggesting many participants do not complete the interventions. Although it can be for genuine reasons such as patients leaving inpatient treatment, Giombini et al. (2022) reports that 36% of dropout's self-discharged against medical advice and 24% disengaged with the broader therapy programme or from CRT

itself. This suggests that the complete data reported in this study reflects mainly individuals who are motivated to participate in treatment and therefore biases the findings and the subsequent interpretations. Furthermore, no study utilised dropout bias assessments and so we do not know whether autistic individuals are more or less likely to drop out from interventions. Future studies need to evaluate whether those that drop out from current ED interventions do so randomly or whether there is a systemic issue that is biasing the results limiting the generalisability.

No studies included in this review used full autism assessments to categorise individuals nor did any studies include individuals with an existing diagnosis. Instead, studies relied on autism screening measures as a proxy for the lack of autism assessments so we cannot be sure that those that were identified as having high autistic traits were autistic. Furthermore Giombini et al. (2022) utilised the SRS-2 as the screening tool which despite being validated for use in adult ED populations, is yet to be validated for use with CYP (Kerr-Gaffney et al., 2020). Screening measures are helpful to give clinicians and researchers guidance on whether an individual might benefit from adaptations however, they come with potential drawbacks. In a study of 476 adults seen in a national autism diagnostic service, the AQ-10 was a poor predictor of individuals receiving a clinical diagnosis of autism (Ashwood et al., 2016). In this clinical sample, the AQ-10 had acceptable sensitivity (77%) but poor specificity (28%), leading to many false positives, i.e., when people score above cut-off on the screener but turn out not to be autistic. There is an urgent need for studies with verified autism diagnosis outcomes

or more robust measures i.e., the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2).

This review demonstrates the lack of studies of EDs other than AN. Despite this review's search strategy including all ED diagnoses, there is a clear focus on AN in the small number of literature identified, especially when evaluating outcomes and autistic traits. This is understandable given the original studies identifying the similarities between autism and AN (Oldershaw et al., 2011) however, this review highlights that this bias for AN research has not yet been addressed. For example, recent systematic reviews show that there are very limited studies assessing autism or autistic traits in other ED diagnosis despite one small sample study suggesting that around 4.3% of Bulimia Nervosa patients score above cut off on the AQ-10 as well as 60% of individuals with Binge Eating Disorder (BED), although there were only five participants with BED included in the analysis (Numata et al., 2021). Furthermore, AN subtype was not taken into account on any of the included interventions, despite some evidence that those with restrictive AN differ significantly on central coherence than those with AN Binge-Purge subtype (Van Autreve et al., 2013). This is a target cognitive feature for interventions such as CRT and CREST but little is known about how autistic individuals with either sub-type respond potentially due to small sample sizes, there has not been enough power for sub-type analysis. However, a more recent systematic review by the same group concluded that there was not enough consistent evidence to draw definitive conclusions about whether the subtypes of AN differ significantly on SS or CC (Van Autreve & Vervaet, 2015).

All intervention studies had multiple uncontrolled confounding variables by being part of larger treatment programmes where individuals were receiving other active treatment elements at the same time. There is a heavy emphasis in the literature on the evaluation of inpatient treatment programmes, in both adult and child services and a lack of evaluations in primary and outpatient settings i.e., (Stewart et al., 2017; Tchanturia et al., 2019). This contrasts with the ratio of individuals who receive treatment in these settings with primary and outpatient services offering treatment to most individuals with ED. Inpatient services are often used as a last resort, for individuals who are most physically compromised and require a multidisciplinary (MDT) approach with 24/7 nursing care (NICE, 2017). Furthermore, treatment programme evaluations often do not adequately describe the elements of treatment involved and therefore make it hard to accurately evaluate what elements of the intervention autistic individuals find helpful and which ones they do not. For example, no studies that were reviewed for inclusion described in any detail what the treatment service or programme offers as interventions i.e., (Tchanturia et al., 2016a). This makes it almost impossible to replicate, limiting any findings to the service the study was undertaken in. There needs to be a move from research investigating how autistic individuals respond to treatment programmes towards how they respond to individual elements of treatment. This will allow for tailoring of treatment pathways to be based on robust clinical evidence rather than clinician experience (Kinnaird et al., 2017).

Furthermore, there is a complete lack of studies assessing the effectiveness of NICE-recommended outpatient first line interventions such as CBT-ED, MANTRA and Specialist Supportive Clinical Management for autistic individuals with an ED (NICE, 2017). There is a big push nationally towards an early intervention in eating disorders with initial findings suggesting improved outcomes for those that receive an intervention sooner (Brown et al., 2018). The current review did not identify any evaluations for autistic individuals receiving these first line interventions and is therefore an urgent gap in the literature that needs addressing. Future studies should explore the effectiveness of therapy approaches in outpatient settings to prevent many autistic individuals from needing inpatient care.

Despite the lack of evidence base for many interventions, clinicians and researchers push on developing adaptations to improve standard ED interventions for autistic individuals. Cognitive Behavioural Therapy (CBT) has been successfully adapted for individuals with autism and other mental health difficulties, namely anxiety disorders (Lang et al., 2010) however, modifications for AN are needed. Within adolescent studies, Family Based Therapy (FBT) is the most common and is recognised as the treatment of choice in NICE (NICE, 2017) however, there are currently no studies assessing efficacy for autistic individuals with pre and post treatment measures. It is therefore hard to say if autistic individuals respond to FBT in the same way as those without autism, considering the family element of the intervention might have similar drawbacks to group therapy i.e., autistic individuals finding it more difficult to manage the social environment (Babb et al., 2021). Recent adaptations for FBT for CYP with AN

has been suggested for individuals with both autism and AN but needs further research to ascertain efficacy of the modifications (Loomes & Bryant-Waugh, 2021). Other suggestions for adjustments to standard ED interventions come largely from from Qualitative papers and investigational research (Li et al., 2021; Tchanturia et al., 2020) and included suggestions such as; the use of handouts for each session, focus on practical skills and clinicians using a more directive approach. Furthermore service level changes i.e., a clearer structure and routine for inpatient services and accommodating sensory sensitivities, across all services i.e., lighting, noise and physical environment of therapy rooms, are equally important (Li et al., 2021).

In conclusion, this review showcases early findings on how individuals with high autistic traits respond to standard ED treatment. It also highlights the sparsity of the current evidence base, and methodological flaws in the current literature and gaps in current understanding. At this point, there is not yet a sufficient evidence base to guide clinicians on clinical pathway decisions. Furthermore, there are no studies yet assessing whether modifications to individual interventions provide a positive improvement in outcomes or are positively received by autistic individuals. All research available on this topic was conducted with the senior author who co-developed the CRT and CREST treatment manuals (Davies et al., 2012; Tchanturia et al., 2007; Tchanturia et al., 2014; Tchanturia et al., 2015). While this is not unusual, more research is needed outside of this research group to improve the generalisability of the findings. There are many gaps in the current research which are identified in this review and a synopsis is provided below. Future reviews could take a different approach to the search strategy by

screening all ED intervention studies and then identify ASD samples within full text articles. This would be a laboursome approach and outside scope of current paper but could identify more studies as ASD may not be stated in the title, abstract or keywords as traditionally screened for, but could be included as a secondary analysis.

Future Research Priority

- Robust evaluation of existing treatment for EDs, utilising full diagnostic assessments for all participants.
- Evaluation of more interventions for EDs, specifically those recommended by NICE.
- Evaluations to include other ED diagnoses and men.
- Evaluations of modified treatments for autistic individuals.

Commentary

Whilst writing this review, we became aware of another review published after the initial search was conducted that also assessed interventions for autistic women with eating disorders (Li et al., 2021). However, Li et al. (2021) focused more on treatment pathways in their review potentially due to the adapted service the same team are currently evaluating (Tchanturia et al., 2020). Furthermore, their search missed a key intervention study, despite it meeting their inclusion criteria (Adamson et al., 2018). This

review also included a more recent study that was likely published shortly after their search was completed (Giombini et al., 2022). The focus and findings of the two reviews are significantly different, despite a cross over in the area of interest. Finally, we acknowledge a few inconsistencies with how the Li et al. (2021) paper reports their findings with the table not accurately describing some of the included studies and missing data such as age ranges. We feel that this review is complementary to Li et al. (2021) with a different focus and two additional studies to evaluate.

Conflict of Interest

The author of this review is the primary author of one of the studies included in the review and a co-author of two others. However, the author does not receive any financial or other benefits related to this or previous work.

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Part 2: Empirical Paper

Title: Towards identifying a method of screening for autism amongst women with restrictive eating disorders

Abstract

Objective

Up to 37% of patients with anorexia nervosa score above cut-off on autism screening measures. These individuals typically have poorer outcomes from standard eating disorder interventions and could therefore benefit from adaptations. Accurately identifying these individuals is important for improving autism referral processes and clinical pathway decisions. This study's aim was to identify subscales of questionnaires measuring constructs associated with either autism or eating disorders that, when combined with traditional autism screening measures, would improve the ability to identify women with restrictive eating disorders who might benefit from a full autism assessment.

Method

160 women with restrictive eating disorders, with (n=42) or without (n=118) an autism diagnosis completed a battery of questionnaires. Using conditional stepwise binary logistic regression, we attempted to improve the autism spectrum quotient 10 item's (AQ-10) ability to discriminate between autistic and non-autistic women in a restrictive eating disorder sample.

Results

In a binary logistic regression model, the AQ-10 reliably discriminated between autistic and non-autistic women with an accuracy rate of 85% but had relatively low (69%) sensitivity, reflecting a high rate of false negatives. Adding three subscales to the model (Glasgow Sensory Questionnaire Auditory, Camouflaging Autistic Traits Questionnaire Compensation and Toronto Alexithymia Scale Externally Orientated Thinking)

significantly improved its differentiating ability (accuracy = 88%, sensitivity =76%, specificity = 92%).

Conclusions

We have identified three subscales that, when used in combination with the AQ-10, may help clinicians understand the pattern of autistic traits in their patients with a restrictive eating disorder. This can inform clinical decisions about whether to refer for a full autism assessment and whether to adapt standard eating disorder treatments to accommodate autistic traits. Future studies are needed to test the model in samples where participants have undergone a full autism assessment.

Highlights

- In a restrictive eating disorder sample, the AQ-10 accurately identified 85% of autistic women, but had a sensitivity of only 69%, indicating that it leads to many false negatives.
- Adding questions about auditory sensitivity, social compensation and externally orientated thinking, in combination with the AQ-10, led to an improved autism screening model (sensitivity = 76%, specificity = 92%).
- The model indicates additional autistic characteristics that when supplemented with the AQ-10 could improve autism screening tools for a restrictive eating disorder population.

Introduction

Up to 37% of patients with Anorexia Nervosa (AN) score above cut-off on autism screening measures (Boltri & Sapuppo, 2021; Huke et al., 2013). 'Autism spectrum disorder' (hereafter 'autism') is a neurodevelopmental condition that is associated with differences in social communication, and the presence of restrictive and repetitive patterns of behaviour (American Psychiatric Association, 2013). In this paper, in line with recommendations from the autism community, we will use the terms 'autism' and 'autistic person' (Bury et al., 2020; Kenny et al., 2016). AN is an eating disorder (ED) characterised by low body weight, an intense fear of gaining weight and extreme weight and shape concerns (American Psychiatric Association, 2013). According to epidemiological research, AN largely affects women, with estimates up to a 18:1 female to male ratio, whereas autism is a condition that is more common in boys and men with a 3:1 male to female ratio (Loomes et al., 2017; Nicholls et al., 2011; Raevuori et al., 2014). Autistic women are likely to be identified and diagnosed later in life than men, potentially because of a different clinical presentation that is missed by standard assessment tools (Gould & Ashton-Smith, 2011; Sedgewick et al., 2019). There is an increased recognition that autism research is skewed towards more male-typical presentations, partially due the diagnostic bias against girls and women. Therefore, more research is needed to improve the recognition of autism in women (Milner et al., 2019).

In patients with AN, higher levels of autistic traits as measured by screening tools are associated with poorer treatment outcomes, more severe presentations and longer stays in in-patient settings (Nielsen et al., 2015; Tchanturia et al., 2019). Furthermore, individuals with high autistic traits respond to standard ED treatment differently than those with low autistic traits (Li et al., 2021; Tchanturia et al., 2019; Westwood & Tchanturia, 2017). For example, patients with AN and high autistic traits show little clinical change after group psychotherapy interventions (Adamson et al., 2018; Baron-Cohen et al., 2013) but show significant improvements if the same intervention is delivered individually (Adamson et al., 2018; Dandil, Smith, Adamson, et al., 2020). It is not surprising that co-occurrence affects treatment outcomes, given that interventions are often designed and validated on non-autistic people. Reflecting evidence that autistic individuals may respond to elements of treatment differently, they could potentially benefit from adaptations to standard AN treatment (Babb et al., 2021; Tchanturia, 2021). Considering the different treatment trajectories for autistic individuals with AN, it is clinically important to be able to recognize autistic traits in an accurate and timely manner. Consequently, clinical services could adapt existing treatment to provide tailored interventions that take account of autistic traits, leading to potential improvements in outcomes (Adamson et al., 2020; Babb et al., 2021).

Most autistic women with an ED do not have an autism diagnosis when they first present to ED services (Brede et al., 2020; Kinnaird et al., 2019; Solmi et al., 2021). Currently, ED services struggle to identify those with undiagnosed autism (Babb et al., 2021). Crane and Hill (2016) surveyed 1000 parents in the UK whose children had gone

through autism assessments and found the average wait time was three and a half years. Wait times are similar in adult settings, partly reflecting the resource-intensive nature of autism assessment, which often takes two trained clinicians and a full day (Crane et al., 2016). Considering typical ED treatment lengths range from a few months to more than a year (Tchanturia et al., 2019), it is often not feasible for patients to receive a full autism diagnostic assessment within the timeframes of their ED treatment. Furthermore, clinicians in child and adolescent ED services report low confidence in identifying and referring on children for an autism assessment (Kinnaird et al., 2017). It is also the case that there will be people with an ED and with sub-clinical levels of autistic traits who, although not autistic, would still benefit from their distinct profile of strengths and difficulties being recognised and considered in treatment programmes (Saure et al., 2021). Clinical services need an efficient and reliable way to identify individuals with high levels of autistic traits at the start of their treatment to make timely clinical decisions around treatment and referral. However, there are currently no established screening methods that have been validated for use in ED services and instead services typically use the autism quotient screening questionnaires such as the AQ-10 (Allison et al., 2012) to indicate autism traits.

A study of 476 adults seen at a national adult autism diagnostic service found that, in this setting, the AQ-10 was a poor predictor of clinical diagnosis, with scores not significantly predicting diagnosis (Ashwood et al., 2016). In this clinical sample the AQ-10, whilst having acceptable sensitivity (77%), demonstrated poor specificity (28%), reflecting high rates of false positives. There is also a concern about the use of the AQ-

10 within ED populations due to the gender differences in the characteristics of autism, with the AQ-10 being originally validated in a mainly male sample (Allison et al., 2012). Clinicians commonly use the AQ-10 in ED settings because there are currently no alternatives of proven accuracy for use with ED patients; and because it is the only measure currently recommended by NICE for screening adults for autism (NICE, 2021).

For ED services, the accuracy of their autism screening tool impacts the extent to which autistic traits are identified in their patients with ED, with knock-on effects for the appropriateness of treatment and referrals (Westwood et al., 2017). Other self-report autism screening tools have been developed, for example the Ritvo Autism Asperger Diagnostic Scale (RAADS) (Ritvo et al., 2011) and used as a screening tool within ED services (Vagni et al., 2016). However, shortened screening tools such as the RAADS-14 (Eriksson et al., 2013) are developed to have high sensitivity to reduce the chance of false negatives, but this is often at the cost of low specificity in clinical samples, leading to high rates of false positives, i.e., scoring above threshold but not actually being autistic. Developing a screening method that has both high sensitivity and specificity for possible autism in ED populations will ensure that appropriate diagnostic referrals can be made and that ED clinicians have reliable and timely insight into the profile of autistic traits in their patients. Ultimately, this can lead to better treatment and outcomes for these patients.

One major issue that screening measures face when used with people with ED is that autism and AN have many overlapping features including cognitive (i.e., rigidity and

attention to detail), social and behavioural difficulties, and atypical eating behaviours (Kinnaird et al., 2019; Tchanturia et al., 2013). These shared features make it difficult for standard autism screening measures and diagnostic tools to distinguish between characteristics of autism versus those reflecting AN. Low specificity within some screening measures combined with an overlap between conditions mean that our current estimates of prevalence may be overinflated. The more severe the illness state of AN, such as requiring inpatient treatment, the higher the incidence of autistic traits, as assessed using screening measures (Westwood & Tchanturia, 2017). Due to the limited research using gold-standard diagnostic tools in these settings, it is difficult to ascertain whether these individuals have undiagnosed autism or whether the illness state of AN combined with the limitations of current self-report screening measures, is leading to some false positives.

Researchers and clinicians in eating disorder services have called for a pragmatic autism screening tool that can be used with predominantly with EDs to inform referrals and clinical decisions (Li et al., 2021; Westwood & Tchanturia, 2017). Such screening tool would need to be able to accurately discriminate between autism and EDs in mainly female populations without being too long or complex to be administered in routine clinical settings. The brevity of the AQ-10 gives it a narrow focus, especially in ED populations where clinical features can be confounding (Kinnaird et al., 2019; Tchanturia et al., 2013). The aim of the study was to generate a screening procedure that enhances the AQ-10's ability to differentiate autistic and non-autistic individuals in an ED sample. We did this by building a statistical model that can, in addition to the AQ-

10, draw on a range of additional self-report questionnaires that tap into diverse characteristics of both autism and EDs. The model can then help to inform future screening measure development by highlighting areas that are more likely to be specific to autism within an ED sample.

Method

The following procedures set out in this cross-sectional study followed the recommendations from the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement (Vandenbroucke et al., 2007).

Participants

Participants were recruited between October 2020 and April 2021 as part of a larger study (Babb et al., 2021; Brede et al., 2020) looking at eating difficulties in autistic women. Since data collection took place during the Covid-19 pandemic, recruitment was conducted predominantly online through existing clinical networks, autism and ED charities, and social media advertising. Participants were reimbursed £15 to complete a set of questionnaires taking approximately one hour. Participants were initially recruited into three groups: (i) those with an autism diagnosis and no ED diagnosis, (ii) those with a current restrictive eating disorder (RED) diagnosis and no autism diagnosis, and (iii) those with both autism and a current RED diagnosis. For this study, to maximise generalisability of findings to ED services, we only included participants with a RED,

thereby excluding from the analysis autistic women with no RED diagnosis. A RED was considered a diagnosis of either Anorexia Nervosa (AN), Atypical Anorexia Nervosa (AAN) or Avoidant Restrictive Food Intake Disorder (ARFID).

Individuals were screened for inclusion, given detailed information about the study and gave written informed consent before being asked to complete the battery of questionnaires. Inclusion criteria for the autistic group was a formal diagnosis of autism from a relevant clinician, as well as a current diagnosed RED. The non-autistic group consisted of individuals with a RED who self-disclosed they had never received a diagnosis of autism, were not currently referred for or currently undergoing an assessment for autism. Given the necessity to conduct remote data collection (due to the COVID-19 pandemic) we had to rely on the accuracy of participants self-reporting RED diagnosis, however, where clinical records were available and consent obtained, we cross-referenced with the current responsible clinician. However, we are unable to report the percentage of those who have cross-referenced diagnoses due to inconsistent data reporting methods. Further inclusion criteria for both groups were the absence of an intellectual disability and being over the age of 18 at time of recruitment. Finally, considering the methodology used in this study, only participants who completed all questionnaires could be included.

Measures and Procedure

Most of the study was conducted online due to the COVID-19 pandemic with only 27% of the participants completing measures in person. Once participants were screened for eligibility and consent was obtained, they were sent a secure link to a questionnaire platform to first provide some demographic and clinical data followed by completing 18 self-report measures. The self-report AQ-50, the full version of the shortened AQ-10 was administered. The AQ-10 can be obtained by selecting only the questions included in the shortened version, as per Ashwood and colleagues (2016). The Ritvo Autism Asperger Diagnostic Scale-Revised Screen (RAADS-14 Screen, (Eriksson et al., 2013)) another autism screening tool was also included, as well as the Adult Repetitive Behaviours Questionnaire-2 (RBQ-2A, (Barrett et al., 2018)), which directly assesses restricted and repetitive behaviours. The Eating Disorder Examination Questionnaire (EDE-Q, (Mond et al., 2004)) and the Swedish Eating Assessment for Autism Spectrum Disorders (SWEAA, (Sullivan & Karlsson, 1998)) were used to assess type and severity of the RED. The Hospital Anxiety and Depression Scale (HADS, (Zigmond & Snaith, 1983)), was used to assess anxiety and depression levels. Further measures were used to tap into domains relevant to both autism and EDs including: the Camouflaging Autistic Traits Questionnaire (CAT-Q, (Hull et al., 2019)), the Intolerance of Uncertainty Scale (IUS, (Lauriola et al., 2018)), the Interoception Sensory Questionnaire (ISQ, (Fiene et al., 2018)), the Glasgow Sensory Questionnaire (GSQ, (Robertson & Simmons, 2013)), the Toronto Alexithymia Scale (TAS, (Bagby et al., 1994)), the Brief Fear of Negative Evaluation (BFNE, (Leary, 2016)), the Social Phobia Inventory (SPIN, (Connor et al., 2000)), the Self-Compassion Scales (SCS, (Neff, 2003)), the Submissive Behaviour Scale (SBS, (Allan & Gilbert, 1997)), the Pride in Eating Pathology Scale

(PEP-S, (Faija et al., 2017)), the Body Shape Questionnaire (BSQ, (Arnow et al., 1995)) and finally, the Sociocultural Attitudes Towards Appearance Questionnaire-3 (SATAQ, (Thompson et al., 2004)).

Statistical Analysis

Analysis was performed using JASP (Version 0.16.1) for Macintosh (JASP Team, 2022), an open-source statistical software application. Demographic group differences were analysed using measures of central tendency and, where appropriate, student t-tests.

Normality of the distributions across all measures was assessed visually using histograms and homogeneity of variance was verified using the Levene test. Our method for generating a screening method followed two steps. First, in Step One, we identified measures that had the potential to contribute to the screening method. Second, in Step Two, we combined the identified measures from Step One in a statistical model to develop an efficient way of combining scores to screen for autism.

For Step One, parametric comparative analysis was performed for all questionnaires' total scores, and sub-scale scores if available. Independent-samples student t-tests were conducted to compare scores for autistic and non-autistic participants with a RED. Only those measures that were significantly different between groups were taken

forward to Step Two. Effects size calculations were conducted using Cohen's d (Cohen, 1992) to inform variable selection.

For Step Two, conditional stepwise binary logistic regression (dependent variable = autistic (1) / non-autistic (0)) was conducted first with AQ-10 alone, to define the comparison model. Then each questionnaire identified in Step One was added to the model in order of effect size until a questionnaire was added that did not significantly contribute to the model. This questionnaire was then removed and the next one added, until all questionnaires had been tested. If the contribution of a questionnaire became non-significant due to the addition of a subsequent questionnaire, then it was removed from the model. Significance was assessed with an alpha error rate of 0.05 (two-tailed) and multicollinearity between the variables was assessed at each stage using the variation inflation factor (VIF). For comparability, a cut-off value of 0.5 was chosen for all models, including the initial comparative AQ-10 model which typically has a cut-off of 0.6 (Allison et al., 2012). Models were compared using both adjusted Nagelkerke's r^2 and area under the curve (AUC) analysis derived from the models' receiver operating characteristic curve (ROC).

Ethics

The study was approved by the University College London's ethics committee (12973/002). Participants provided written informed consent after reading an information

sheet, approved by the ethics committee. Participants were fully debriefed at the end of the study and offered the opportunity to get a summary of their results.

Results

Participants

All participants were women with a RED, with 42 in the autistic group with a mean age of 29.2 years (SD=9.4), and 118 in the non-autistic group who had a mean age of 29.8 years (SD=9.1). Thirty-six (85.7%) of the autistic group and 107 (90.7%) of the non-autistic group identified ethnically as White British. All participants were living in and registered to a General Practitioner (i.e., family doctor) in the UK. Thirty-one (75.6%) of the autistic group had a current diagnosis of AN, seven (17%) had AAN and three (7%) were diagnosed with ARFID. The non-autistic group was comprised of 100 (84.8% of participants with a current AN diagnosis, 17 (14.4%) with AAN and one participant with ARFID. There was a small significant difference between the groups as to what age they received their RED diagnosis, $t(156) = -2.1$, $p < .05$, with the autistic group receiving a diagnosis on average at the age of 18.8 years (SD=5.8) and the non-autistic group receiving a diagnosis at the age of 21.9 (SD=8.1). BMI data was available for 91% of participants and demonstrates that the autistic group had an average BMI of 18.3 (SD=3.2) and the non-autistic group a BMI of 17.2 (SD=2.6) but this was not a significant difference, $t(144) = 1.94$, $p > .05$. There were also no significant difference

between the groups' lowest ever weight, $t(148) = 0.81$, $p > .05$, suggesting comparable RED severity.

Step One – identifying measures of potential value for autism screening

Significant differences between the autistic and non-autistic groups with small to large effect sizes were found across 52 full and subscale scores, with the AQ-10 providing the largest difference. There were no significant group differences in EDEQ global scores or any of its subscales, suggesting that the groups were similar in ED symptom severity. Descriptive statistics for the total scores on each measure are displayed for each group in Table 1. Group comparison significance and effect sizes with 95% confidence intervals (CI) are displayed in Table 2.

Table 1

Descriptive statistics for each group for all included measures.

Measures	Group	N	Mean	SD	Min	Max
AQ-10	Non-autistic	118	4	2	0	10
	Autistic	42	8	2	4	10
RAADS-14	Non-autistic	118	16	11	0	42
	Autistic	42	34	7	17	42
RBQ-2A	Non-autistic	118	2	0	1	3
	Autistic	42	2	0	2	3
GSQ	Non-autistic	118	50	23	4	137
	Autistic	42	79	26	39	164
CAT-Q	Non-autistic	118	103	25	43	166
	Autistic	42	131	21	88	164
TAS-20	Non-autistic	118	60	14	27	96
	Autistic	42	69	12	28	84
SWEAA	Non-autistic	118	15	3	8	24
	Autistic	42	18	3	13	26
HAADS-D	Non-autistic	118	10	4	0	20
	Autistic	42	10	6	0	21
HAADS-A	Non-autistic	118	14	4	4	20
	Autistic	42	15	4	5	21
IUS	Non-autistic	118	43	10	20	60
	Autistic	42	49	8	26	60
ISQ	Non-autistic	118	76	27	28	139
	Autistic	42	94	32	20	140
SBS	Non-autistic	118	39	12	13	64
	Autistic	42	44	10	22	64
SPIN	Non-autistic	118	39	14	5	68
	Autistic	42	45	13	19	68
SATAQ	Non-autistic	118	101	28	38	150
	Autistic	42	89	28	38	150
SCS	Non-autistic	118	33	15	11	72
	Autistic	42	30	15	11	71
PEPS	Non-autistic	118	83	26	19	114
	Autistic	42	76	26	17	113
BFNE	Non-autistic	118	52	8	17	60
	Autistic	42	50	11	26	60
EDE-Q Global	Non-autistic	118	4	1	1	6

	Autistic	42	3	1	1	6
BSQ	Non-autistic	118	141	38	47	198
	Autistic	42	125	37	47	189

Autism Spectrum Quotient (AQ-10), Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-14), Eating Disorder Examination Questionnaire (EDEQ), Hospital Anxiety and Depression Scale (HADS), Camouflaging Autistic Traits Questionnaire (CAT-Q), Swedish Eating Assessment for Autism Spectrum Disorders (SWEAA), Intolerance of Uncertainty Scale (IUS), Interoception Sensory Questionnaire (ISQ), Glasgow Sensory Questionnaire (GSQ), Toronto Alexithymia Scale (TAS), Adult Repetitive Behaviours Questionnaire-2 (RBQ-2A), Brief Fear of Negative Evaluation (BFNE), Social Phobia Inventory (SPIN), Self-Compassion Scales (SCS), Submissive Behaviour Scale (SBS), Pride in Eating Pathology Scale (PEP-S), Body Shape Questionnaire (BSQ), Sociocultural Attitudes Towards Appearance Questionnaire-3 (SATAQ).

Table 2

Group comparisons for all measures total and subscale scores

				95% CI						95% CI	
Measure	**t**	**p**	**Cohen's d***	**Lower**	**Upper**	**Measure**	**t**	**p**	**Cohen's d***	**Lower**	**Upper**
AQ-10	10.07	< .001	1.81	1.40	2.21	ISQ Total	3.47	< .001	0.62	0.26	0.98
RAADS-14 Total	9.62	< .001	1.73	1.33	2.13	IUS Total	3.44	< .001	0.62	0.26	0.98
RAADS-14 Mentalizing Deficit	9.04	< .001	1.62	1.23	2.02	GSQ Gustatory Hypo	3.43	< .001	0.62	0.26	0.98
RBQ-2A Total	8.95	< .001	1.61	1.21	2.00	SWEAA Purchase of Food	3.33	0.00	0.60	0.24	0.96
RAADS-14 Sensory Reactivity	8.59	< .001	1.54	1.15	1.93	GSQ Vestibular Hyper	3.14	0.00	0.56	0.21	0.92
GSQ Auditory Total	8.51	< .001	1.53	1.14	1.92	GSQ Tactile Hypo	3.01	0.00	0.54	0.18	0.90
CAT-Q Compensation	7.71	< .001	1.39	1.00	1.77	SWEAA Mealtime Surroundings	2.86	0.01	0.51	0.16	0.87
GSQ Auditory Hyper	7.36	< .001	1.32	0.94	1.70	SBS Total	2.57	0.01	0.46	0.11	0.82
RAADS-14 Social Anxiety	7.05	< .001	1.27	0.89	1.64	SWEAA Simultaneous Capacity	2.56	0.01	0.46	0.10	0.82
RBQ-2A Repetitive Motor Behaviours	7.03	< .001	1.26	0.88	1.64	SWEAA Pica	2.50	0.01	0.45	0.09	0.80
RBQ-2A Insistence Sameness	7.03	< .001	1.26	0.88	1.64	IUS Inhibitory Anxiety	2.42	0.02	0.43	0.08	0.79
GSQ Auditory Hypo	6.82	< .001	1.23	0.85	1.60	SPIN Total	2.38	0.02	0.43	0.07	0.78
TAS Difficulty Describing Feelings	6.75	< .001	1.21	0.84	1.59	SWEAA Social Situation	2.28	0.02	0.41	0.06	0.77
GSQ Total	6.75	< .001	1.21	0.83	1.59	SWEAA Eating Behaviour	1.65	0.10	0.30	-0.06	0.65
GSQ Total Hyper	6.71	< .001	1.21	0.83	1.58	GSQ Olfactory Hypo	1.54	0.13	0.28	-0.08	0.63
TAS Difficulty Identifying Feelings	6.56	< .001	1.18	0.80	1.55	HADS-A	1.28	0.20	0.23	-0.12	0.58
GSQ Vestibular Hypo	6.55	< .001	1.18	0.80	1.55	CAT-Q Masking	1.08	0.28	0.19	-0.16	0.55
GSQ Visual Total	6.51	< .001	1.17	0.79	1.54	SWEAA Hunger Satiety	0.92	0.36	0.17	-0.19	0.52
TAS Externally Oriented Thinking	6.43	< .001	1.16	0.78	1.53	HADS-D	-0.14	0.89	-0.03	-0.38	0.33
CAT-Q Total	6.25	< .001	1.12	0.75	1.50	PEP-S Capturing Others Attention	-0.17	0.87	-0.03	-0.38	0.32
GSQ Visual Hyper	6.18	< .001	1.11	0.74	1.48	SWEAA Other Behaviour Disturbed Eating	-0.67	0.51	-0.12	-0.47	0.23

GSQ Total Hypo	6.06	< .001	1.09	0.72	1.46	PEP-S Healthy Weight Eating	-0.94	0.35	-0.17	-0.52	0.18
GSQ Proprioception Total	5.85	< .001	1.05	0.68	1.42	SATAQ Internalisation Athlete	-1.15	0.25	-0.21	-0.56	0.15
GSQ Vestibular Total	5.64	< .001	1.01	0.64	1.38	SCS Total	-1.18	0.24	-0.21	-0.56	0.14
CAT-Q Assimilation	5.54	< .001	1.00	0.63	1.36	PEP-S Weight Loss Food Control Thinness	-1.23	0.22	-0.22	-0.57	0.13
GSQ Proprioception Hyper	5.34	< .001	0.96	0.59	1.33	PEP-S Total	-1.39	0.17	-0.25	-0.60	0.10
GSQ Tactile Hyper	5.26	< .001	0.95	0.58	1.31	BFNE Total	-1.57	0.12	-0.28	-0.63	0.07
GSQ Visual Hypo	5.21	< .001	0.94	0.57	1.30	PEP-S Outperforming Others Social	-1.65	0.10	-0.30	-0.65	0.06
GSQ Tactile Total	4.93	< .001	0.89	0.52	1.25	SATAQ Pressures	-2.00	0.05	-0.36	-0.71	-0.01
GSQ Proprioception Hypo	4.81	< .001	0.86	0.50	1.23	EDE-Q Restraint	-2.05	0.04	-0.37	-0.72	-0.01
GSQ Olfactory Hyper	4.23	< .001	0.76	0.40	1.12	EDE-Q Weight Concerns	-2.08	0.04	-0.37	-0.73	-0.02
SWEAA Perception	4.12	< .001	0.74	0.38	1.10	SATAQ Information	-2.25	0.03	-0.40	-0.76	-0.05
GSQ Gustatory Total	4.11	< .001	0.74	0.38	1.10	EDE-Q Eating Concerns	-2.34	0.02	-0.42	-0.78	-0.07
TAS Total	4.06	< .001	0.73	0.37	1.09	SATAQ Internalisation General	-2.36	0.02	-0.42	-0.78	-0.07
IUS Prospective Anxiety	4.04	< .001	0.73	0.36	1.09	SATAQ Total	-2.40	0.02	-0.43	-0.79	-0.08
GSQ Olfactory Total	3.86	< .001	0.69	0.33	1.05	BSQ Total	-2.45	0.02	-0.44	-0.80	-0.08
SWEAA Motor Control	3.78	< .001	0.68	0.32	1.04	EDE-Q Global Score	-2.66	0.01	-0.48	-0.83	-0.12
GSQ Gustatory Hyper	3.70	< .001	0.67	0.31	1.02	EDE-Q Shape Concerns	-2.71	0.01	-0.49	-0.84	-0.13
SWEAA Total	3.57	< .001	0.64	0.28	1.00						

Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-14), Autism Spectrum Quotient (AQ-10), Eating Disorder Examination Questionnaire (EDEQ), Hospital Anxiety and Depression Scale (HADS), Camouflaging Autistic Traits Questionnaire (CAT-Q), Swedish Eating Assessment for Autism Spectrum Disorders (SWEAA), Intolerance of Uncertainty Scale (IUS), Interoception Sensory Questionnaire (ISQ), Glasgow Sensory Questionnaire (GSQ), Toronto Alexithymia Scale (TAS), Adult Repetitive Behaviours Questionnaire-2 (RBQ-2A), Brief Fear of Negative Evaluation (BFNE), Social Phobia Inventory (SPIN), Self-Compassion Scales (SCS), Submissive Behaviour Scale (SBS), Pride in Eating Pathology Scale (PEP-S), Body Shape Questionnaire (BSQ), Sociocultural Attitudes Towards Appearance Questionnaire-3 (SATAQ).

*A positive result on the Cohen's D indicates a higher score in the autistic group, a negative score indicates a higher score in the non-autistic group.

Step Two – identifying autism screening model

Comparison model

Binary logistic regression was conducted to classify participants into either the autistic or non-autistic group using the AQ-10. The model was statistically significant (x^2 (158) = 72.3 $p < .01$), indicating that the AQ-10 significantly improves the model's ability to discriminate between the two groups over random chance alone. The model explained 53.2% (Nagelkerke's r^2) of the variance and correctly classified 85.0% of cases (Sensitivity 69.1% (95% CI 52.9 – 82.4), Specificity 90.7% (83.9 – 95.3)) with an AUC of 0.90. The AQ-10 within the regression model correctly classified 29 out of 42 individuals within the autistic group and 107 out of 118 in the non-autistic group.

Improving the Model

Additional variables were then included using the manual multistep procedure described above in 'Analysis'. The first measure to provide a significant, albeit modest, addition to the model was the RAADS-14 which increased the model's explanatory power to 58.0% and correctly classified 83.8% of cases (Sensitivity 71.4% (55.4 – 84.3), Specificity 88.1% (80.9 – 93.4)) with an AUC of 0.92. The addition of the GSQ Auditory subscale only increased the specificity with one additional participant being correctly identified as having autism. The addition of the GSQ Auditory subscale meant the RAADS-14 became non-significant and was therefore dropped from the model. Further iterations

were constructed until no more significant variables increased the accuracy of the model. The final model consisted of the AQ-10 along with the three subscales: GSQ Auditory, CAT-Q Compensation and TAS Externally Oriented Thinking (EOT). This model increased the explanatory ability to 65.8% and correctly classified 88.1% of cases (Sensitivity 76.2% (60.6 – 88.0), Specificity 92.4% (86.0 – 96.5)) with an AUC of 0.94. The model correctly classified 32 of the 42 individuals from the autism group, an increase of three over AQ-10 alone and correctly classified 109 out of 118 for the no autism group, an increase of two over AQ-10 alone and an overall increase of five participants, representing 3.1% improvement in accuracy. The model also marginally outperformed the full AQ which achieved an explanatory power of 59.5% and correctly classified 86.9% of cases (Sensitivity 76.2% (60.6 – 88.0), Specificity 90.7% (83.9 – 95.3)) with an AUC of 0.92. The AQ-10, inclusion of RAADS-14 and the final model are depicted in Table 3 below.

Table 3

Binomial logistic regression model for predicting autism within a restrictive eating disorder sample.

				Wald Test				95% Confidence Interval Exp(B)	
Variables	**B**	**SE**	**z**	**Wald**	**df**	**p**	**Exp(B)**	**Lower**	**Upper**
Step 1[a]									
(Intercept)	-5.10	0.77	-6.65	44.20	1	< .01	0.01	0.01	0.03
AQ-10	0.68	0.11	6.32	39.99	1	< .01	1.97	1.60	2.43
Step 2[b]									
AQ-10	0.40	0.13	2.99	8.91	1	< .01	1.49	1.15	1.93
RAADS-14	0.10	0.03	2.79	7.77	1	< .01	1.10	1.03	1.18
Step 3[c]									
AQ-10	0.54	0.14	3.76	14.12	1	< .01	1.72	1.30	2.28

				Wald Test				95% Confidence Interval Exp(B)	
Variables	**B**	**SE**	**z**	**Wald**	**df**	**p**	**Exp(B)**	**Lower**	**Upper**
GSQ Auditory Thinking	0.42	0.12	3.38	11.44	1	< .01	1.52	1.19	1.93
CAT-Q Compensation	0.07	0.03	2.50	6.27	1	< .05	1.07	1.01	1.13
TAS Externally oriented Thinking	-0.02	0.01	-2.71	7.35	1	< .01	0.98	0.97	1.00

a. Autism Spectrum Quotient (AQ-10).
b. Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-14).
c. Glasgow Sensory Questionnaire (GSQ), Camouflaging Autistic Traits Questionnaire (CAT-Q), Toronto Alexithymia Scale (TAS).

Secondary Analysis

There were 21 (18%) participants within the RED group that, despite self-reporting an absence of autism, scored above cut-off on both autism screening measures, AQ-10 and the RAADS-14 and above cut-off on the restricted and repetitive behaviours scale the RBQ-2A. Removing them from the analysis and re-running the model increases the explanatory power to 86.1% and correctly classified 93.5% of the cases (Sensitivity 85.7% (71.5 – 94.6), Specificity 96.9% (91.2 – 99.4)). This marginally outperforms the AQ-10 with the same participants removed, by correctly identifying one more case in the non-autism group.

Discussion

This study aimed to identify a brief questionnaire-based screening procedure for autism within a sample of women with a RED. We intended to identify a screening method that can be tested subsequently in an independent sample. When comparing the questionnaire responses of the autistic and non-autistic groups, the largest significant differences were unsurprisingly the three autism measures of diagnostic features of autism, indicating their efficacy in discriminating between autistic and non-autistic women in a RED sample. However, none of them were included in our final screening model, suggesting it is unlikely to be helpful to screen for autism in an ED group with more than one autism screening measure. However, including questionnaire subscales on auditory sensitivity (GSQ), social compensation (CAT-Q) and externally orientated thinking (TAS) significantly improved the model's ability to discriminate between the two groups. This suggests the possibility that including these questionnaire subscales could increase the accuracy of the screening process. Including these subscales result in a screening process involving 33 questions, including the ten from the AQ-10, and correctly identified five more individuals out of 160 (3.1%) compared to using the AQ-10 alone. This means 3.1% of women with a RED could go on to receive a more appropriate referral and clinical treatment pathway as a direct result of more accurate screening.

Considering the limitations of the AQ-10 as a screening tool within ED populations, it performed well within this RED sample, correctly classifying 85% of autistic women with only 10 questions. Our findings have some consistencies with the original validation of the AQ-10 with identical specificity rates of 91% (Allison et al., 2012). However, The

AQ-10 in our RED sample had a 69% sensitivity rate, suggesting the presence of many false negatives, an almost 19% reduction versus the validation study. This suggests that in our RED sample, the AQ-10 was less sensitive when identifying autistic people than in a general population sample. Also, our finding of relatively low sensitivity and high specificity for the AQ-10 is in contrast to Ashwood et al. (2016), who found a high sensitivity rate of 77% but a very low specificity rate of 28%, due to many false positives. One possibility is that our finding of low sensitivity for the AQ-10 arose, in part, because our sample comprised only women; whereas the AQ-10 has been clinically validated on majority male samples (Wigham et al., 2019). The AQ-10 in our RED sample does a good job at identifying those that do not have autism with a 9% false positive rate but misses 31% of individuals who are in fact autistic. However, overall accuracy is important when making clinical decisions for patient care, and we also need to consider the impact on the individual of scoring negative on a screening tool when they are in fact autistic and could therefore benefit from an appropriate referral and treatment adaptations.

Including the auditory sensitivity subscale from the GSQ, which includes both hyper- and hypo- sensitivity, is the biggest contributor to the improved model suggesting that it might be a more specific feature of autism that is less likely to be seen in those with a RED without autism. Auditory sensitivity is not considered to be characteristic of RED, but it is a recognised feature of autism and is commonly included in screening and assessment measures (American Psychiatric Association, 2013). Furthermore, the AQ-10 includes only one question that relates to auditory hypersensitivity, the remaining

questions tap into domains such as social communication and cognitive differences that can be present in both autism and REDs (Westwood et al., 2017). The GSQ has been shown to be highly correlated with the full AQ, meaning that using the full versions of both measures would likely be unhelpful (Ujiie & Wakabayashi, 2015). However, within the GSQ validation study, the auditory subscale was one of the least correlated to the full AQ and therefore more likely to make a unique contribution to a screening questionnaire that already includes the shortened AQ (Sapey-Triomphe et al., 2018).

The second significant addition to the improved model was the compensation subscale from the CAT-Q, which is defined as strategies actively employed to compensate for difficulties in social situations, for example, mirroring body language or learning social cues from movies and books (Hull et al., 2019). This is another set of characteristics that are likely to be prevalent amongst autistic women, who commonly utilise camouflaging strategies to manage the challenges of being autistic in social environments that are generally designed by and for non-autistic people (Cook et al., 2021). Social camouflaging is one of the many reasons why some women go undetected until much later in life, in comparison to males who typically receive a diagnosis at a younger age (Ratto et al., 2018). Furthermore, women are likely to score differently to men on the gold standard diagnostic observation measure due to the measure focusing on social communication difficulties, which are more likely to be successfully masked by women (Ratto et al., 2018). Social camouflaging is less common in autistic males (Cook et al., 2021) and it is therefore uncertain whether this subscale would remain significant in a sample that included males.

The final subscale that significantly contributed to the improved model was the TAS Externally Orientated Thinking Scale, which is one aspect of alexithymia. Alexithymia is broadly described as a tendency to focus on concrete external events, rather than attend to one's inner experience such as feelings and fantasies (Bagby et al., 1994). Alexithymia is a trait found in both REDs and autism, especially in terms of difficulties identifying and describing one's own feelings (Nuske et al., 2013), which were captured in other subscales of the TAS. However, this study suggests that externally oriented thinking is an aspect of alexithymia more likely to be seen in autism. The TAS Externally Oriented Thinking Subscale was the weakest addition to the model and became a non-significant contributor once women that may have been autistic were removed from the RED only group. This suggests that if the groups were screened using a full autism assessment, the TAS externally oriented thinking is not likely to significantly contribute to the differentiating ability of the model.

Limitations

Whilst participants in the non-autistic group were carefully screened for not having an autism diagnosis, nor a suspected diagnosis, there is a likelihood that some may actually be undiagnosed autistic women. Indeed, 18% of participants in the non-autistic group scored above clinical cut-off on both screening measures and a measure assessing a core diagnostic feature of autism. This will likely have caused us to underestimate the true validity of our model by depressing specificity and positive

predictive value estimates (i.e., some findings that in our study are counted as false positives will be true positives). Future studies will need independent face-to-face autism assessment of all participants, including those in the non-autistic group, to investigate thoroughly our proposed algorithm.

Due to the study design, we chose to use only complete data where participants had finished all questionnaires and therefore excluded participants who stopped before reaching the end. The data therefore excludes individuals who felt unable to finish the whole battery of questionnaires, for a multitude of reasons and no attempts were made to chase these up. The included data may therefore represent those more able to complete 19 self-report questionnaires, which may bias the data. However, this was kept to a minimum when the study moved online due to the questionnaire platform forcing complete responses and providing prompts for participants to complete. Future research could attempt to chase those that do not complete and support them to finish.

Furthermore, the measure selection methodology utilised multiple between group comparisons which naturally increases the likelihood of false positive findings, i.e., finding a significant difference between the groups when really there is no difference. Future research could use backwards or forwards stepwise regression methods in order to avoid this limitation but would need sufficient power to do so, depending on the number of included measures.

Our findings indicate areas of assessment that could improve traditional autism screening measures within a RED population. However, it should not be used clinically until further validation is completed in an independent sample with participants who have undergone full autism diagnostic assessments and a reliable cutoff is ascertained. Furthermore, the sample consisted of only adult women and therefore we cannot be sure if our findings would be replicated in male populations or those under 18.

Conclusion

In conclusion, improvements in autism screening measures for individuals with REDs should look towards questions in the areas of auditory sensitivity, social compensation, and externally orientated thinking. These areas are more likely to be specific to autism and less likely to be influenced by non-autistic RED symptoms, which means they may be helpful in differentiating between the two conditions. This can lead to more accurate referrals to the autism diagnostic pathway and the application of appropriate treatments. Importantly, an accurate autism screening measure can support clinicians in understanding the profile of autistic traits in their patients with REDs, so that treatment adaptations can be considered regardless of diagnostic status. Furthermore, identifying autistic characteristics that improve the identification of possible autism in women with a RED reduces the chance of overinflation from autistic-like traits that can be exaggerated in more severe illness states of REDs (Westwood & Tchanturia, 2017). Future research is needed to test the model we generated in a larger sample where all participants are given full autism diagnostic assessments to confirm group eligibility. Our model had

stronger specificity (91%) than sensitivity (76%), which is not ideal for pre-assessment screening, where false negatives are more problematic than false positives. Therefore, as part of future work to test and develop the screening model we propose, it will be useful to investigate how the threshold for possible autism can be manipulated, to further reduce false negative rates.

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Part 3: Critical Appraisal

My critical reflections on the process of conducting the thesis.

Previous Experiences

Having worked in Eating Disorder (ED) settings for about four years prior to starting training, it was an easy decision to continue this line of research. Having worked in quite a research heavy team in the ED service as the most junior researcher, I would follow the research interests of the senior researchers in the team. Some of this research I found fascinating and inevitably some of it was less interesting to me. Conducting research as part of the Doctorate in Clinical Psychology was an opportunity for me to explore my own research interests within the context of a new research team with a focus predominantly on autism. This has helped me develop as a researcher and become more aware of the realities of clinical research.

Interestingly, it was an opportunity to look at my own research again, some six years later, with the lens of more experience and training. A lot of the knowledge and information I drew upon throughout the thesis process has a foundation in my past experiences but has been update along the way. For example, I have more of an appreciation now for using a person-centered approach when describing autism in clinical journals. My original papers six years ago would be very diagnostic and clinical language heavy which is not how autistic individuals want to be referred to. Indeed, most people do not want to be known as a clinical diagnosis, especially when it includes

the term “disorder”. Using more person-centered language in clinical journals helps to bridge the gap between research and patients and respects them as individuals.

Another learning point related to my past experience was having the opportunity to evaluate some of my own work when conducting the systematic review. When you are outside of the team with which it was written and in a different context you can be more critical of your own work. It taught me the importance of using quality assessment tools to guide research design as the different between a poor and good research design is often minor changes at the initial stage. It also helped me to appreciate the practical realities of naturalistic clinical research. From a research methods design perspective, it would be easy to discount most of my previous studies due to the numerous methodological flaws. However, working in these settings gives you insight as to why dropout rates are so high in naturalistic designs and why you often use quick and easy measures over longer but more robust ones.

Dilemmas

Joining an existing research project

The decision to join an existing research project was born from experience navigating the complex nature of research ethics in previous roles and not wanting to put myself through that unless absolutely necessary. There were many advantages to joining a study team that already had the foundations of the research sorted. For example, ethics

was already granted and only a minor amendment was needed to cover the scope of the research I wanted to conduct for my thesis. Furthermore, information sheets, consent and feedback forms needed only minor tweaks to allow for the scope of my research question. However, it is not all plain sailing when you join an established team, and I learned a few cautionary tales along the way.

Potentially due to the arduous process of setting up a large study from scratch, including all the little details, the study team naturally end up forgetting some of the decisions and processes they have made along the way. For example, how to connect an existing study to a new Qualtrics user account. When you did not set up the processes yourself nor were part of the early stages of the study development and recruitment, you find yourself asking a lot of questions and not always getting straight forward answers. This extends to using datasets not built by you, understanding abbreviations and shorthand is rather difficult when you were not the one to decide what “CAP” stood for. Just like starting any new job, you need to account for a learning process that involves being brought up to speed on all the processes.

One concrete example was that the participant groups were coded one, two and three in the dataset, perfectly logical however, when using the data for a logistic model the groups need to be denoted zero or one. This was only discovered after completing the analysis and results and wondering why the data didn’t quite add up. The statistical software, in this case JASP, will use the higher number as your “exposed” group and results in your data being reversed. The importance of a second pair of eyes, especially

an experienced supervisor, cannot be understated because spotting the error was only found when taking a step back and trying to make sense of the output considering the raw numbers. In these moments it is also helpful to go back to basics and work out the key calculations by hand, this helps to give clarity of thought on what is actually happening to the data.

as much as you inherit the positive work that the team have already completed and put in place you also inherit any backlog or difficulties. Due to the COVID-19 pandemic the team had to quickly pivot to conduct the research online, this was a massive time burden for the team and understandably some of the tasks such as sending participants their personalized results in a report were pushed down the priority list. In these times it is important to be a team player, especially when joining a new team when it is important for you to establish yourself as a helpful addition rather than a burden. By helping the team with their backlog and providing feedback for over half of the research participants, not only did I help participants to get timely results, as promised in the information sheet but also the team were grateful for my contribution. The largest benefit of joining an existing team is that it allows you to use data that you would otherwise not have had the time or the scope to collect yourself. The full dataset for the empirical paper included over 250 participants which would simply not be feasible to recruit and assess by yourself or even with a colleague in the short amount of time a Clinical Psychology trainee has to conduct participant recruitment.

In the future, if I was to join an existing research team again, I would consider what questions I might need answers to in the future and not wait until I discover I need a crucial bit of information when PhD students have already finished and left. Furthermore, I would attempt to gauge right at the beginning what stage the study is at and whether they are behind or have a backlog. I would then consider whether it is feasible within the confines of my existing duties, to support the team to bring the project up to speed and manage expectations accordingly.

Publishing a thesis

Many Clinical Psychology Trainee's go on to publish their thesis in peer reviewed journals however, few publish it before it has been submitted. Tempted by the offer of submitting the empirical paper to a special edition of a high impact journal, I agreed to meet a deadline that would otherwise be more than three months early. Whilst on paper this is all very positive, it is easy to forget how much time the revisions process and editorial adjustments take. For example, deadlines set by journals are often very short for edits, often days rather than weeks. Furthermore, due to the thesis needing to be original work and the tight deadline of the journal, it was not until last minute that the co-authors were given an opportunity to contribute to the submission. Perhaps the system is designed with predominantly academics in mind where they are more likely to have an office or space and it is part of the job description to publish research. However, as a clinical researcher in training, there were often conflicting deadlines throughout. When the course needs you to prioritise one thing, the journal is chasing you for a response.

Good open communication with the editor is key to manage conflicting deadlines as there is often more flexibility when needed. The benefits of the process mean that you get to hone the paper through independent feedback and criticism that ultimate improves the quality of the work.

Conflict of interest

One unforeseen dilemma in the process of conducting a systematic review is when your own studies dominate the review. Despite the widest search possible to cast the largest net and capture any possible study on how autistic individuals respond to Eating Disorder treatment, only four studies were identified. Out of the four included studies, three were studies that I had some influence in, either as a co-author or one as the primary author. I was not expecting this result and I was genuinely surprised that no one else has conducted research in this field. On the one hand, it highlights the lack of data on the topic and gives an opportunity to pull it all together. On the other hand, it brings with it some ethical challenges. For example, when analysing the methodological rigor of the study I am effectively marking my own homework. Using objective tools in this instance is imperative to reduce any potential bias. When you have spent some time in an area of research, especially when it is relatively niche within an area, you spend a lot of time referencing yourself and using your own past research to justify and support your current and future research. This can't always be helped but it emphasizes the importance of dissemination in order to engage other research teams to replicate your findings in different settings.

Managing expectations

One learning point from the process of doing the research is learning to manage your own expectations. One big hurdle that felt like lots of smaller random hurdles was managing time for research when there are competing demands of the training course. One strategy that was helpful, and I regret not using more, is to book off a chunk of time regularly throughout the year to tackle bigger tasks. Many tasks in research such as sending feedback forms to over 100 participants can take a lot of time but once you are in a flow with it, you can get a lot done. Doing small bits as and when you can does not always work for many of the cognitively heavy research tasks that benefit from sustained attention for longer periods of time. Another aspect of managing your own expectations is to not get carried away with the excitement of the possibility of research and then inevitably set yourself something unachievable. At the start of the process, I wanted to jump straight to validating an adapted screening tool. I had visions of what I would name the new tool, what it might look like, even how it would change clinical services. However, the process has taught me that research is also a process that first needs to be built on good foundations. It is good to have future plans and research goals, but the focus needs to be on how you can push towards the bigger goal a little bit. Developing a questionnaire takes many years, often decades to refine it, learning to enjoy the process makes it that little bit easier.

Impact of covid

Empirical Paper

COVID impacted the empirical paper quite considerably with some of the lessons learnt being relevant to situations other than a pandemic. The study was originally designed to be conducted in person with participants being largely recruitment from NHS treatment sites. However, when COVID lockdowns started, NHS services understandably stopped allowing researchers access, many sent clients home or moved to remote delivery. Furthermore, many research studies were halted as a result or pivoted into online designs. Just prior to me joining the study team they had pivoted the study to be completely online which brought with it some advantages and disadvantages that needed considering.

Early on my study design had to slightly change as I was no longer able to confirm the autism diagnosis of all groups. This meant we were reliant on self-report accounts for individuals recruited online, not through NHS sites where we could verify clinical information with consent. The results are still valuable insights, but we have to acknowledge the limitations of not being able to confirm diagnosis and hope that future studies will be able to address that. This did affect the findings and generalisability as we found that 18% of participants in the ED only group who self-reported that they did not have autism, did not have suspected and had never been referred for an assessment, scored above clinical cut-off on both autism screening measures. Furthermore, they all scored above cut-off on a measure assessing a core diagnostic

feature of autism. To score above cut-off on all three measures suggests that at least some of them might actually be autistic and therefore have confounded the results, unknowingly.

It does however bring some benefits that are worth noting. Firstly, An online study does allow for an easier recruitment process of participants by opening up recruitment streams such as charities and social media. One of our largest recruitment drivers was being advertised on Autistica's email list, an autism research charity. Within 24 hours we had 80 potential participants. This also provided some challenge as we did not have the ethical approval to recruit as many as expressed interest and by that point I was recruiting alone. Screening through email, although is reasonably quick, if you account for 15 minutes per participant the time soon adds up. By the time you have got some way through, a few days have passed with more people expressing interest and the ones you have not got back to yet sending chasers. Despite the difficulties, it is a real privilege to have so much expression of interest in your research and be able to recruit large numbers very easily, something that would have been infeasible in person. Secondly, the assessment was converted to an online platform which was able to record all participant responses accurately and safely as well as facilitate data extraction for analysis. This is a vast improvement over using paper and pen for self-report questionnaires and then having to input them all manually. Any future research, even in person, I would consider using an electronic device to record self-report data for ease of management and extraction.

Systematic Review

One novel experience that was hypothesized to be due to COVID was the large increase in systematic reviews being published between 2020 and 2022. Perhaps due to the aforementioned halt on many in-person research studies, researchers instead used their freed-up time to conduct research that does not involve leaving the computer. Initially I had planned to conduct an update on an old systematic review looking at the prevalence rates of autism in eating disorders. However, when I started the search, I discovered that one had just been published doing exactly that. I then spent a few weeks thinking about and researching other ideas and decided to instead look at intervention studies for autistic individuals with an ED. After researching for a while to make sure it had not yet been done, I set upon starting. During the write up phase, after the search had been completed and results written, I stumbled upon a brand-new systematic review, also looking at interventions for autistic individuals with an ED. Due to some methodological differences, the reviews are complimentary rather than similar, but the experience highlights the importance to check Prospero for upcoming systematic reviews.

Future Research Direction

One big limitation in autism research is the complexity of the diagnostic process. Gold standard autism assessments utilize a combination of observational assessments, informant report and clinician consensus. However, this can make research very slow

as the time and budget needed to complete this level of assessment on all participants is often prohibitive. Furthermore, there is not yet a validated and widely accepted online version, so researchers or participants have to travel and conduct the assessments in person. This often results in small samples when full assessments are used. For the majority of studies, they utilise screening measures as an alternative which limits findings as no screening measure can accurately predict autism with 100% certainty. Validated online assessment for autism would accelerate research and improve the quality and therefore generalizability to clinical settings, ultimately benefiting autistic individuals. In an ideal world future research in autism should utilise validated assessments in both the experimental and control group.

Until that becomes more of a reality, researchers and clinicians will continue to rely on screening measures to guide both research and clinical decisions. It is therefore important that we develop an accurate screening tool that is validated for use in ED populations, in order to guide this research and subsequent clinical decisions. The data used for the empirical study has the potential to be utilised for future research by developing the screening model we developed further. Since all participants within the autism group have a confirmed diagnosis of autism, only those who self-reported as not having autism would need a diagnostic assessment to rule out the possibility that they might actually be autistic. As noted previously, the study was designed originally to use full autism assessments with many participants already completed in person but due to COVID a lot of the data is based on self-report. The resulting model could be developed into an adapted screening tool and validated against individuals who agreed to be

contacted for future research. If successful, the resulting screening tool would become the new standard for screening autistic individuals with an ED and would help guide future research and clinical decisions.

Appendix 1. Joint Project Statement

The empirical paper was conducted as part of an existing project including two PhD students, two senior supervisors, one clinical researcher and one academic researcher across both University College London (UCL) and Cardiff University. I contributed to the recruitment, assessment and management of participants including providing feedback and gift vouchers for their participation. In total I recruited and assessed around one third of the total recruitment numbers and provided feedback for more than two thirds. Although it was part of an existing project, the empirical papers study design, ethics and write up was solely my own as I utilised the dataset in a completely novel way that was not linked to the PhD students' projects, that were due for submission a year before mine. Once the empirical paper was written the study team provided minor feedback on the written language in order for it to be sent for publication in a high impact journal. However, the study team had no influence over the design, analysis or original write up of the paper.

The systematic review was completed separate to the study team and is in no way affiliated.

Appendix 2. Ethical Approval

As ethics amendments do not receive an official letter, please see below email correspondence confirming the approval.

APPROVED: Ethics Amendment 12973.002

VPRO.Ethics <ethics@ucl.ac.uk>

Tuesday, 2 March 2021 at 14:47

To: Adamson, James

Cc: Mandy, William; Brede, Janina

12973.002 Amendm...
60.8 KB

Download All • Preview All

Dear James

Good news, the reviewer has got back to me already. The UCL REC has approved your attached amendment request. Please take this email as confirmation of that approval.

IMPORTANT: For projects collecting personal data only
You should inform the Data Protection Team – data-protection@ucl.ac.uk of your proposed amendments, including requests to extend ethics approval for an additional period.

Best wishes,
Lola

Lola Alaska (she/her)
Research Ethics and Evaluation Administrator

Office of the Vice-Provost (Research)
University College London, Gower Street, London WC1E 6BT
Email: l.alaska@ucl.ac.uk
Web: www.ucl.ac.uk/research

Appendix 3. Participant Information Sheet

Participant Information Sheet for Autistic Women

UCL Research Ethics Committee Approval ID Number: 12973/002

Title of Study: The influence of social communication styles and cognitive profiles on restrictive eating disorders in women

Department: *Research Department of Clinical, Educational and Health Psychology, UCL / School of Psychology, Cardiff University*
Name and Contact Details of the Researchers: *[redacted]*
Name and Contact Details of the Principal Researchers: *[redacted]*

You are being invited to take part in a research project. It is important that you understand exactly what participation will involve and why the research is being done. Please take your time to read this information sheet and discuss it with others if you wish. If anything is not clear, please do not hesitate to ask one of us. Take time to decide whether or not you wish to take part.

1. What is the project's purpose?

The purpose of this project is to gain a better understanding of restrictive eating disorders in individuals with autism. It is estimated that at least 8,000 autistic women suffer with anorexia nervosa in the UK and evidence suggests these women tend to have lower recovery rates than non-autistic women. There is currently a lack of research into eating difficulties in autistic women, which means that eating disorder services lack sufficient understanding and treatment options for this client group.

This project aims to understand what might make autistic women more vulnerable to developing eating disorders and how these difficulties are maintained. In a previous study we interviewed autistic women with anorexia, their parents/carers and healthcare professionals to help us understand eating difficulties in autistic women. In the current study, we are hoping to explore this further by understanding how autistic women with eating disorders, autistic women without eating disorders and non-autistic women with eating disorders vary on a number of different measures. With this understanding, we hope to inform eating disorders services on how to become more accessible and beneficial for autistic women.

2. Why have I been chosen?

In order to understand how autism specifically relates to restrictive eating difficulties, it is helpful for us to include in our research autistic women without an eating disorders. If you would like to take part in this study, you should meet the following inclusion criteria: (1) female; (2) aged over 18 years; (3) formally diagnosed with autism spectrum disorder (including autism spectrum disorder, autism, Asperger's syndrome, high functioning autism, and pervasive developmental disorder) and; (4) you are not formally diagnosed with an eating disorder (and have not had an eating disorder in the past). If you

meet the inclusion criteria and decide you want to take part, you will be completing the same measures as the other women participating in the study.

3. Do I have to take part?

It is completely up to you whether you take part. If you do decide to take part, you will be asked to agree by ticking relevant boxes on an electronic consent form. You can withdraw from the study at any time without having to give a reason. If you decide to withdraw, you will be asked what you wish to happen to the data you have provided up to that point.

4. What will happen if I decide to take part?

If you decide to take part, you will be sent a secure link to the consent form and online survey containing some background questions, a computerised task and a variety of questionnaires. You will only be able to complete the survey if you agree to take part by ticking the appropriate boxes on the consent form. All together it should take around 45-60 minutes to complete the survey. You can take your time completing the survey and you can take a break at any time. You will have to complete the survey within two weeks of receiving the link; after this, the link will expire.

For the background questions, you will also be asked to provide some details about yourself, such as information about your mental health history and your height and weight. Some people may find it uncomfortable to report their height and weight or might not know their height and weight. You do not have to report this if you do not want to or if you do not know your height and weight. However, this information is very helpful to our research and we encourage you to provide this if it is not too distressing for you. In addition, we will ask some brief questions about how the current COVID-19 situation has affected you.

After providing this information, you will be asked to complete a short computerised task, which will be explained in detail within the survey.

Finally, you will be asked to complete a variety of questionnaires, which form part of the survey. Some of the questionnaires will be about interaction styles and thinking profiles, some about your eating habits and some will be about other things such as your relationships with others. If you are not sure about the meaning or relevance of a question, you can ask the researcher via email or telephone to explain at any time.

Some of the questionnaires screen for eating disorder behaviours, autistic traits, anxiety and depression. You can decide whether you would like to be informed of your scores on these measures, as this may indicate that you are experiencing a mental health difficulty. If you choose to be informed, the researcher will give you feedback after you have taken part in the study about what your scores might mean and give you advice about accessing further support.

If you decide to take part, we will also ask if you would be happy for us to conduct an interview with someone who has known you well since childhood, for example a family member, to gather some more information about what you were like when you were younger. This is completely optional – if you do

not want us to do this interview with someone who has known you since childhood, you can still take part in the rest of our study. And your family member does not have to talk to us if they do not want to. In the interview, we would ask your family member questions about your current and childhood social communication style and interests. This would take 30 min of their time, and would be done over the phone. We will ask you at the end of the survey if you have someone who might be willing to talk to us and if you would be happy for us to talk to them. If so, we would get in touch with you after you completed the survey to get their contact details. We request that you ask them for permission before providing us with these details.

If for any reason you find the survey distressing or uncomfortable, you can stop at any time. When you have completed the survey, you will be debriefed, in form of a summary of the activities you have completed as part of this study, and receive further information about ways to access support if you feel you might need it. You will be offered a £15 voucher to thank you for your time. In order to process the thank-you voucher, your contact details may be shared with the Cardiff University or UCL Finance Department. You will be asked to indicate whether you would like to receive a thank-you voucher at the end of the survey.

Timeline of the individual steps involved in taking part:

- Agree to take part
- Receive secure link (expires within two weeks)
- Complete consent form
- Provide background information
- Complete online tasks
- Complete questionnaires
- Indicate whether you would like to receive feedback on mental health related questionnaires
- Indicate whether you would like to be contacted to provide informant contact details
- Indicate whether you would like to receive thank-you voucher
- Indicate whether you would like to be contacted for future research opportunities
- Indicate whether you would like to be informed about the findings of this research
- Debrief
- If consent is given, relative is interviewed

5. What will happen after the study?

You will be asked whether you would like to be contacted if there is opportunity to be involved in future research or to receive a copy of the research report resulting from this study. This is completely voluntary and you would be appropriately compensated for any further input. Should you wish to be contacted, your details will be stored securely and separately from other data.

6. What will happen with my data/the answers I give?

If you consent to take part in the study, your data (e.g. the answers you gave on the questionnaires) will be stored securely and confidentially. They will be stored separately from any identifying information. You can choose to withdraw your data at any time and you do not have to give a reason.

7. What are the possible disadvantages and risks of taking part?

Some of the questions on the questionnaires may bring up some sensitive topics, such as your mental health. Some questions ask about Covid-19 and how it is affecting you. Thinking about these questions may make some people have negative thoughts or feel upset. You do not have to answer any of these questions if you do not feel comfortable answering. As part of the computerised task you will be presented with computer-generated illustrations of different body types. Some individuals may find this uncomfortable. If you are distressed as a consequence of taking part in this study, please contact the researchers and they will advise you on how to access further advice and support. At the end of this information sheet we have provided some phone numbers and websites for accessing further information and support on topics explored in this study. These will also be shared with you in the debrief after you have completed the survey.

If you chose to find out your scores on the questionnaires you complete, there may be a chance that your scores indicate you are experiencing mental health difficulties such as anxiety, depression or eating difficulties. This might be upsetting or worrying for you. If this is the case, you can talk to the researcher who can advise you how to access further advice and support. However, if you would prefer not to know about your scores on the questionnaires, this is okay too.

8. What are the possible benefits of taking part?

While there are no other immediate benefits for those participating in the project, it is hoped that this work will help to inform future research and clinical practice so that eating disorders services and other mental health services will become more accessible; particularly for autistic individuals. You will be offered a £15 voucher as a thank-you for taking part.

9. What if something goes wrong?

If you are unhappy or dissatisfied about any aspects of your participation, we encourage you to let us know so we can try to resolve any concerns and find a solution. If you wish to raise a complaint, you should contact one of the Principal Researchers, Will Mandy or John Fox (contact details above). However, if you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk quoting the Ethics Committee Approval ID Number for this study as stated above.

10. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. All data are stored without any identifying details under secure conditions at UCL/Cardiff University. You will not be able to be identified in any ensuing reports or publications. Data collected will be used for the purpose of this research only, and will not be shared with anyone outside the research team or any commercial organisations.

11. Limits to confidentiality

Please note that assurances on confidentiality will be strictly adhered to unless evidence of potential serious harm or danger to you or someone else is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

12. What will happen to the results of the research project?

We plan to distribute the findings via publications in peer reviewed academic journals, social media, including a blog, and conference presentations. We also plan to publish tailored reports to share our findings with the autism community and clinical professionals. The research team will ensure that all responses are anonymised, so that you cannot be identified. The researchers in this project are all involved with a range of clinical training activities, and will circulate relevant findings to directly and rapidly improve clinical practice (e.g. within mental health services). You will have the option to be sent a summary of the research and be contacted at the end of the study to discuss the findings of the study with the researchers. You may also contact the researchers and ask for copies of any publications if you wish to read them.

13. Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data. UCL's Data Protection Officer is Lee Shailer and he can be contacted at data-protection@ucl.ac.uk**.**

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

14. Who is organising and funding the research?

The research is part funded by Autistica – a charity that funds and campaigns for research to increase our understanding of autism, improve diagnosis and develop evidence-based interventions.

15. Contact for further information

Should you have any questions about the study, please find our contact details below:

[redacted]

Thank you for reading this information sheet and for considering to take part in this research study.

Where can I find out more information and access support related to about the topics explored in this study?

If you would like more information about eating disorders and support for individuals struggling with eating disorders, you may find the Beat website useful: https://www.beateatingdisorders.org.uk/

If you would like more information about autism and support for individuals on the autism spectrum, you may find the National Autistic Society website useful: http://www.autism.org.uk/

If you are ever experiencing mental health problems or need urgent support, you can also contact the Samaritans via contact details on their website (www.samaritans.org) or by calling: 116 123 (24 hours a day, free to call).

More information, support, and resources for autistic people during the Covid-19 pandemic can

be found at:

https://www.autistica.org.uk/what-is-autism/coronavirus

https://www.autism.org.uk/services/helplines/coronavirus.aspx

More information, support, and resources for people with an eating disorder during the Covid-19 pandemic can be found at:

https://www.beateatingdisorders.org.uk/coronavirus

Appendix 4. Informed Consent Form

LONDON'S GLOBAL UNIVERSITY

Consent Form

Title of Study: The influence of social communication styles and cognitive profiles on restrictive eating disorders in women

Department: *Research Department of Clinical, Educational and Health Psychology, UCL / School of Psychology, Cardiff University*
Name and Contact Details of the Researchers: *[redacted]*
Name and Contact Details of the Principal Researchers: *[redacted]*
Name and Contact Details of the UCL Data Protection Officer: Lee Shailer (*data-protection@ucl.ac.uk*)

Thank you for considering taking part in this research. The researchers organising the study [redacted] must provide you with an information sheet about the project and give you the opportunity to ask any questions you may have before you agree to take part. If you have any questions arising from this consent form or the information sheet, please contact the researcher before you decide whether to join in.

By initialling each box below, you are consenting to this element of the study. It will be assumed that un-initialled boxes mean that YOU DO NOT consent to that part of the study. Not giving consent for any one element may mean that you are deemed ineligible for the study.

Participant Statements:	**Tick Box**
• I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction.	
• I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my medical care or legal rights being affected.	
• I understand that if I decide to withdraw, any personal data I have provided up to that point may still be used in the study, unless I request otherwise.	
• I consent to my answers and personal information being used for the purposes of this research study only, as explained to me in the Information Sheet. I understand that such information will be handled in accordance with all applicable data protection legislation.	
• I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that my data gathered in this study will be stored securely. It will not be possible to identify me in any publications.	
• I understand the potential risks of participating as outlined in the Information Sheet, and that I can contact the research team to get advice on how to access support should I become distressed during the course of the research.	
• I understand the direct and indirect benefits of participating as outlined in the Information Sheet.	
• I understand that the data will not be made available to any commercial organisations.	

• I understand that in order to process the thank-you voucher, my contact details may be shared with the Cardiff University or UCL Finance Department. You will be asked to indicate whether you would like to receive a thank-you voucher at the end of the survey.	
• I confirm that I understand the inclusion criteria as detailed in the Information Sheet, and that I fit into this inclusion criteria.	
• I am aware of who I should contact if I wish to lodge a complaint as outlined in the Information Sheet.	
• I voluntarily agree to take part in this study.	

The following questions about preferences for future contact will be moved to the end of the survey:

If you would like to receive a copy of the publication/report that will result from this study, please tick the appropriate box below.

Yes, I would like to receive a copy of the resulting publication/report	
No, I would not like to receive any resulting publication/report	

If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.

Yes, I would be happy to be contacted in this way.	
No, I would not like to be contacted.	

Some of the measures used in this study screen for autistic traits, eating disordered behaviours, anxiety and depression. Please indicate whether you would like to be given more information about your scores on these measures. If you choose to be informed, the researcher will give you feedback about what your scores might mean and give you advice about accessing further support. Please tick the appropriate box below.

Yes, I would like to be informed about my scores on mental health measures.	
• I understand by choosing to receive feedback about my scores that the researchers will not be able to diagnose or provide clinical advice and intervention related to mental health issues.	
No, I would not like to be informed about my scores on mental health measures.	

We would like to conduct an interview with someone who has known you well since childhood (such as a parent or an older sibling) to gather some more information about what you were like when you were younger. This would take around 30 minutes of their time and would be done over the phone. It is completely optional. It is up to you whether you are happy for us to do this interview with a family member. And your family member does not have to talk to us if they do not want to. Please indicate below whether you would be happy for a member of the research team to contact a family member for this purpose. If so, we would get in touch with you after you completed this survey to get their contact details. We request that you ask them for permission before providing us with these details.

Yes, I am happy for the study researcher to get in touch, so I can provide them with a family members contact details.	

No, please to not get in touch about this.	