Towards a better understanding of autistic women's eating disorder service experiences

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Thesis summary

There is growing evidence to suggest that autistic women are overrepresented in populations of individuals with a restrictive eating disorder (ED). Recent research indicates that autistic women's needs are not addressed by the available ED treatment options and clinicians working in ED services report lacking confidence treating autistic individuals. This thesis aims to explore autistic women's experiences of an ED and its treatment within ED services through a series of qualitative and quantitative investigations.

An examination of the current literature exploring service users' perspectives of ED services (Chapter 2). The study highlights the importance of adopting individualised approaches to meet different needs. Chapter 3 specifically explores autistic women's experiences of ED services via in-depth interviews with autistic women, parents, and healthcare professionals. Some similarities are drawn from Chapter 2, but Chapter 3 highlights the unique barriers that autistic women face when in treatment for an ED. The findings also suggest that the underpinnings of autistic women's ED may differ from characteristics typically associated with an ED, such as body dissatisfaction.

Chapter 4 compares traditional ED characteristics – namely pride in eating, body dissatisfaction and internalisation of the thin ideal (ITI) – in autistic women with an ED, non-autistic women with an ED and autistic women without an ED. Results suggest that autistic women with an ED present with significantly less body dissatisfaction and ITI than non-autistic women with an ED. Chapter 5 expands on these findings by exploring ITI and body dissatisfaction implicitly, finding similar patterns as in Chapter 4. Chapter 6 compares autistic and non-autistic women's experiences of ED services, finding that autistic women consistently report poorer experiences than non-autistic women.

In summary, this thesis presents evidence that highlights the individualised, autism-informed approach needed within ED services for autistic women and provides recommendations for services to implement such changes.

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List of Abbreviations

ADOS-2	Autism Diagnostic Observation Schedule-2nd Edition
AN	Anorexia Nervosa
ANOVA	Analysis of Variance
APA	American Psychological Association
AQ	Autism-Spectrum Quotient
ARFID	Avoidant/Restrictive Food Intake Disorder
ASC	Autism Spectrum Condition
BED	Binge Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
BSQ	Body Shape Questionnaire
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CBT-E	Enhanced-Cognitive Behavioural Therapy
CBT-ED	Cognitive Behavioural Therapy for Eating Disorders
CI	Confidence Intervals
COVID-19	Coronavirus disease
DBT	Dialectical Behaviour Therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Eating Disorder
EDE-Q	Eating Disorder Examination-Questionnaire
EDNOS	Eating Disorder-Not Otherwise Specified
FT-AN	Anorexia Nervosa-focused Family Therapy
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HCP	Healthcare Professional
IAT	Implicit Association Test
ITI	Internalisation of the Thin Ideal
MANTRA	Maudsley Model of Anorexia Nervosa Treatment for Adults
MCAR	Missing Completely At Random
MI	Multiple Imputation

NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OCD	Obsessive-Compulsive Disorder
OSFED	Other Specified Food or Eating Disorder
OT	Occupational Therapy
P-IAT	Picture-based Implicit Association Test
PEP-S	Pride in Eating Pathology Scale
Q-IAT	Questionnaire-based Implicit Association Test
RAADS	Ritvo Autism Asperger’s Diagnostic Scale
RCT	Randomised Control Trial
RED	Restrictive Eating Disorder
RRBs	Restrictive and Repetitive Behaviours
SATAQ	Sociocultural Attitude Towards Appearance Questionnaire
SD	Standard Deviation
SEDAF	Study of Eating Disorders in Autistic Females
SSCM	Specialist Supportive Clinical Management
SWEAA	Swedish Eating Assessment for Autism Spectrum Disorders
TA	Thematic Analysis
ToM	Theory of Mind

Chapter 1: Introduction

The aim of this thesis is to explore autistic women's experiences of eating disorder (ED) services. In this Chapter, ED subtypes and the current interventions used to treat them will be outlined. The characteristics of autism spectrum condition (ASC) will also be described, with a discussion of the underdiagnosis of autism in females. A review of the literature concerning overlaps between EDs and autism will follow, with a view to understanding the overrepresentation of autism in restrictive EDs (REDs). Finally, the thesis plan will be outlined.

1.1 Eating Disorders (EDs)

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines feeding and EDs as a disturbance in eating or eating-related behaviours, resulting in significant impairments in psychosocial functioning and/or physical health (American Psychiatric Association, 2013). Eight feeding and EDs are described in the DSM-5, namely, Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), Avoidant/Restrictive Food Intake Disorder (ARFID), Pica, Rumination Disorder, Other Specified Feeding or ED (OSFED; previously known as Eating Disorder Not Otherwise Specified/EDNOS), and Unspecified Feeding or Eating Disorder. For the purpose of this thesis, the focus will be on EDs with a component of food/weight restriction, specifically AN, ARFID and the OSFED sub-type of Atypical Anorexia Nervosa.

1.1.1 Anorexia Nervosa (AN)

AN is characterised by: (1) a restriction in energy intake (e.g. through food restriction or excessive exercise) resulting in a significantly low body weight; (2) an intense fear of weight gain, or persistent behaviour that interferes with the gaining of weight; and (3) an undue influence of weight or shape on self-evaluation, a disturbance in the experience of one's body shape or weight, or a lack of recognition of the significance of their current low body weight (American Psychiatric Association, 2013).

AN commonly develops during adolescence, prevailing more often in females (Geddes & Andreasen, 2020), and reported lifetime prevalence rates for AN range from 0.3-1.7% across females, and up to 0.3% in males (Hudson, Hiripi, Pope Jr, & Kessler, 2007; Preti et al., 2009; Smink, van Hoeken, Oldehinkel, & Hoek, 2014; Stice, Marti, Shaw, &

Jaconis, 2009; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011). However, due to the use of different DSM editions and diagnostic tools across the reported prevalence studies, comparisons should be made with caution. AN has one of the highest mortality rates among all psychiatric conditions (Arcelus, Mitchell, Wales, & Nielsen, 2011). The observed elevated mortality rate in AN is typically due to related medical complications (e.g. Sachs, Harnke, Mehler, & Krantz, 2016), suicide (Zerwas et al., 2015), and psychiatric co-morbidities, e.g. Substance Use Disorders and Personality Disorders (Himmerich et al., 2019). Indeed, psychiatric co-morbidities are frequently reported in AN, which can sometimes lead to complications with assessment and treatment (Marucci et al., 2018).

1.1.2 Atypical Anorexia Nervosa

The DSM-5 categorises Atypical AN as a subtype of the umbrella term ‘Other Specified Feeding and ED’ (OSFED) that describes an individual showing all of the features of AN (e.g. fear of weight gain, food restriction) without the significantly low body weight (American Psychiatric Association, 2013). Interestingly, before the diagnostic introduction of Atypical AN in the DSM-5, this term would be used to describe individuals who did not endorse traditional AN over-evaluations of body shape and weight (e.g. Dalle Grave, Calugi, & Marchesini, 2008) or with sensory aversions to food, leading to low body weight (Moskowitz & Weiselberg, 2017). These presentations would now more typically be characteristic of the new DSM-5 category of Avoidant/Restrictive Food Intake Disorder (ARFID; American Psychiatric Association, 2013). This irregularity in ED diagnostic label provides support for the transdiagnostic view of EDs, which is discussed further below.

1.1.3 Psychological treatment recommendations for Anorexia Nervosa

The National Institute for Health and Care Excellence (NICE) outlines recommendations for the treatment of EDs in the UK, and the leading, evidence-based treatment Cognitive Behavioural Therapy for EDs (CBT-ED) is recommended as one of the first-line approaches for treating AN (National Institute for Health and Care Excellence, 2017). CBT-ED is used as an umbrella term for Cognitive Behavioural Therapy (CBT) that has been modified to target EDs, although arguably the most commonly used form of this is Enhanced CBT (CBT-E; Fairburn, 2008) and they can sometimes be seen used interchangeably. CBT has been indicated as a particularly strong choice of treatment for EDs due to the cognitive nature of one of its core psychopathologies: the over-evaluation of weight and shape (Murphy, Straebler, Cooper, & Fairburn, 2010). The NICE guidelines recommend that CBT-ED should consist of up to 40 individual sessions covering topics such as nutrition, body image concern, cognitive restructuring and psychoeducation around healthy eating and the risks of malnutrition (National Institute for Health and Care Excellence, 2017).

Other first-line NICE-recommended psychological interventions for the treatment of AN are: Maudsley Anorexia Nervosa Treatment for Adults (MANTRA); specialist supportive clinical management (SSCM); and AN-focused Family Therapy (FT-AN) for children and adolescents (National Institute for Health and Care Excellence, 2017). MANTRA is a manual-based treatment built around the cognitive-interpersonal model of AN – that is, pre-disposing cognitive (e.g. obsessive-compulsive features) and interpersonal (e.g. anxious-avoidance of relationships) factors contribute to the development and maintenance of the ED (Schmidt et al., 2012). This intervention draws on a range of approaches, including motivational interviewing, cognitive remediation and flexible carer involvement (Treasure & Schmidt, 2013). SSCM combines features of: (i) clinical management, used to alleviate symptoms of AN by supporting weight gain through psychoeducation and physical health monitoring, and (ii) supportive psychotherapy, to address other life issues impacting on the ED as identified by the clinician and service user. FT-AN is recommended more frequently for children and young adults and the approach emphasises the role of family in supporting an individual to recover, without placing blame or fault on the family for its development (Jewell, Blessitt, Stewart, Simic, & Eisler, 2016).

Several randomised control trials (RCTs) have been carried out to compare the efficacy of recommended treatments for AN. In a comparison of MANTRA and SSCM (Schmidt et al., 2015), it was found that both interventions produced similar outcomes in terms of Body Mass Index (BMI) and ED psychopathology. However, qualitative findings suggested that MANTRA was the more acceptable and credible intervention reported by participants, and it also yielded greater BMI increases in more underweight participants at 6- and 12-month follow-ups (Schmidt et al., 2015). One limitation of this study was that MANTRA was developed at one of the sites participating in the RCT, which may carry with it subtle biases towards this intervention. Another RCT comparing CBT-E, MANTRA and SSCM found similar improvements in BMI and ED psychopathology across all three interventions (Byrne et al., 2017). It should be noted, however, that despite observing BMI improvements across interventions, only 50% of participants had achieved a healthy weight

(BMI>18.5) at the 12-month follow-up, highlighting that there is still much more room for improvement for the currently available, recommended interventions. Fewer RCTs have compared FT-AN with the recommended psychological treatments outlined above, but a meta-analysis of studies measuring efficacy found that FT-AN is superior over individual interventions at 6- and 12-month follow-ups (Couturier, Kimber, & Szatmari, 2013). The most recent NICE guidelines convey that much of the current evidence into the effectiveness of psychological treatments for adults with AN is deemed to be of low quality, e.g. because of small sample sizes or risk of bias due to lack of clarity, and further research is recommended (National Institute for Health and Care Excellence, 2017).

1.1.4 Avoidant/Restrictive Food Intake Disorder (ARFID)

ARFID was introduced as a feeding and ED in the DSM-5 (American Psychiatric Association, 2013). It is characterised by feeding or eating disturbance associated with at least one of the following: significant weight loss, significant nutritional deficiency, dependence on nutritional supplements or significant interference with psychosocial functioning. Notably, this disturbance, and its subsequent consequences, are not attributable to a comorbid medical or psychological condition and cannot be explained by a disturbance in body shape or weight, as typically seen in AN. Rather, food restriction may be due to a lack of interest in eating or food, sensory aversions to food, or marked concern about aversive consequences of eating, such as choking.

ARFID replaced the DSM-IV-TR Feeding and Eating Disorder category of Feeding Disorder of Infancy or Early Childhood, which is characterised as a feeding disturbance with an onset before the age of 6 years old, leading to significant weight loss or lack of weight gain (American Psychiatric Association, 2000). Due to its lack of diagnostic specificity, rare clinical use and the scarcity of relevant literature (Bryant-Waugh, Markham, Kreipe, & Walsh, 2010; Nicely, Lane-Loney, Masciulli, Hollenbeak, & Ornstein, 2014), Feeding Disorder of Infancy or Early Childhood was replaced and expanded on in the DSM-5 with the more specified category of ARFID. An important difference between ARFID and its predecessor is that ARFID allows for the disorder to be diagnosed in adulthood, although it is still more commonly recognised and diagnosed in children and young adolescents (Zimmerman & Fisher, 2017). Despite its recognition in the National Health Service (NHS) England’s Commissioning Guide for ‘Access and waiting time standard for children and young people with an ED' (NHS England, 2015), most ED services across the UK are not commissioned to manage ARFID (Coglan & Otasowie, 2019).

1.1.5 Psychological treatment recommendations for ARFID

There are currently no NICE treatment recommendations for ARFID (National Institute for Health and Care Excellence, 2017), and this lack of guidance has reportedly led to difficulties in the access and provision of suitable services for those with ARFID (Bullivant & Woods, 2020). However, there are some promising developments in cognitive-behavioural interventions specifically for treating ARFID in children, adolescents and adults, e.g. CBT-AR (Thomas et al., 2020; Thomas & Eddy, 2018). Despite these early advances in its definition and treatment, healthcare professionals still report a lack of understanding and training about ARFID (Magel, Hewitt, Dimitropoulos, von Ranson, & McMorris, 2020).

Evidence suggests that autistic individuals may be more at risk to develop ARFID, compared to the general population (American Psychiatric Association, 2013; Nicely et al., 2014). Indeed, an overlap can be recognised in the aetiology of ARFID (e.g., sensory aversions to food tastes and textures) and common characteristics of autism. Atypical sensory processing is reported to occur in 45-95% of autistic children (Ben-Sasson et al., 2009; Schreck & Williams, 2006; Tomchek & Dunn, 2007), and this has been associated with food selectivity (Chistol et al., 2018). Similar sensory patterns have also been reported in autistic adults (Kuschner et al., 2015). However, there is currently a lack of further research into the overlap between autism and ARFID beyond anecdotal evidence and case reports (e.g. Coglan & Otasowie, 2019; Lucarelli, Pappas, Welchons, & Augustyn, 2017).

1.1.6 The transdiagnostic view of EDs

As described above, EDs are traditionally viewed as categorical diagnoses. However, an alternative perspective has been hypothesised, due to significant overlaps between different EDs, namely AN, BN and EDNOS (Fairburn & Bohn, 2005). This is known as the transdiagnostic model of EDs. One of the core psychopathology which is shared by these three categorical disorders is the over-evaluation of weight and shape (Fairburn, 2008). With this in mind, EDs have been described as a cognitive disorder (due to the cognitive aspect of over-evaluation). Fairburn (2008) also describe a subgroup of individuals who do not endorse an over-evaluation of weight and shape; rather, there is an "over-evaluation of control over eating" (Fairburn, 2008, p. 94). This presentation can be speculated to be more characteristic of an ARFID presentation. Given the overlap in the EDs' core psychopathological features and high levels of diagnostic fluidity across EDs (i.e. migration between different eating disorder diagnoses; Castellini et al., 2011), a case is made to see these EDs as transdiagnostic, as opposed to distinct disorders. This model has had its criticisms, with researchers suggesting that while some transdiagnostic processes are implicated in the maintenance of an ED, there are also disorder-specific processes that clearly differentiate EDs (Lampard, Tasca, Balfour, & Bissada, 2013), and could have clinical implications for the treatment of different EDs (e.g. self-esteem as a particular target for AN and EDNOS; Puttevils, Vanderhasselt, & Vervaet, 2019). Nevertheless, the transdiagnostic view is an influential model that has been the foundation and shaped interventions for EDs such as CBT-E (Fairburn, 2008) and the Schematic Propositional Analogical Associative Representation System applied to EDs (SPAARS-ED) model (Fox & Power, 2009).

1.2 Autism Spectrum Condition

Autism spectrum condition (hereafter, autism[1]) is a lifelong neurodevelopmental condition affecting approximately 1.1% of the population (Brugha et al., 2012). In the DSM-5, autism is characterised through the presence of two domains of traits (American Psychiatric Association, 2013). First, deficits in social communication and social interaction must be present, e.g., difficulties with social-emotional reciprocity, abnormal eye contact, and difficulty in the maintenance of relationships. Second, manifestation of restricted and repetitive patterns of behaviour, interests and/or activities must be evident, which could include repetitive motor movements, an insistence on sameness in relation to routine or thinking patterns, intense and restricted interests, or hyper-/hypo-reactivity to sensory input. Importantly, these traits must be present in early childhood and should cause significant impairment to usual functioning.

1.2.1 Autism in girls and women

Traditionally, autism has been understood as a predominantly male disorder, and indeed, prevalence studies calculate the male-to-female ratio of autism diagnoses to be

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[1] The terms 'autism' and 'autistic' (as opposed to 'with autism') will be used throughout the thesis. This is based on evidence that (i) members of the autism community feel the label 'disorder' produces stigma, emphasising difficulties associated with autism and minimising strengths (Hull, Petrides, & Mandy, 2020), and (ii) autistic adults prefer the term "autistic" to "with autism" when describing themselves (Kenny et al., 2016; Robison, 2019).

approximately 4:1, respectively (Fombonne, 2009). It has been theorised that sex differences in autism are due to a genetic, female protective factor, which led to the development of the Extreme Male Brain theory (EMB; Baron-Cohen, 2002). While this might explain some of the sex differences in autism diagnoses, a contrasting theory suggests that autistic females are underdiagnosed in the population, and recent estimates suggest the ratio is closer to 3:1 when using gold standard autism assessments to screen whole populations (Loomes, Hull, & Mandy, 2017).

The female autism phenotype has been proposed as a reason for the underdiagnosis of autistic females (Kopp & Gillberg, 1992). This theory suggests that autistic girls and women may present with qualitatively different autistic traits to autistic boys and men which are not recognised when using standard diagnostic tools as they differ to the traditional autism diagnostic criteria (Hull et al., 2020). For example, the ability to form and maintain social relationships and type of intense interests differ in autistic females and males (Hiller, Young, & Weber, 2014). Other explanations for the underdiagnosis of autism in females include the overrepresentation of male samples in previous research (Kirkovski, Enticott, & Fitzgerald, 2013), on which current diagnostic tools are based. Furthermore, the stereotypical portrayal of autism as a male condition may mean that health and education professionals miss the presentation of autistic traits and do not consider a diagnosis of autism for girls (Bargiela, Steward, & Mandy, 2016). Indeed, research has found that, despite presenting with equivalent levels of autistic characteristics, females require more additional emotional and behavioural difficulties than males in order to receive an autism diagnosis (Duvekot et al., 2017).

Research has estimated that 70-80% of autistic people will experience a mental health condition in their lifetime (Lever & Geurts, 2016; Simonoff et al., 2008). A large, online study of autistic and non-autistic adults found positive correlations between self-reported levels of autistic traits and (i) depression, (ii) anxiety, and (iii) ED symptomology (Sedgewick, Leppanen, & Tchanturia, 2020). There are reported gender differences in the development of mental health issues within autistic populations, particularly relating to internalising problems such as anxiety and depression (Oswald et al., 2016; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). Within an autistic sample, a significant effect of gender was found in reported levels of anxiety and ED symptoms, namely that autistic women had higher levels of both anxiety and ED symptoms than autistic men (Sedgewick et al., 2020), suggesting that autistic women may be at higher risk of some mental health difficulties than autistic men. One area of mental health research in autistic populations that has been gaining attention centres on restrictive EDs in autistic women.

1.3 The overlap between autism and anorexia nervosa

Within the literature, the majority of links between autism and REDs have been focused on AN (e.g. C. Gillberg, 1983; Westwood & Tchanturia, 2017). The link between AN and autism was first considered via case study observations of familial links and a recognition of genetic and behavioural similarities across the two conditions (C. Gillberg, 1983). Since then, studies continue to find an overrepresentation of autism in AN populations. For example, in their systematic review, Huke, Turk, Saeidi, Kent, and Morgan (2013) found an average autism prevalence rate of 23% in AN populations across eight studies. However, it is important to note that the samples in six of these eight studies were from the same Swedish community cohort (Anckarsäter et al., 2012; I. C. Gillberg, Råstam, & Gillberg, 1995; Nilsson, Gillberg, Gillberg, & Raastam, 1999; Nilsson, Gillberg, & Råstam, 1998; Råstam, 1992; Råstam, Gillberg, & Wentz, 2003).

Estimates vary across samples when using gold standard diagnostic assessments to detect autism, such as the Autism Diagnostic Observational Scale (ADOS-2; C Lord et al., 2012), with 10-50% of women with AN reported to display clinically significant levels of autistic traits (Postorino et al., 2017; Westwood, Mandy, Simic, & Tchanturia, 2018; Westwood, Mandy, & Tchanturia, 2017). Notably, some of these estimates decrease when taking into account parental reports of developmental history. This is significant given the requirement for traits to have been present during early childhood for an autism diagnosis to be given. Nonetheless, an overrepresentation of autism is clearly present in populations of women with AN.

1.3.1 Overlaps in nonclinical populations

Due to the perceived overlap between autism and AN (e.g. C. Gillberg, 1983), traits and symptoms relating to these two conditions have been measured in the general population. Autistic traits and ED symptomology were measured using the Autism Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) and the Eating Attitudes Test (EAT-26; Garner, Olmsted, Bohr, & Garfinkel, 1982) respectively in typically-developing schoolchildren aged 11-14 (Coombs, Brosnan, Bryant-Waugh, & Skevington, 2011). They found a significant relationship between these measures, even after controlling for gender, suggesting that the link between EDs and autism exists in a non-clinical, adolescent population. Moreover, they found that the AQ's Attention to Detail subscale and Communication subscale best predicted ED symptomatology (Coombs et al., 2011). The relationship between autistic traits and ED symptoms has also been replicated in an adult population. Using the same measures, Carton and Smith (2014) found a significant, positive relationship between EAT-26 scores and AQ scores, suggesting that the non-clinical link between autistic traits and ED symptomatology may also persist into adulthood.

Whilst they are widely used, there are limitations to using the EAT-26 and AQ measures, particularly within a non-clinical sample. The EAT-26 has been reported to be a poor indicator of specific ED diagnosis symptoms; rather it may merely measure general 'abnormal' eating, which could also include relatively typical dieting behaviours, and result in a high number of false-positives in nonclinical samples (Mintz & O'Halloran, 2000; Nunes, Camey, Olinto, & Mari, 2005). The AQ has been criticised for its poor internal consistency, ambiguous factor structuring and weak criterion validity, particularly in comparison to other measures of autistic traits, when used in a nonclinical population (Ingersoll, Hopwood, Wainer, & Donnellan, 2011). Nonetheless, a recent systematic review of the literature, which examined studies using various measures of ED symptomatology and autistic traits, concluded that autistic-like traits and behaviours seem to correlate with problematic eating behaviours across the lifespan in nonclinical samples, particularly in relation to the neurocognitive deficits observed in many autistic individuals (Christensen, Bentz, Clemmensen, Strandberg-Larsen, & Olsen, 2019). Given the theoretical understanding of both autistic traits and ED symptoms to lie along a continuum across both clinical and non-clinical populations (Happé & Frith, 2006; Mintz, O'Halloran, Mulholland, & Schneider, 1997), these findings in the general populations may help us to understand the relationship between the two conditions in clinical populations.

1.3.2 Overlaps in clinical populations

Beyond looking at non-clinical samples, researchers have constantly recognised similarities between clinical populations of individuals with AN and autistic individuals across different domains, which may partly explain the observed comorbidity between the two conditions. Theoretical understandings and research into the overlaps in neurocognition, biology, behaviour and socioemotional traits are discussed further below.

1.3.2.1 Neurocognitive overlaps

There are three main neurocognitive theories of autism, namely, the Empathising-Systemising hypothesis (Baron-Cohen, 2002); Executive Dysfunction (Hill, 2004); and the Weak Central Coherence theory (Frith, 1989). Interestingly, these theories have also been measured and linked to individuals with AN (Oldershaw, Treasure, Hambrook, Tchanturia, & Schmidt, 2011).

Empathising-Sympathising hypothesis

The Empathising-Systemising hypothesis (Baron-Cohen, 2002) is a two-factor theory that aims to explain the deficits in empathising (including Theory of Mind (ToM) and emotional Theory of Mind (eToM) abilities) and the strengths in systemising that have been recognised in autistic individuals (e.g. Auyeung et al., 2009; Greenberg, Warrier, Allison, & Baron-Cohen, 2018). Empathising refers to the ability to recognise the desires, beliefs, thoughts and intentions of others and react with appropriate, spontaneous emotion, whereas systemising is the ability to analyse and build systems in order to understand and predict non-agentive events (Lawson, Baron-Cohen, & Wheelwright, 2004).

Deficits in ToM and empathising have been found in individuals with AN, when compared to healthy controls (T. A. Russell, Schmidt, Doherty, Young, & Tchanturia, 2009). There are mixed findings from samples of individuals recovered from AN, with some showing a similar pattern of ToM deficit to those with AN, compared to health controls (Amy Harrison, Tchanturia, Naumann, & Treasure, 2012), and others finding little evidence to support this (Oldershaw, Hambrook, Tchanturia, Treasure, & Schmidt, 2010). These contradictory findings could be explained by the different ToM measures used across the two studies, but further research utilising a range of measures would be needed to verify this. However, a familial study found impairments in ToM in unaffected first-degree relatives of individuals with AN (Tapajóz, Soneira, Catoira, Aulicino, & Allegri, 2019), suggesting a degree of heritability and further supporting the stability of ToM deficits. It could be deduced that whilst being in a state of starvation (i.e., in acute stages of illness) may exacerbate and explain some of these ToM deficits, it seems that for some, these are long-standing, stable traits that may be characteristic of autism.

Most research has focused on empathising abilities, as opposed to systemising abilities, in individuals with AN. However, where systemising has been explored, the

Systemising Quotient (SQ; Baron-Cohen, Richler, Bisarya, Gurunathan, & Wheelwright, 2003) has been used to measure this attribute. Mixed findings have been reported when measuring systemising with the SQ in individuals with AN, with one study finding elevated rates of systemising in these individuals (Baron-Cohen et al., 2013) and others finding low levels of systemising in individuals with AN, similar to healthy controls (Courty et al., 2013; Hambrook, Tchanturia, Schmidt, Russell, & Treasure, 2008).

The controversial EMB theory of autism (Baron-Cohen, 2002), which was born out of Baron-Cohen's Empathising-Systemising hypothesis, has been heavily criticised. Firstly, the depiction of the EMB theory as merely a linear distinction between empathising and systemising cognitive styles has been criticised for being essentialist, reductionist and conceptually narrow, which fails to capture the diversity of cognitive style across sexes (Ridley, 2019). Secondly, the EMB theory notion that males and females are "hard-wired" (Baron-Cohen, 2004, p. 1) differently (e.g. females as natural empathisers and males as natural systemisers) fails to acknowledge the sociocultural factors and societal gender norms that are likely to play a role in these observed differences (Krahn & Fenton, 2012) Finally, as discussed previously, the EMB theory may in part create a diagnostic barrier for autistic girls and women, as the theory reinforces gendered beliefs about autism (Krahn & Fenton, 2012; Whitlock, Fulton, Lai, Pellicano, & Mandy, 2020).

Executive Dysfunction

Executive function (EF) describes a set of cognitive processes that give rise to goal-directed behaviours (Benson, 2020). The theory concerning EF in autism has been termed the 'Executive Dysfunction' theory and attempts to explain autistic traits such as rigid thinking styles and repetitive behaviours (Hill, 2004). EF comprises of multiple domains, but the key domains that have been related to autism and autistic traits are planning, set-shifting, inhibition, and self-monitoring (Demetriou, DeMayo, & Guastella, 2019). A meta-analysis of 235 studies found that on average, autistic individuals had poorer EF abilities compared to non-autistic controls (Demetriou et al., 2018), suggesting a robust deficit across key, autism-specific EF domains.

Within AN populations (and other ED populations), reduced EF abilities have also been reported. For example, in a meta-analysis of studies measuring EF in individuals with AN, BN and controls, they found that overall, individuals with AN and BN had significantly poorer EF abilities than control groups (Hirst et al., 2017). One domain of EF that has received particular attention within AN research is set-shifting (i.e., the ability to move between different tasks or mental states). Importantly, set-shifting abilities have been shown to be poorer in individuals with AN whilst underweight (Steinglass, Walsh, & Stern, 2006), but also in those who have recovered from AN (Danner et al., 2012). This is supported by a meta-analysis of studies measuring set-shifting in AN, which found consistent set-shifting impairments across studies, in both ill and recovered samples of individuals with AN (Fuglset, 2019). Moreover, two studies also found these impairments in the healthy sisters of individuals with AN (Holliday, Tchanturia, Landau, Collier, & Treasure, 2005; Tenconi et al., 2010). Together, these findings suggests that set-shifting impairment might be a stable trait for this population as opposed to a state marker, i.e., an impairment that improves once weight is restored.

Weak Central Coherence

Central coherence refers to the ability to pull information together to derive meaning, which can also be understood as ‘seeing the bigger picture’ (Happé, 2013). It has been theorised that autistic people tend to have a weak central coherence and instead, can be overly detail-focussed, at the expense of the bigger picture (Frith, 1989). In conjunction with poorer global processing (i.e. seeing the bigger picture), the weak central coherence theory promotes superior local processing (i.e. detail-focus), leading to better performance on tasks such as the Embedded Figures Task (Witkin, 1971), for which a local processing bias is advantageous (R. D. Booth & Happé, 2018). Interestingly, meta-analyses of studies using tasks to measure central coherence are mixed. One review found only small effect sizes of differences in levels of global and local processing across autistic and non-autistic samples (Muth, Hönekopp, & Falter, 2014). Another review found that there were no differences in global and local processing performance overall, but they did find temporal differences across measures, with autistic individuals being slower in global-order perception (Van der Hallen, Evers, Brewaeys, Van den Noortgate, & Wagemans, 2015). R. D. Booth and Happé (2018) argue that slower global processing, as reported in both the meta-analysis and their own study, still represents an impairment in this cognitive process, and therefore provides support for the weak central coherence theory.

Within AN populations, the weak central coherence theory has gained considerable attention. A meta-analysis of 12 studies that measured central coherence in individuals with an ED and healthy controls found that the ED group showed superior local processing and poorer global processing compared to the healthy controls, suggestive of weak central coherence (K. Lang, Lopez, Stahl, Tchanturia, & Treasure, 2014). Moreover, this cognitive profile was found to be most accentuated in those with AN (K. Lang, Lopez, et al., 2014). A study comparing a group of individuals recovered from AN and a healthy control group found superior local processing in the recovered group, but did not find any differences in global processing, suggesting there may be something distinct about local processing abilities that is a stable trait in AN populations (Lindner, Fichter, & Quadflieg, 2013). Finally, a meta-analysis of neuropsychological characteristics of individuals with AN found that a cognitive profile indicative of weak central coherence is associated with a longer illness duration in AN (Saure et al., 2020).

State or trait?

The role of neurocognitive profiles in AN is unclear and contrasting theories have been suggested to explain these phenomena. One argument suggests that prolonged illness magnifies neuropsychological characteristics which may in turn cause a ‘neurological scar effect’ – that is, neurocognitive impairments are evident through their illness and, in part, may persist after recovery (K. Lang, Stahl, Espie, Treasure, & Tchanturia, 2014). Reductions in brain volume have been observed in adults with AN and this could contribute to prolonged neuropsychological impairments (K. Lang, Stahl, et al., 2014). Moreover, studies have shown that these brain abnormalities associated with AN are relatively reversible after recovery (Mainz, Schulte-Rüther, Fink, Herpertz-Dahlmann, & Konrad, 2012), dependent on age (Kaufmann et al., 2020), and this may explain the mixed findings in recovered samples. However, longitudinal studies are needed to observe whether these impairments are present before AN, as this would be suggestive of a more stable trait regardless of stage of illness.

Another argument proposes that neurocognitive impairments are a stable trait that may be indicative of a risk factor for AN, and this is supported by the familial links observed across different neurocognitive impairments (e.g. Holliday et al., 2005; K. Lang, Treasure, & Tchanturia, 2016). More conservatively, it could be suggested that neurocognitive impairments are a risk factor for AN in a small but significant subset of individuals (Zhou, McAdam, & Donnelly, 2018).

1.3.2.2 Biological overlaps

Much attention has been given to the neurocognitive overlaps in autism and AN. However, some research has also observed biological similarities across the two conditions. Indeed, a neurodevelopmental model of AN has been proposed (Connan, Campbell, Katzman, Lightman, & Treasure, 2003), and it has been suggested that AN belongs to a spectrum of neurodevelopmental conditions alongside others such as autism (C. Gillberg & Råstam, 1992). Below, some of the genetic and neurological overlaps implicated in both autism and AN are discussed.

The hormone oxytocin has been studied in autism and AN, finding deficits in the processing of this hormone across both populations. For example, studies have found that autistic children have lower levels of oxytocin than healthy controls (Husarova et al., 2016; Modahl et al., 1998). Oxytocin is thought to play a role in social cognition (Hammock, 2015), which may in part explain some social communication difficulties observed in autistic individuals. Interestingly, oxytocin may also play a role in eating behaviours and control of food intake in humans, with implications for the contribution of the hormone in the development of EDs and its subsequent use in treatments for AN (Spetter & Hallschmid, 2017). Indeed, a meta-analysis found that oxytocin levels were abnormal across AN groups when compared to healthy controls (Maguire, O'Dell, Touyz, & Russell, 2013). Studies utilising groups who are recovered from AN are more scarce and current findings are mixed, but some do suggest that oxytocin levels remain abnormal even after full weight recovery (Plessow, Eddy, & Lawson, 2018). There is currently a lack of longitudinal evidence to determine whether this oxytocin abnormality observed in those with AN predates their ED or whether it occurs due to the condition. Similarly to the neurocognitive deficits discussed earlier, it may be that a neurological scar effect occurs, meaning that hormone abnormalities remain even after recovery from AN.

The serotonergic system has also been implicated as an area of interest in both conditions. In autism, evidence accumulated from neuroimaging (Chugani et al., 1999), neuropathological (Bauman & Kemper, 2005) and genetic (Prasad, Steiner, Sutcliffe, & Blakely, 2009) studies have indicated abnormal serotonin levels in autistic individuals. However, genetic studies in particular have tended to be less conclusive, with studies reporting mixed findings (e.g. Veenstra-VanderWeele et al., 2002). Pharmacological interventions that target disrupted serotonergic systems have been implicated as potential early interventions for autistic traits, such as repetitive behaviours (Zafeiriou, Ververi, &

Vargiami, 2009). In the AN literature, the serotonergic system, which is thought to play a role in enhanced satiety, impulse control and mood (Kaye, Fudge, & Paulus, 2009), shows abnormal functional activity in those with AN (Kaye, Frank, Bailer, & Henry, 2005). This abnormal functioning finding has been replicated in studies of those recovered from AN (Frank et al., 2002), suggesting a trait – rather than state – serotonergic abnormality. Again, however, the current evidence base lacks longitudinal studies of serotonin activity preceding the onset of AN.

Genetic overlaps have been implied due to the increased co-existence of both AN and autism within families (Oldershaw et al., 2011). For example, an early study observed that the families of three males with an infantile autism diagnosis were reported to contain second degree female relatives with AN (C. Gillberg, 1985; as cited in C. Gillberg & Råstam, 1992). A community-based study found that there were significantly more first-degree relatives with two or more of the four social impairment autistic traits listed in the DSM-IV (American Psychiatric Association, 2000) in their AN group than a group of matched healthy controls (Nilsson et al., 1998). Finally, a more recent study found that occurrence of autism in families of AN probands was increased, however, did not differ significantly from familial autism and comorbid major depression or any other psychiatric disorder, suggesting that the increased familial risk may not be specific to autism and AN (Koch et al., 2015).

1.3.2.3 Behavioural and socioemotional overlaps

Behavioural and socioemotional similarities have been observed in AN and autism, which may partly explain why autistic individuals are at an increased risk of developing AN. Some of these, including sensory profiles, restricted and repetitive behaviours, and social and emotional difficulties are explored further below.

Sensory profiles

The most recent diagnostic criteria for autism recognises characteristics relating to a hyper- or hypo-reaction to sensory input or an interest in environmental sensory aspects (American Psychiatric Association, 2013). Research has estimated that up to 95% of autistic children and adults (Crane, Goddard, & Pring, 2009; Tomchek & Dunn, 2007) report some kind of sensory processing dysfunction across sensory modalities (e.g. taste/smell, movement, visual, touch, activity and auditory). It has been reported that sensory sensitivities are heightened in AN populations when compared to healthy controls and hypersensitivity is also observed in individuals with AN who are weight-restored (Merwin et al., 2013; Zucker et al., 2013). Moreover, self-reported hypersensitivity is accentuated in individuals with AN presenting with high autistic traits (Kinnaird et al., 2020).

Particularly pertinent for disordered eating are senses relating to taste and smell. Autistic children show impairments in taste and olfactory identification compared to non-autistic children (Bennetto, Kuschner, & Hyman, 2007) and taste and smell disturbances in autism have been linked to problematic eating behaviours (Lane, Geraghty, Young, & Rostorfer, 2014). Similar patterns of sensory impairment relating to taste have been reported in autistic adults (Tavassoli & Baron-Cohen, 2012) and qualitative studies of autistic adults indicate that sensitivities to smell and taste can lead to food refusal and in some case, disordered eating behaviours (Brede et al., 2020; Kinnaird, Norton, Pimblett, Stewart, & Tchanturia, 2019). In AN on the other hand, a meta-analysis of 14 studies found that overall, olfactory processing is abnormal in AN populations when compared to healthy controls (Islam et al., 2015). Moreover, a systematic review of taste sensitivity in AN found that there may be some differences in taste processing in AN samples compared to healthy controls, however findings to support this are mixed (Kinnaird, Stewart, & Tchanturia, 2018).

Restricted and repetitive behaviours

One of the core domains of characteristics that is recognised in autism is that of restricted and repetitive behaviours (RRB's; American Psychiatric Association, 2013). RRB’s comprise of a range of behaviours, including a preoccupation with intense interests, repetitive speech, motor stereotypies, and an insistence on sameness, e.g. via a strict adherence to a routine (Leekam, Prior, & Uljarevic, 2011). RRB’s must be present in some capacity in order to diagnose someone as autistic (American Psychiatric Association, 2013). Interestingly, behavioural rigidity has been linked to selective eating in both autistic and non-autistic children and young adults (Zickgraf, Richard, Zucker, & Wallace, 2020), implying a possible association between unusual eating behaviours and restricted behaviours observed in autistic individuals.

RRB’s have also been related to individuals with AN. For example, Zucker and Losh (2008) described the insistence on sameness in daily routines in the development of AN and the rigid adherence to dietary rules that may maintain AN, which are reflective of the RRB’s observed in autistic individuals. Furthermore, excessive exercise as a form of energy restriction has been described as a rigid, repetitive behaviour in AN (Murray, Griffiths, Rieger, & Touyz, 2014). From this perspective, the routine and rigidity that the ED invites may feed into the characteristic traits of autism. Relating back to the abnormal hormone processing that has been observed in both AN and autistic populations, oxytocin has been implicated in motor stereotypies characteristic of autism (Insel, O'Brien, & Leckman, 1999). Moreover, neurocognitive deficits in set-shifting have been linked to the presence of RRB's, particularly relating to an insistence of sameness, which may explain some of the behavioural rigidity and strict routine adherence observed in both autistic individuals and those with AN (H. L. Miller, Ragozzino, Cook, Sweeney, & Mosconi, 2015; Roberts, Tchanturia, & Treasure, 2010).

Alexithymia

Alexithymia is defined as an inability or difficulty in identifying and describing one's own emotions, constricted imaginal processes and externally oriented thinking (Aleman, 2005). Emotion processing difficulties are often considered to be diagnostic markers of autism and more recently, the 'alexithymia hypothesis' has been proposed, which suggests that alexithymia drives emotion processing difficulties that are observed in autistic individuals, rather than representing a core feature itself (Bird & Cook, 2013). It is estimated that approximately half of autistic individuals exhibit some alexithymic traits (Berthoz & Hill, 2005; Bird & Cook, 2013). A recent study found that 55% of autistic adolescents had elevated rates of alexithymia, compared to 16% of non-autistic adolescents, suggesting an overrepresentation of alexithymic traits in autistic populations (Milosavljevic et al., 2016).

Within the ED literature, alexithymia has been implicated in the development and maintenance of AN (Treasure & Schmidt, 2013). To further support these findings, a meta-analysis found that alexithymic traits, as measured using the 20-item Toronto Alexithymia Scale (TAS-20; Bagby, Parker, & Taylor, 1994), were significantly higher across all ED diagnoses explored (AN, BN, AN-restrictive subtype, AN-binge-purge subtype and Binge ED) when compared to healthy controls (Westwood, Kerr-Gaffney, Stahl, & Tchanturia, 2017). Some research suggests that alexithymia is related to poor treatment outcomes in EDs and subsequently has been identified as a potential target for treatment (Pinna, Sanna, & Carpiniello, 2015). Conversely, it has been suggested that alexithymic traits observed in AN may be related to anxiety and depression, rather than the ED itself. For example, when controlling for anxiety and depression, researchers found that the relationship previously found between alexithymia and disordered eating disappeared in ED populations, including those with AN (Eizaguirre, de Cabezón, de Alda, Olariaga, & Juaniz, 2004). However, a more recent mediation study found that, while the presence of alexithymia was partially explained by measures of depression in AN, it could not account for all aspects of alexithymia, particularly in relation to the subscale measuring difficulties identifying feelings, whereby a relationship was still present even when controlling for depression (Torres et al., 2015).

Interestingly, recent research has suggested that alexithymia may partially mediate the relationship found between autism and EDs. In a nonclinical sample, researchers found that the correlation between ED symptoms (measured with the EAT-26) and autistic traits (measured with the AQ) substantially reduced when taking into account self-reported alexithymic traits using the TAS-20 (Vuillier, Carter, Teixeira, & Moseley, 2020). An additional, performance-based measure of alexithymia – the Levels of Emotional Awareness Scale (LEAS) – did not produce the same results, suggesting it may only be specific aspects of alexithymia that account for this mediated relationship. Furthermore, when taking gender into account, the mediation effect was only present in female participants (Vuillier et al., 2020). Moreover, in an AN population, a study found that those scoring above the threshold on the TAS-20 had an increased likelihood of meeting the diagnostic cut-off for autism, as measured using the ADOS-2 (Hobson et al., 2020). Longitudinal research is needed to further understand this relationship and in order to infer causality.

A limitation to consider for much of the alexithymia literature is the frequent reliance on a single self-report measure – the TAS-20. Despite its widespread use globally (for review, see G. J. Taylor, Bagby, & Parker, 2003), there are some shortcomings reported in relation to the measure's psychometric properties, particularly relating to its criterion validity, test-retest reliability and factor structure stability (Kooiman, Spinhoven, & Trijsburg, 2002). Previous research has also criticised the TAS because it does not appear to measure some core aspects of alexithymia, e.g. fantasising, and it has been suggested that other measures should be used alongside it, such as the Bermond–Vorst alexithymia questionnaire (BVAQ; Vorst & Bermond, 2001) to compensate for this (Kinnaird, Stewart, & Tchanturia, 2019). Aside from the concerns raised with its validity as a measure, it could be considered poor scientific practice to rely on one measure to inform the literature on alexithymia (Fox, 2009).

Social interactions and relationships

The second core domain of autistic characteristics relates to social communication and interactions (American Psychiatric Association, 2013). This covers a wide range of social behaviours, including difficulties with reciprocity of social interactions, deficits in the production and understanding of nonverbal, communicative cues and language, and difficulties in the development and maintenance of relationships (American Psychiatric Association, 2013).

AN is often characterised by deficits in social functioning (e.g. Cardi et al., 2018; Amy Harrison, Mountford, & Tchanturia, 2014; Tchanturia et al., 2012), which has traditionally thought to be due to being in a state of starvation, e.g. leading to social withdrawal (Keys, Brožek, Henschel, Mickelsen, & Taylor, 1950). However, more recent studies have suggested that social difficulties are often present prior to the onset of AN (Treasure & Schmidt, 2013) and experiencing difficulties with developing social relationships may even be a risk factor for the development and maintenance of the ED (Westwood, Lawrence, Fleming, & Tchanturia, 2016). Furthermore, it has been found that social difficulties related to autism continue to persist once individuals have recovered from AN (Bentz et al., 2017), reinforcing the idea that social impairments are a stable trait in individuals with AN.

As outlined above, the vast number of domains in which an overlap between autism and AN is suggested is staggering evidence and support for the overrepresentation of REDs in autistic individuals. Despite the observed co-morbidity of autism and AN, there is little research into these individual's experiences of an ED and importantly, how autism affects their experiences of being treated for an ED.

1.4 Autism in ED services

Some research has focused on the effect of the presence of high autistic traits in samples of individuals who are in treatment for AN and the impact that this may have on their treatment outcomes. First, in a study of 409 adolescent girls in specialist treatment for AN, it was found that for those with higher levels of autistic traits: (1) the change in cognitive symptoms of AN was reduced and; (2) there was a greater need for treatment augmentation (Stewart, McEwen, Konstantellou, Eisler, & Simic, 2017). Second, the presence of high autistic traits has also been linked to poorer outcomes in AN relating to mental, psychosexual and economic state (Nielsen et al., 2015), as measured by the Morgan-Russell outcome assessment schedule (Morgan & Hayward, 1988). Third, individuals with high autistic traits were found to present with more severe mental health symptoms than those with lower autistic traits, both in terms of self-reported ED symptoms and other self-reported mental health symptoms such as anxiety and depression (Tchanturia, Adamson, Leppanen, & Westwood, 2019). Fourth, it has been suggested that current interventions available in ED services may be less effective for those with high levels of autistic traits, and therefore they may need specific treatment adaptations made in order to benefit from these (Tchanturia, Larsson, & Adamson, 2016). Finally, researchers have found that neurocognitive traits related to autism were more pronounced among individuals with a prolonged duration of AN, than those who had a shorter illness duration (Saure et al., 2020). Taken together, this evidence suggests that the presence of high autistic traits is likely to lead to poorer outcomes in AN, particularly relating to mental health, illness duration and treatment outcomes.

Whilst it is useful to explore the presence of high autistic traits in an AN population, it is possible that some of the traits observed may be inflated due to being in a state of starvation. Early research suggests that being in a starved state can lead to impaired cognitive, social and emotional functioning (Keys et al., 1950) and these symptoms have been observed and utilised to understand the impact of self-starvation on those with AN (Calugi, Chignola, El Ghoch, & Dalle Grave, 2018). Some of these symptoms, which would be likely to alleviate once weight is restored, may mimic autistic traits, e.g. social withdrawal and cognitive rigidity (Westwood, Eisler, et al., 2016). However, evidence suggests that, at least for a significant subgroup of women with AN, autistic traits predate the ED (Vagni, Moscone, Travaglione, & Cotugno, 2016) and persist after weight-restoration (Bentz et al., 2017; Dinkler et al., 2019).

Little research has been carried out that includes women who are diagnosed with both autism and AN. Kinnaird, Norton, Stewart, and Tchanturia (2019) carried out interviews with a sample of individuals with AN who: (i) had an autism diagnosis (n=9), or (ii) currently presented with high autistic traits (n=4), determined by scoring above the clinical cut-offs for the Short Autism Spectrum Quotient (AQ-10; Allison, Auyeung, & Baron-Cohen, 2012) or the Autism Diagnostic Observation Schedule (Lord et al., 2000). Other research has suggested that the process of receiving an autism diagnosis can have a significant effect on a person's understanding of their disordered eating (Brede et al., 2020), and this nuance may be missed when using a sample including those without an autism diagnosis.

Therefore, carrying out research with a population of women who are all diagnosed with both AN and autism can help to capture the true experience of those who are diagnosed as autistic. As discussed previously, an autism diagnosis can only be given if symptoms were present in the early developmental period (American Psychiatric Association, 2013). Consequently, ensuring all participants have an autism diagnosis can enhance confidence in the fact that their current autistic traits reflect ‘true’ autism, as opposed to a phenocopy arising from the effects of semi-starvation (Calugi, Chignola, et al., 2018).

The combination of: (1) overwhelming evidence for the overrepresentation of autistic individuals with a RED and (2) the dearth of research and understanding about autistic women’s ED service experiences, leads to the identification of an important gap in the literature. This is particularly significant as research suggests that autistic individuals already face barriers when accessing healthcare services, including communication difficulties, feeling overwhelmed by help-seeking, and experiencing stigma/a lack of understanding about autism from healthcare professionals (Nicolaidis et al., 2015; Vogan, Lake, Tint, Weiss, & Lunsky, 2017). It could be hypothesised that similar barriers may be faced within ED services, or indeed these could be heightened due to aspects unique to ED services that are associated with common autistic traits, e.g., the sensory aspect of food. As outlined earlier, research suggests that overall, those presenting with higher autistic traits have poorer ED service experiences than those with low levels of autistic traits, and this warrants further investigation with autistic women with AN.

1.5 Summary and aims of the thesis

1.5.1 Chapter summary

We have defined restrictive EDs (AN, atypical AN, ARFID) and reviewed the current psychological interventions recommended for their treatment. For AN, there are evidence-based treatment recommendations outlined by government bodies like NICE, but the overall efficacy of these recommended psychological interventions is modest at best, and there is a need for additional, higher quality RCTs to investigate these and other interventions further (Solmi et al., 2021). For ARFID, current treatment options are less clear, with a lack of evidence-based recommendations (Bryant-Waugh, Loomes, Munuve, & Rhind, 2021) and commissioning for the management of ARFID in the NHS (Coglan & Otasowie, 2019).

We also defined autism and explored the possible reasonings behind the underdiagnosis of autistic women and girls. Autistic individuals are more likely than their non-autistic counterparts to experience mental health difficulties in their lifetime (Lai et al., 2019; White, Oswald, Ollendick, & Scahill, 2009), and there is emerging evidence to suggest that autistic women experience more mental health difficulties, such as anxiety and EDs, than autistic men (Sedgewick et al., 2020).

Next, we explored the growing evidence to suggest there is an overlap between autism and REDs. Early anecdotal evidence (e.g., C. Gillberg, 1983) led to a wealth of research focusing on: (i) the overrepresentation of autism in individuals with a RED such as AN, (ii) the relationship between autistic traits and ED psychopathology in the general population, and (iii) the neurocognitive, biological, behavioural and socioemotional similarities across individuals with AN and autistic individuals. There are some mixed findings within this research and there is a need for more longitudinal studies to help unpick the state versus trait argument further, but the evidence overwhelmingly points towards the understanding that autism is overrepresented in those with a RED.

Finally, we reviewed the current literature with a focus on the impact of autism on ED service experiences. The literature base is relatively sparse and relies mostly on a dimensional perspective of autism, i.e., utilising current, measurable autistic traits and characteristics to distinguish between high and low levels of autistic traits within AN populations, as opposed to those with and without an autism diagnosis. Whilst this method has its benefits, e.g., includes those who may be autistic but not yet diagnosed, it may lead to an overestimation of true autistic traits due to the artificial amplification of autistic characteristics and traits observed in those in a state of semi-starvation (Calugi, Chignola, et al., 2018; Keys et al., 1950). Moreover, it does not take into account the experience of receiving an autism diagnosis and the impact this might have on self-understanding (Huang, Arnold, Foley, & Trollor, 2020), and more pertinently, on their understanding of their eating difficulties (Brede et al., 2020). Therefore, a case is made to explore the ED service experiences of autistic women.

1.5.2 Thesis aims

The overarching aims of this thesis are as follows:

1) To gain a better understanding of autistic women's ED service and treatment experiences. Due to the exploratory nature of this aim, this will be investigated using qualitative interviewing methodology.
2) To utilise the findings of the qualitative research to inform a quantitative exploration of: (i) the profile of REDs in autistic women, via a comparison of autistic women with a RED, autistic women without a RED, and non-autistic women with a RED, and; (ii) compare autistic and non-autistic women's ED service and treatment experiences.

1.5.3 Thesis outline

Chapter 2 will synthesise qualitative literature with a focus on service user experiences of ED services. This will help us to understand current perspectives, barriers and facilitators to the access and engagement within EDs services across all service users.

Chapter 3 presents a qualitative study of autistic women with experience of AN, parents of autistic women and healthcare professionals working in ED services to explore autistic women's experiences and perspectives of ED services.

Chapter 4 presents a sample of autistic women with a RED, autistic women without an ED and non-autistic women with a RED, and compares their levels of traditional ED characteristics.

Chapter 5 introduces two implicit measures used to determine levels of body dissatisfaction and internalisation of the thin ideal. A sub-sample from Chapter 4 completed these measures and comparisons of their levels are body dissatisfaction and internalisation of the thin ideal are made.

Chapter 6 compares the ED service experiences reported by the autistic and non-autistic women with a RED from the sample in Chapter 4. These service experience findings are also compared with the findings from Chapter 4 and 5.

Finally, Chapter 7 outlines the key findings from the studies described throughout the thesis, highlighting the strengths, limitations and importantly, the clinical implications of these findings and future recommendations.

Chapter 2: Investigating Service Users' Perspectives of Eating Disorder Services: A Meta-Synthesis

2.1 Introduction

As outlined in Chapter 1, EDs are debilitating mental health conditions, and they have one of the highest mortality rates across all psychiatric disorders (Chesney, Goodwin, & Fazel, 2014). The course and outcome of an ED is hugely variable (Ken Goss & Fox, 2012), but it has been estimated in fundamental longitudinal studies that up to 55% of people with BN and 53% with AN will not fully recover nine years after onset, with a significant proportion developing a severe and enduring presentation of the disorder (Steinhausen, 2002; Steinhausen & Weber, 2009). Furthermore, similar rates of recovery have been reported since the publication of these studies, with illness duration often predicting recovery rates (Keel & Brown, 2010; Nagl et al., 2016). There can also be serious medical complications as a result of an ED, including, but not limited to, osteoporosis (Mehler, Cleary, & Gaudiani, 2011), refeeding syndrome (Crook, Hally, & Panteli, 2001), gastrointestinal complications (Hetterich, Mack, Giel, Zipfel, & Stengel, 2019) and cardiac abnormalities (Sachs et al., 2016). Psychological and medical consequences mean that many individuals with an ED require healthcare service input. In the UK, the National Institute for Health and Care Excellence (NICE; National Institute for Health and Care Excellence, 2017) sets out standardised guidelines for the treatment of EDs.

There are consistent challenges reported by those working in ED services, and these include: treating psychiatric and medical symptoms alongside each other (Fox & Goss, 2012), maintaining a therapeutic relationship when faced with denial and treatment resistance from service users (Snell, Crowe, & Jordan, 2010), and being aware of the influence of one's own personal attributes (e.g. appearance and eating behaviours) on service users (C. S. Warren, Crowley, Olivardia, & Schoen, 2008). Given the challenges reported by healthcare professionals working with ED client groups, it is crucial that we aim to understand not only the experiences of those working in these services, but also the experiences of those using ED services to begin to provide solutions to some of these challenges.

A recent meta-ethnography synthesised qualitative research focusing on healthcare professionals' experiences of working with people with an ED (Graham, Tierney, Chisholm,

& Fox, 2020). They generated a model to understand ED healthcare professionals' experiences, providing clinical recommendations for improving support for staff. Taking a broader approach by including perspectives of individuals with an ED, their families and health professionals, a recent systematic review employed a narrative synthesis methodology to explore experiences of primary and secondary care for EDs (Johns, Taylor, John, & Tan, 2019). This synthesis explored both qualitative and quantitative research and identified barriers across ED healthcare interfaces, such as a lack of ED knowledge in primary care, a need for better communication across services, and a lack of partnership between ED services, patients, and families.

While these reviews provide us with valuable insights into the perspectives of ED service users and providers, there is still a need for a review of ED services exclusively from the service users' perspectives. The synthesis including service user, parent and healthcare professionals' views has an element of comparison across these three groups' views, which limits a nuanced investigation of the exclusive views of service users. Moreover, while there are existing reviews that have synthesised the views of specific groups of ED service users, e.g., the treatment experiences of males with an ED (Thapliyal & Hay, 2014), these are not generalisable to the wider population of ED service users. Taking a more holistic approach and synthesising qualitative accounts from all ED service users can provide healthcare services with in-depth, personal experiences and perspectives across different characteristics and populations. Consequently, these accounts can be utilised to inform care provision, treatment and service policies, ensuring a person-centred approach is endorsed (Holloway & Galvin, 2016). This warrants the synthesis of qualitative studies from service users' perspective to understand their experiences more holistically, or conversely seek out any differences across populations.

For the current review, a meta-synthesis approach was chosen (Walsh & Downe, 2005). A meta-synthesis aims to "produce a new and integrative interpretation of findings that is more substantive than those resulting from individual investigations" (Finfgeld, 2003, p. 894). The meta-synthesis approach described by Walsh and Downe (2005) follows the steps for synthesis of qualitative studies outlined by Noblit and Hare (1988). Following the same guidance allows for meaningful comparisons for discussion to other meta-syntheses and meta-ethnographies, such as the meta-ethnography of healthcare professionals' experiences of ED services (Graham et al., 2020).

The aim of this meta-synthesis is to explore the experiences of ED services from the service user perspective.

2.2 Method

2.2.1 Meta-synthesis

I used the guidance described in the seminal meta-ethnographic paper by Noblit and Hare (1988), and utilised the further refinement relating to meta-synthesis approaches outlined by Walsh and Downe (2005). The seven phases outlined by Noblit and Hare (1988) for synthesising qualitative studies were followed: (i) getting started; (ii) deciding what is relevant to the initial interest; (iii) reading the studies; (iv) determining how the studies are related; (v) translating the studies into one another; (vi) synthesising translations and; (vii) expressing the synthesis.

2.2.2 Systematic Literature Search

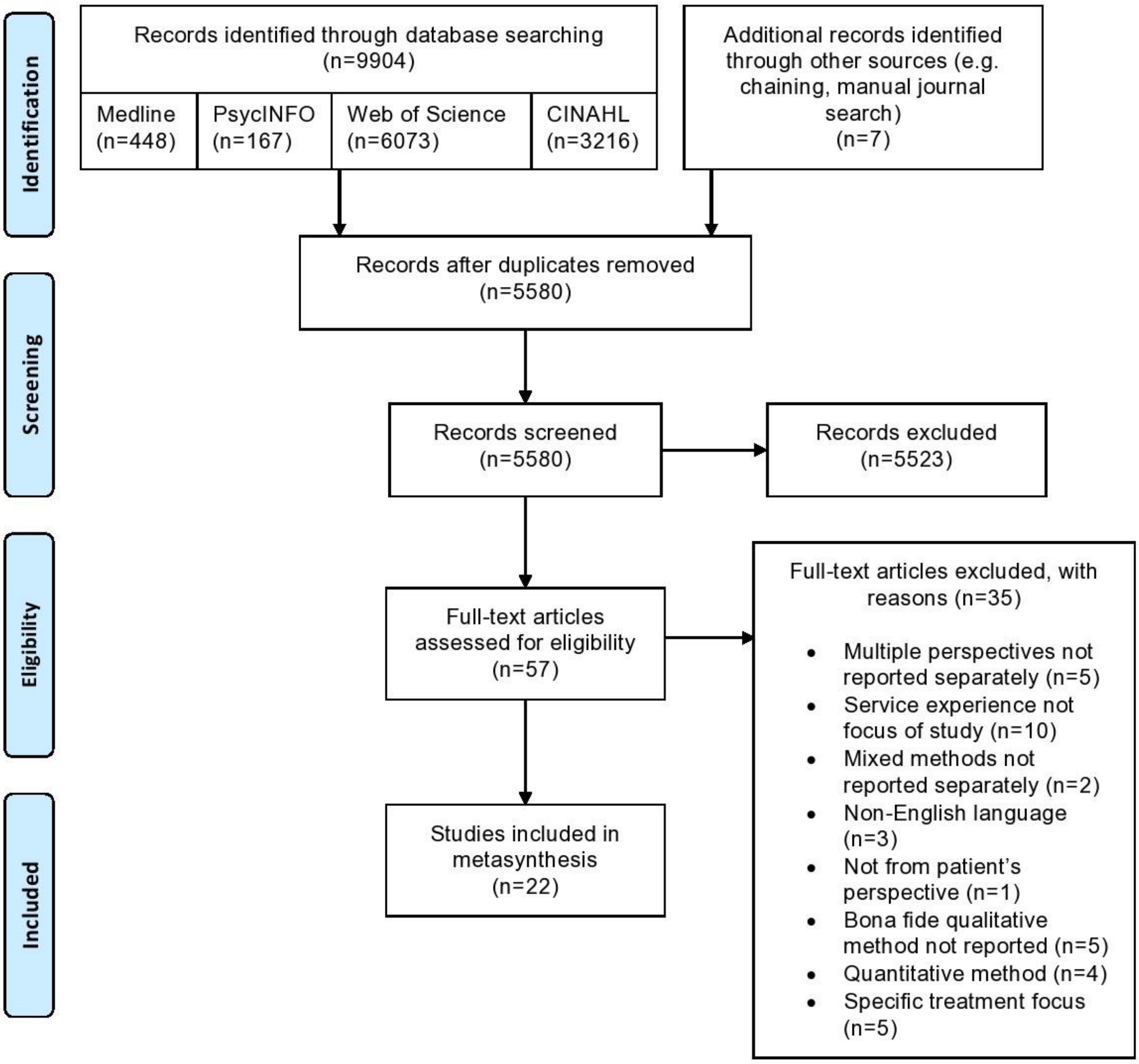
Studies were identified using four blocks of terms relating to: the disorder under investigation (EDs); the population (service users); the type of research (qualitative); and the phenomenon of interest (ED services). Blocks were combined using the Boolean operator ‘AND’, and terms within each block combined using ‘OR’. Search terms are outlined in Table 2.1. A comprehensive systematic search was carried out in November 2020 using the following databases: Medline, PsycINFO, Web of Science and CINAHL. Additional studies were identified through a process of chaining and manual journal searches.

Table 2.1. Search terms and Boolean operators used to identify studies for the meta-synthesis. Blocks were combined in the Boolean operator 'AND'.

Block 1 – Disorder	**Block 2 - Population**	**Block 3 – Type of research**	**Block 4 – Phenomenon of interest**
"Eating disorder*" OR anore* OR bulimi* OR EDNOS OR OSFED OR ED	Patient* OR individual* OR adolescent* OR adult* OR "service user*" OR client*	Perspective* OR view* OR experience* OR "point of view" OR reflect* OR qual* OR interview*	"Eating disorder service*" OR "eating disorder unit*" OR inpatient OR outpatient OR "day patient" OR "eating disorder treatment" OR treatment OR therapy

Screening processes and reasons for exclusions are presented in Figure 2.1 (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). An independent researcher reviewed a random selection (~30%) of the 57 full-text articles that were assessed for eligibility against the inclusion criteria to aid the selection process. There was unanimous agreement on the suitability of the included and excluded papers for the meta-synthesis.

Figure 2.1 PRISMA flow diagram of search process, study selection and exclusion (Moher et al., 2009).



2.2.3 Inclusion Criteria

Studies that met the following criteria were included: (i) study adopts a qualitative methodology (or mixed methods, if qualitative results are reported separately) and uses a named, bona fide analytic approach for qualitative data, e.g., grounded theory, thematic analysis, interpretative phenomenological analysis; (ii) participants had a current or past ED (e.g. AN, BN, OSFED/EDNOS) from any age group (e.g. adolescent or adult); (iii) participants' ED led them to be current or past service users; (iv) the discussion was relevant to the ED service as a whole (any studies that focused on specific parts of a service, such as a novel treatment intervention, were not included as this would not allow us to develop an understanding of the whole service experience); (v) study was based in any country (providing the paper was written in English). No date limits were imposed when selecting papers.

In the inclusion criteria, I decided to include EDs as a homogenous group, rather than focusing on a specific ED, in order to be as inclusive as possible and to capture a range of experiences. The transdiagnostic view of EDs highlights that the core features of an ED are often present across all ED sub-categories (Fairburn, Cooper, & Shafran, 2003) and this is supported by the recognition of high levels of diagnostic fluidity (i.e., migration between different ED diagnostic categories) across the illness duration (Castellini et al., 2011).

2.2.4 Quality Appraisal

Included papers underwent a quality appraisal check before analysis. The Critical Appraisal Skills Programme (CASP) tool for qualitative research (Critical Appraisal Skills Programme, 2018) was chosen due to its accessibility and widespread use in meta-syntheses, notably in healthcare research (e.g. M. A. Kelly et al., 2018; Strandås & Bondas, 2018). A grading system adapted from Fox, Dean, and Whittlesea (2017) was used, taking into account the updated CASP scoring (Critical Appraisal Skills Programme, 2018) since its publication. Scores of 8+ received an A, implicating low likelihood of methodological flaws, scores of 4.5-7.5 received a B, denoting moderate likelihood of methodological flaws, and scores of 4 and below received a C, suggesting high likelihood of methodological flaws. CASP scores and grades are presented in Table 2.2. All papers were rated by the first author. To increase the objectivity and rigour of quality appraisals, a random selection of approximately 20% (5/22) of papers were also rated by an independent researcher. There was unanimous agreement on 82% of scores, and remaining discrepancies were resolved via discussion between the first author and the independent researcher. Given that all selected papers were rated to be of a relatively high-quality standard (scoring A or B), no papers were excluded on methodological grounds.

Table 2.2. Quality ratings using the Critical Appraisal Skills Programme (CASP) tool for qualitative research.

Study	**Items**									**Overall Score**	**Grade**
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?		
1.	1	1	1	0.5	1	1	0.5	1	1	8	A
2.	1	1	1	0	1	1	1	1	1	8	A
3.	1	1	1	1	1	0	1	0	1	7	B
4.	1	1	1	0	0.5	0	1	0	0.5	5	B
5.	1	1	1	1	1	0	0.5	1	1	7.5	B
6.	1	1	1	1	1	1	0.5	1	1	8.5	A
7.	1	1	1	1	1	1	1	1	0.5	8.5	A
8.	1	1	1	1	1	1	1	1	0.5	8.5	A
9.	1	1	1	1	0.5	0	0	0.5	0.5	5.5	B

10.	1	1	1	1	1	0.5	0.5	1	0.5	7.5	B
11.	1	1	1	0.5	1	0.5	1	1	1	8	A
12.	1	1	1	0.5	1	1	1	0.5	0.5	7.5	B
13.	1	1	1	1	1	1	1	1	1	9	A
14.	1	1	1	0.5	1	0	1	0.5	0.5	6.5	B
15.	1	1	1	0.5	1	1	1	1	1	8.5	A
16.	1	1	1	1	1	0	1	0	0	6	B
17.	1	1	1	1	1	0.5	1	0.5	1	8	A
18.	1	1	1	1	1	1	1	1	1	9	A
19.	1	1	1	0.5	1	0	1	1	1	7.5	B
20.	1	1	1	1	1	0.5	0	1	1	7.5	B
21.	1	1	0.5	0.5	1	0	1	1	1	7	B
22.	1	1	1	0.5	1	1	1	1	1	8.5	A

Response options: 1 = Yes; 0.5 = Can’t Tell; 0 = No

2.2.5 Thematic Synthesis

The full papers were entered into the software programme QSR NVivo 12 (QSR International Pty Ltd., 2018) for analysis and initial codes were developed from relevant areas of the papers (e.g. Results sections) where service users described their experiences. Data were extracted from first-order (participant quotes) and second-order (author interpretation of participant quotes) constructs. Following guidance from Noblit and Hare (1988), studies were compared and translated into one another to identify third-order concepts (i.e. my interpretations of the original authors' interpretations). This was done by identifying overlapping (reciprocal translations) and contrasting (refutational translations) codes across studies. Finally, codes were synthesised and refined to create overarching themes and sub-themes that represent concepts across the studies.

2.3 Results

In total, 22 studies were included (see Table 2.3). The total number of participants across all studies was 712, of which 23 were male. Where data was reported, ages ranged from 11-64 years, although five studies did not report exact age ranges (e.g., only reported mean age). Participants reported to have AN (n=296), BN (n=15), EDNOS or OSFED (n=13) or orthorexia (n=1). Two studies reported that participants had "AN and/or BN" (n=59; Malson, Finn, Treasure, Clarke, & Anderson, 2004; Reid, Burr, Williams, & Hammersley, 2008). Some studies were less specific with reporting diagnoses, with 12 participants reported having "AN or EDNOS" (Eli, 2014), 294 participants identifying as a "person with an ED" (Escobar-Koch et al., 2010), eight participants with a severe and enduring ED (Joyce, Greasley, Weatherhead, & Seal, 2019), and six participants unspecified (Rother & Buckroyd, 2004). Ten studies focused primarily on inpatient experiences, two on outpatient experiences and six included a combination of both inpatient and outpatient experiences. The remaining three studies did not specify service type. Samples came from eight countries, but the majority were United Kingdom (UK) samples (either exclusively from the UK or mixed; n=13). Other countries included Australia (n=5), United States of America (USA; n=3), Israel (n=1), Chile (n=1), Sweden (n=1), Republic of Ireland (n=1) and China (n=1). Only three studies reported on ethnicity – of these, all were White/Caucasian, with the exception of one participant identifying as Afro-Caribbean.

Table 2.3. Summary of included papers.

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
1.	Colton and Pistrang (2004) UK	To provide a detailed description of how adolescents on inpatient, specialist eating disorder units view their treatment.	N=19 (19 Female) Aged 12-17 years (mean = 15.4 years) White British n=17; White Irish n=1; Afro-Caribbean n=1	All had primary diagnosis of anorexia nervosa	Adolescent inpatient eating disorder service	Semi-structured interviews
2.	Eli (2014) Israel	To identify the ways in which inpatient ambivalence might be embedded in the special social institutional setting that an eating disorder ward presents, beyond patient-specific motivation for recovery.	N=13 (12 Female; 1 Male) Aged 18-38 years	"Anorexia nervosa or eating disorder not otherwise specified" (N=12); bulimia nervosa (N=1)	Inpatient eating disorder ward for adults	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
3.	Escobar-Koch et al. (2010) USA and UK	To obtain an in-depth view of a large number of US and UK eating disorder patients' perspectives on treatment and service provision, to perform a comparison between these countries.	N=294 UK: N=150 (145 Female; 5 Male) Mean age = 26.6 years USA: N=144 (140 Female; 4 Male) Mean age = 30.1 years	Not specified; inclusion criteria = "a person with an eating disorder"	Not specified	Online questionnaire (open-ended questions)
4.	Escobar-Koch, Mandich, and Urzúa (2012) Chile	To identify the views of Chilean patients who have received treatment for an eating disorder about these treatments, including aspects they value, and feel have helped them in their recovery as well as aspects they feel have	N=10 (10 Female) Aged 16-47 years (mean = 30.7 years)	Bulimia nervosa (N=6); anorexia nervosa (N=3); eating disorder not otherwise specified (N=1)	Treated for eating disorder at general hospital	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
		hindered their recovery or been missing from their treatments.				
5.	Fogarty and Ramjan (2016) UK and Australia	To better understand the care experience during treatment for anorexia nervosa in individuals with self-reported anorexia nervosa or recovery from anorexia nervosa.	N=161 (75 Female) Mean age = 25.11 years [Note: only 46.6% of participants completed age/gender questions]	Self-reported anorexia nervosa	Inpatient, outpatient, or combination of both (reported by 97% of respondents)	Online questionnaire (open-ended questions)
6.	Fox and Diab (2015) UK	To explore sufferer's perceived experiences of living with and being treated within an Eating Disorders Unit for their chronic anorexia nervosa	N=6 (6 Female) Aged 19-50 years (mean = 27 years)	Chronic anorexia nervosa	Inpatient	Semi-structured interviews
7.	Joyce et al. (2019) UK	To explore the following questions:	N=8 (7 Female; 1 Male)	Severe and enduring eating disorder	"Self-reported experience of specialist eating	Interviews with a focus

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
		1. What are people's experiences of receiving input from services for long-term eating disorders? 2. What are the social, political, and cultural narratives which impact on those experiences?	Aged 20-64 years (mean = 44 years)	(specific type of eating disorder not reported)	disorder services"; multiple inpatient admission (N=5); singular inpatient admission (N=1); no inpatient admission (N=2)	on narrative inquiry
8.	Lindstedt, Neander, Kjellin, and Gustafsson (2015) Sweden	To investigate how young people with experience from adolescent outpatient treatment for eating disorders, involving family-based and individual based interventions, perceive their time in treatment.	N=15 (14 Female; 1 Male) Aged 13-18 years	Anorexia nervosa (N=6); eating disorder not otherwise specified ("with a restrictive symptomology") (N=9)	Outpatient and/or inpatient (inpatient N=4)	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
9.	Maine (1985) USA	To examine the efficacy of treatment of anorexia from the recovered patient's point of view, with the underlying assumption that she best knows the interactions of phenomena stimulating or threatening her recovery.	N=25 (25 Female) Aged 13-23 years (mean = 16.8 years)	Anorexia nervosa	Combination of inpatient and outpatient	Semi-structured interviews
10.	Malson et al. (2004) Australia and UK	To explore participants' accounts of their treatment experiences and, in particular, to elucidate the ways in which 'the eating disordered patient' is constituted both in terms of participants' self-	N=39 (38 Female; 1 Male) Aged 14-45 years	Anorexia nervosa and/or bulimia nervosa	Inpatient	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
		constructions and of constructions of 'the patient' that are attributed to healthcare workers.				
11.	Offord, Turner, and Cooper (2006) UK	To explore young adults' views regarding: the inpatient treatment they received for anorexia nervosa during their adolescences; their experiences of discharge; and the impact their admission had on issues of control and low self-esteem.	N=7 (7 Female) Aged 16-23 years White British N = 7	Anorexia nervosa	Inpatient (general adolescent inpatient setting)	Semi-structured interviews
12.	Patterson, Bellair, Jeffrey, and Ward (2017) Australia	To assess the perceived helpfulness of various components of treatment, and	N=12 (12 Female) Aged 18-50 years	Anorexia nervosa-binge-purge subtype (N=1); anorexia nervosa-	Inpatient	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
		clinician behaviours and attitudes valued by patients.		restrictive subtype (N=11)		
13.	Rance, Moller, and Clarke (2017) UK	to begin the process of eliciting clients' views by giving anorexia nervosa sufferers the opportunity to talk about their experiences of being treated for their eating disorder.	N=12 (12 Female) Aged 18-50 years (mean = 31.5 years)	Anorexia nervosa (self-diagnosis N=1)	Combination on inpatient and outpatient	Semi-structured interviews
14.	Reid et al. (2008) UK	To describe sufferers' perspectives of their eating disorders and their experiences of an outpatient service and provide related practical recommendations for treatment.	N=20 (19 Female; 1 Male) Aged 17-41 years	Anorexia nervosa and/or bulimia nervosa	Outpatient	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
15.	Ross and Green (2011) UK	To consider the question of whether inpatient admission was a therapeutic experience for two women with chronic anorexia nervosa.	N=2 (2 Female) Aged 18+	Anorexia nervosa	Inpatient	Semi-structured interviews
16.	Rother and Buckroyd (2004) UK	To identify the service provision used, if any, by adolescent sufferers of eating disorders and what, in their opinion, would have been desirable at that time.	N=6 (6 Female) Aged ~18-28 years [Note: Recruitment targeted 18–28-year-olds; actual ages of final sample unknown]	Not specified	“Past adult users of a voluntary sector agency”; does not specify service type	Semi-structured interviews
17.	Sheridan and McArdle (2016) Republic of Ireland	To explore the treatment experiences of both current and discharged eating disorder patients to gain insight into those factors that	N=14 (14 Female) Aged 18-31 years (mean = 23.2 years)	Anorexia nervosa (N=6); bulimia nervosa (N=2); other specified feeding or eating disorder (N=3)	Inpatient and outpatient (N=9) or outpatient only (N=5)	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
		influenced their motivational treatment trajectory				
18.	V. Smith et al. (2016) UK	To explore women's experiences of specialist inpatient treatment for anorexia nervosa during their treatment admission.	N=21 (21 Female) Aged 18-41 years (mean = 25.2 years)	Anorexia nervosa	Inpatient	Semi-structured interviews
19.	(Thapliyal, Conti, Bandara, & Hay, 2020) Australasia and North America	To investigate the treatment experiences of a group of men who had sought help, were diagnosed with an eating disorder, and received eating disorder specific treatment.	N=8 (8 Male) Aged 20-33 years (mean = 26 years)	Anorexia nervosa (N=4); bulimia nervosa (N=3); orthorexia (N=1)	Combination of inpatient and outpatient	Semi-structured interviews
20.	Tierney (2008) UK	To explore the views of young people about being	N=10 (9 Female; 1 Male)	Anorexia nervosa-restrictive	Combination of inpatient and	Semi-structured interviews

Study	Authors (Year) Country	Aim	Sample characteristics	Type of eating disorder	Type of service	Data collection
		treated for anorexia nervosa.	Aged 11-18 years (mean = 17 years) Caucasian N = 10	subtype (N=5); anorexia nervosa-binge-purge subtype (N=5)	outpatient service input	
21.	Walker and Lloyd (2011) Australia	To explore the service user's perspectives of treatment experiences.	N=6 (6 Female) Aged 18+ years	Anorexia nervosa-restrictive subtype (N=2); anorexia nervosa-binge-purge subtype (N=1); bulimia nervosa (N=3)	Not specified; recruited from caseloads of an eating disorder service so all participants had some service input at time of study; criteria states: "not currently receiving inpatient treatment"	Focus group
22.	Wu and Harrison (2019) China	To understand the experiences of four adolescents receiving inpatient treatment for eating disorders in mainland China.	N=4 (4 Female) Aged 16-19 years	Anorexia nervosa-binge-purge subtype	Inpatient	Semi-structured interviews

Four overall themes were established, relating to: Treatment, Service Environment, Staff, and Peer Influence (see Table 2.4 for overview).

Table 2.4. Overview of themes and sub-themes.

Theme	***Sub-theme***
Treatment: Focus on physical vs. psychological symptoms	Access to treatment
	During treatment
	Discharge from services
Service Environment: The role of control within services	Shifts in control during treatment
	Control as punishment
Staff: Experiences with staff and the value of rapport	“Another anorexic”
	Staff consistency
	Hopelessness vs. hopefulness
	Being seen as an individual
Peer Influence: Camaraderie vs comparison	Support from peers
	Distress caused by peers

Theme 1: Treatment: Focus on physical vs. psychological symptoms

Many participants perceived ED services to overfocus on weight and food intake, subsequently dismissing or minimising the psychological underpinnings of their ED. This perceived overfocus was encountered throughout participants’ experience of services – from accessing treatment through to discharge.

Sub-theme: Access to treatment

Participants described being refused treatment because their weight was not low enough:

> ***“Treatment was often, inaccessible… with participants experiencing “being sent home until critical and in need of life saving (45)” and trouble “getting the GP to refer me to specialists as I was told my weight was not low enough (142)”.” (Fogarty & Ramjan, 2016, p. 6)***

This led participants to incentivise further weight loss, as it was the only way to be “[taken] seriously” (participant; Tierney, 2008, p. 370) and receive help. One participant likened it to playing a “game”:

> ***“I feel that I’m forced to be manipulative sometimes to get the help that I need … when it’s kind of focused on ‘Well if you lose another kilo then we’ll, then we’ll escalate you up the waiting list’ … you [are] kind of almost forced to play that game” (participant; Rance et al., 2017, p. 587).***

Subtheme: During treatment

Participants also noted that treatment itself focused on weight restoration with little regard for the psychological strain of weight gain:

> ***“Patient 5 was also concerned that practitioners concentrated on ‘getting your weight up, and then they expect everything else to level off in your head, but it doesn’t’” (participant; Tierney, 2008, p. 370).***

Some participants expressed a need for “psychological support to ‘soothe’ the distress related to re-feeding” (Wu & Harrison, 2019, p. 5). ED services that recognised the “emotional impact of weight gain and addressed psychological and physical issues in parallel were viewed as most helpful” (Offord et al., 2006, p. 382). Notably, services described as consisting of a well-coordinated and “connected” multi-disciplinary team seemed best equipped to address both psychological and physical needs, emphasising the importance of strong communication links across professions within the service (Escobar-Koch et al., 2012, p. 256).

Many participants demonstrated awareness of the importance of weight restoration and food intake within their treatment plan, with inpatient care in particular described as "saving [their] lives" (Wu & Harrison, 2019, p. 9). However, the overwhelming message was that this should be accompanied by other types of support, such as psychological, practical, and emotional support. A more "holistic" and individualised approach to care was desirable, in which participants felt supported "to uncover and address the underlying issues" (Offord et al., 2006, p. 381):

> ***"The turning point came when they… found a supportive space within services to help them make sense of this as a whole." (Joyce et al., 2019, p. 2077).***

Some participants reported having unique or complex struggles relating to their ED and its treatment. For these samples, a tailored, individualised treatment approach addressing these issues was particularly important. For example, in a sample of men, many found that services were "unable to acknowledge or provide space for them to talk about their unique struggles" because "programs were not tailored to their needs and preferences as men" (Thapliyal et al., 2020, p. 540).

Subtheme: Discharge from services

Finally, participants described being discharged from services when they reached their "target weight", despite not feeling ready psychologically:

> ***"The focus was on physical restoration so when I was discharged at the 'target weight', I was still the same emotionally as when I was admitted" (participant; Fogarty & Ramjan, 2016, p. 8).***

> ***"You feel very alone, you put weight on and then you're told you can go when you're struggling the most with your weight" (participant; Ross & Green, 2011, p. 114).***

The description of "[feeling] very alone" stresses the lack of support felt by some participants. Some expressed how this inclination to discharge at a certain weight meant they felt at high risk of relapsing after discharge:

> ***"They did make me eat, they stopped me from dying. As for solving the problem, considering that 18 months later I was back where I started almost, that wasn't tackled at all" (participant; Rother & Buckroyd, 2004, p. 157).***

While this participant acknowledged that the service helped them, the solution was temporary and not enough to avoid relapse. Many participants suggested that because underlying psychological issues were not addressed in treatment, this ultimately led them to believe that "relapse… was inevitable" (Tierney, 2008, p. 370).

To summarise, participants perceived an overfocus on the physical symptoms of their ED at the cost of tackling the psychological difficulties driving their ED. Importantly, this was experienced throughout their involvement with ED services, from accessing support through to being discharged from services. There was an emphasis on the need for an individualised treatment approach when accessing services, particularly for those with unique struggles relating to their ED (e.g., male service users).

Theme 2. Service Environment: The role of control within services

Many of the participants' narratives related to the role of control within services, and these experiences were often confusing, and at times conflicting. Although this was described in both inpatient and outpatient service experiences, the majority centred around inpatient experiences. The subthemes illustrate the shifts in control reported by participants and how control within services sometimes felt punitive.

Subtheme: Shifts in control during treatment

Some participants, including those reflecting on both inpatient and outpatient experiences, expressed that initially, letting go of and handing over control to the service provider was a difficult process:

> ***"It was very scary thinking if I come into treatment, I have to hand over all control the ED gave me. That made me feel very unsafe" (participant; V. Smith et al., 2016, p. 20).***

However, many reflected in hindsight that handing over control was something that "needed" to happen and overall, it was reported as a positive process:

> ***“Somebody took over and said this can’t carry on you have to do this and I think at that time I needed it” (participant; Ross & Green, 2011, p. 116).***

Participants described this feeling of handing over control as a “relief” (Joyce et al., 2019, p. 2073) that served to “[lessen] the guilt” (participant; Offord et al., 2006, p. 382) they felt. Moreover, as treatment and recovery progressed, some participants described a care plan that allowed them to gradually regain control, which tended to be positively received:

> ***“Right at the beginning, when I was so seriously ill, I couldn’t actually decide for myself… but later on, when I started getting well, I wanted to control things myself a little bit more” (participant; Lindstedt et al., 2015, p. 5).***

For many participants, this seemed to help with transitioning towards discharge from treatment, as it began to mirror ‘normal life’. There was an emphasis on the importance of gradually phasing back into the ‘real world’, as some described “difficulty transitioning from a medical/hospital environment back to day-to-day life outside of this setting” (Sheridan & McArdle, 2016, p. 1991). Getting the pace right in this shift in control was key for many participants. When a gradual transition did not occur, participants described difficulties adjusting back to having full control and freedom:

> ***“I’d been given all this freedom suddenly, I was like ‘well ok!’ so I did try to experiment, and I just experimented a bit too much and... lost weight again” (participant; Offord et al., 2006, p. 383).***

Moreover, those who experienced ED services during adolescence reported that inpatient care had stunted their social development, setting them back in their transition to ‘normal life’ and having full control:

> ***“I knew that I couldn’t cope as an adult. Cos I’d been like hidden away from society so was still only a 14-year-old really, in my head” (participant; Offord et al., 2006, p. 380).***

Overall, participants suggested they needed balance across the shifts in control they experienced, and this required services to adopt an adaptive, individualised, and collaborative approach to their treatment:

> ***"Complete control over treatment… was undesirable and… a combination of autonomy and direction was the balance that constituted a successful approach" (Reid et al., 2008, p. 958).***

> ***"(My treatment provider) allowed me to set the pace, meaning I felt a great sense of self-satisfaction as I took charge of my own recovery" (participant; Fogarty & Ramjan, 2016, p. 5).***

Adopting a collaborative approach between service user and provider that acknowledged individual needs and preference in pace of treatment provided a sense of empowerment in recovery, and participants described they subsequently "more often wanted to comply" (Colton & Pistrang, 2004, p. 313). This emphasises the need for a truly individualised approach, as seen previously in the 'Treatment' theme, which could subsequently facilitate engagement.

Subtheme: Control as punishment

Alongside reflection on how control changed during treatment, an overriding narrative for many participants was feeling punished by service providers when the services providers took control. This was particularly evident within the descriptions of some inpatient environments:

> ***"Set treatment programs for patients with AN… were often perceived as inflexible and punishing" (Offord et al., 2006, p. 381).***

> ***"I felt punished if I didn't eat in a certain amount of time." (participant; Walker & Lloyd, 2011, p. 546).***

In multiple accounts, participants used language relating to feeling imprisoned and punished. Some described their experience of an inpatient environment as "prison-like" (participant; Joyce et al., 2019, p. 2075) and participants referred to feeling "locked up" (participant; Escobar-Koch et al., 2012, p. 261). Some participants reported “control being taken away in many non-eating related areas of their life” (Offord et al., 2006, p. 382), and these restrictions were described as “disempowering” (Eli, 2014, p. 7). Such restrictive practices within some inpatient settings reinforced core ED beliefs that participants held:

> ***“I felt a very bad person like I was very unworthy of things, and like I should, I needed, I deserved to be punished. So the way I was treated when I was there was, to me, proof that I was being punished and, you know. So that was right really” (participant; Offord et al., 2006, p. 382).***

> ***“There probably is an atavistic sense of self punishment and lack of worth associated with ED, that the structure and nature of inpatient treatment exacerbates” (participant; Joyce et al., 2019, p. 2075).***

In summary, the current theme presents some conflicting yet significant experiences. In particular, the second subtheme of control being perceived as punishment seems to contradict the previous subtheme that reflects a more balanced letting go and gradual regaining of control. Offord et al. (2006) observed that, while some service users perceive services as over-controlling at the time, retrospectively they acknowledged the restrictions imposed on them as “a necessary aspect of treatment” (Offord et al., 2006, p. 385). Interestingly, while this gaining of insight may be true for some individuals, the narrative of feeling punished was reported by participants describing both current and retrospective experiences, suggesting this insight may not be universal.

Theme 3. Staff: Experiences with staff and the value of rapport

Participants described a wide spectrum of experiences with healthcare professionals involved in their treatment. Both negative and positive encounters were described, but importantly, these encounters played a significant role in their treatment and recovery, over and above many other aspects of the service experience.

Subtheme: “Another anorexic”

The most prevalent negative experience of healthcare professionals was of those who treated them as an illness rather than a person, and being seen only as, “another anorexic coming through the unit on the ‘conveyor belt’ of anorexics” (Colton & Pistrang, 2004, p. 312). Participants described being talked about in a dehumanising manner:

> ***"They see it as an eating problem, while that's the symptom . . . the person gets forgotten and we sit there and talk collectively about ED or [Severe and Enduring Eating Disorder] as opposed to the person who struggles for so many years with this illness" (participant; Joyce et al., 2019, p. 2078).***

Participants reported being viewed collectively as an illness, rather than as individuals, which related to a lack of individualised care, as "staff did not listen to them and tried only to fit them into theories" (Maine, 1985, p. 51). Again, this idea of individualised treatment is paramount to participants' narratives, mirroring the 'Treatment' and 'Service Environment' themes. Many noted that stereotyping tended to come from staff who did not specialise in EDs:

> ***"Untrained staff describe you as an ED… they have no trust in us really… hold grudges and go about bringing things up in front of other patients" (participant; Patterson et al., 2017, p. 4).***

There was agreement across accounts that services required more ED-specialist training for all staff:

> ***"It was important that staff had the right levels of expertise, not because experts were expected to have the solution or cure, but because they knew enough to be sensitive about the concerns of ED patients." (Reid et al., 2008, p. 959)***

Sub-theme: Staff consistency

One reason for encounters with "untrained" staff was due to the high turnover participants observed within services. Staff consistency played a significant role in participants' narratives:

> ***"The high turnover rate of inpatient staff… acted as a barrier to consistency and compassionate understanding, as staff were not provided with necessary training" (Joyce et al., 2019, p. 2078).***

Issues with staff consistency were closely linked to participants' feelings of trust which sometimes left them feeling vulnerable:

> ***"Since [current psychologist has] finished his training, I'm going to end up with another psychologist… it's like starting over, because it's really difficult for me to maintain trust with a psychologist" (participant; Escobar-Koch et al., 2012, p. 258).***

Subtheme: Hopelessness vs. hopefulness

Participants also reflected on a sense of staff feeling hopeless about their ED, which impacted on their perceptions of recovery:

> ***"I very much got the message from the ED service that an ED was something I managed for the rest of my life… and I didn't even know like you could ever get fully better" (participant; Rance et al., 2017, p. 589).***

This hopelessness narrative was particularly pertinent for samples of participants with chronic AN:

> ***"Experiences of being passed around different services, especially non-eating-disorders services (e.g. medical wards), engendered feelings of hopelessness and a sense of being abandoned by professionals" (Fox & Diab, 2015, p. 33).***

Conversely, when staff instilled hope, it was perceived to motivate participants in recovery:

> ***"We all want to know that we can beat this and that there is a life that doesn't involve AN" (participant; Fogarty & Ramjan, 2016, p. 4).***

Instilling hope may be perceived as particularly important to participants with more complex needs, such as chronic AN. When hopefulness was not present, this could hinder recovery and “reinforced their wish to ‘stay with the anorexia’” (Fox & Diab, 2015, p. 33). This links back to concepts observed in the ‘Service Environment’ theme, whereby ED beliefs were reinforced by their service experiences, highlighting a complex relationship between the ED and the provisions of an ED service.

Subtheme: Being seen as an individual

For many participants, feeling understood and validated by staff was, unsurprisingly, positively received. Participants appreciated when staff could separate the individual from their ED:

> ***“They are quite good at seeing you as an individual and they do like to get to know you without your ED” (participant; V. Smith et al., 2016, p. 22).***

> ***“She helped me to see how the anorexic side of me was being really harsh on the normal side of me” (participant; Fox & Diab, 2015, p. 32)***

This emphasises the running narrative of positive service experiences being facilitated by an individualised approach. Staff who showed compassion, understanding and empathy were felt to have a positive impact on participants’ lives. It is important to stress the significance of these traits as they were often key in motivating participants to comply with treatment and feel empowered to recover:

> ***“When treated by specialists they felt more empathy and understanding and were more motivated to continue with treatment.” (Walker & Lloyd, 2011, p. 545)***

> ***“When they’re more encouraging and supportive it makes me want to try harder” (participant; Colton & Pistrang, 2004, p. 313).***

The specific therapeutic interventions received by the service users, such as Cognitive Behavioural Therapy (Rance et al., 2017), were described by very few participants. A much more dominant narrative was the therapeutic alliances and rapport built with healthcare professionals, suggesting that this may be as important as – if not more than - the treatment approach itself:

> ***“Participants agreed that being able to communicate and feeling a connection with your therapist, having a rapport, and not feeling judged were all important determinants as to whether they would stay in treatment, regardless of the treatment modality” (Walker & Lloyd, 2011, p. 544).***

In summary, negative experiences of healthcare professionals included being viewed as a stereotypical ‘anorexic’ - typically by those without specialist ED training - rather than being seen as an individual. Participants also implicated that high rates of staff turnover jeopardised trust in healthcare professionals, hindering recovery. Moreover, perceived hopelessness in recovery from healthcare professionals was believed to be detrimental to prognosis. Conversely, positive staff traits included taking an empathetic, individualised approach to care, being able to separate the ED from the individual and instilling hope in service users.

Theme 4. Peer Influence: Camaraderie vs comparison

Due to the high number of inpatient experiences reported, a significant influence on participants’ service experiences included being in close proximity with peers with an ED. Participants reported conflicting experiences, with some suggesting it was helpful, and others feeling it was detrimental to their recovery.

Subtheme: Support from peers

Some participants spoke of the power of peer support, through a true shared understanding of what the other was going through. For some, this support was reported as more helpful than support from family or healthcare professionals:

> ***“Nobody is looking at you or judging you … they know exactly what you are going through… it is just almost understood” (participant; V. Smith et al., 2016, p. 22).***

> ***“You can see in their eyes that they are feeling exactly the same” (participant; Joyce et al., 2019, p. 2076).***

This shared understanding extended to a sense of belonging for many participants; something that some spoke of striving for throughout their lives:

> ***“She felt mutual understanding and belonging for the first time in her adolescent and adult life” (Eli, 2014, p. 5).***

A sense of belonging with peers was particularly significant due to feelings of isolation and loneliness that the ED perpetuated; a feeling that was also highlighted in the ‘Treatment’ theme. Participants described how the ED made them feel “so alone, because [they] felt that no one understood what [they were] feeling” (participant; Eli, 2014, p. 5), so finding a “sense of camaraderie between patients experiencing a similar transformation” (participant; Patterson et al., 2017, p. 4) was a powerful and cathartic experience for some.

However, it is important to note that this was not the case for all participants. In a sample of male participants, they described often being the only male in their treatment setting, which “contributed further to a sense of loneliness and isolation” (Thapliyal et al., 2020, p. 540). This suggests that in some cases where individuals do not relate to their peers, feelings of isolation can be exacerbated by being around others, further emphasising the running idea of needing tailored, individualised support.

Subtheme: Distress caused by peers

Despite the reported benefits of peers, many participants also spoke about its disadvantages. Participants described the tendency to compare themselves to others, creating a competitive environment:

> ***“I feel I was living in a space full of comparison, everything would be compared between us. They (peers) compared things like whose was larger or smaller, who ate more or less, who gained weight faster or slower” (participant; Wu & Harrison, 2019, p. 5).***

Spending time with others also led to learning new ED behaviours for some participants:

> ***“I didn’t really know ... about self-harm, um, about pacing to stop your weight going up, you know, walking around, exercise. I soon cottoned on.” (participant; Colton & Pistrang, 2004, p. 311).***

Discovering new ED behaviours and constantly comparing oneself to others subsequently worsened some participants' illness. Participants described fearing "being seen as 'greedy' or overweight… [resulting] in a desire for further weight loss" (V. Smith et al., 2016, p. 23). One participant described this experience as feeling like she was "being dragged back more than going forward" (participant; Eli, 2014, p. 6). This conflicting experience of peer influence tended to be the case across multiple accounts, regardless of other factors, such as age.

In summary, being in an inpatient setting was described as a "unique social environment" (Eli, 2014, p. 5), evident through narratives of both negative and positive peer influence. For some, the presence of others in a similar situation "functioned as a core element of treatment" (Eli, 2014, p. 5). For others, it was depicted as "[intensifying their] illness" (Eli, 2014, p. 5). Again, there are individual differences impacting peer influence, highlighting the importance of adopting individualised approaches.

2.4 Discussion

The aim of this meta-synthesis was to gain an understanding of ED service experiences by exploring the perspectives of service users. Notably, this is the first meta-synthesis to focus exclusively on the service experiences of ED service users. Twenty-two qualitative studies were selected with a total of 712 participants who were identified as past or present ED service users. Four overarching themes were identified: 'Treatment: Focus on physical vs. psychological symptoms'; 'Service Environment: The role of control within services'; 'Staff: Experiences with staff and the value of rapport'; and 'Peer Influence: Camaraderie vs. comparison'. The findings of this meta-synthesis emphasise servicer users' need for individualised care within ED treatment settings, with a desire for more psychological support from specialist ED healthcare professionals. It is also apparent that the role of peers and perceived shifts in control throughout treatment play an important part in recovery.

The current findings support some of the findings of the systematic review by Johns et al. (2019) relating to the overfocus on physical symptoms within services, the value of collaboration in treatment, and the importance of rapport and understanding from staff. A limitation of this previous review is that their narrow focus on the facilitators and barriers in primary and secondary care for EDs meant there was a lack of primary papers focusing specifically on their aim, resulting in a reliance on papers that had a main focus elsewhere (Johns et al., 2019). I was able to build upon this limitation for the previous review, which allowed us to produce a more detailed, explicit understanding of the ED service experience as a whole.

In the findings, service users highlighted a lack of specialist ED training and use of stereotyping during their service experience. These findings complement those found by Graham et al. (2020) in their meta-ethnography of ED healthcare professionals' experiences in which healthcare professionals experienced their work as emotionally draining, leading to burnout. It has been suggested that to cope with these pressures, ED staff may turn to 'depersonalising' service users, i.e. seeing them as a collective to relieve the strain of meeting individual needs (Fox, Woodrow, & Leonard, 2012). This may explain why service users described a lack of individualised care and reported being seen as 'another anorexic'. Fox et al. (2012) highlight that there is an irony in the lack of specialist ED training for those spending the most time with service users (e.g., nurses, healthcare assistants). Instead, they may rely on stereotypical portrayals of EDs to understand service users. The findings of the current meta-synthesis emphasise the need for more ED training across all disciplines, but particularly for frontline workers within these services.

Moreover, the importance of staff consistency was a common theme across studies, and participants reported that a high turnover of staff diminished their trust within services. While there are many reasons why someone might leave a role in any setting, it is important to acknowledge that this may have additional consequences within a clinical setting. Relational continuity – an ongoing relationship between the service user and one healthcare professional – has been reported in the literature to be particularly salient within mental health services and can promote safety and trust in the service's ability to provide adequate treatment and care (Biringer, Hartveit, Sundfør, Ruud, & Borg, 2017; Green et al., 2008). This study highlights the importance of ensuring a smooth and comprehensive transition, should a service user's care need to be handed over to another professional, to promote continuity of care and sustain trust within the ED service.

This meta-synthesis highlighted a perceived overfocus on physical symptoms of an ED (e.g., weight, food intake) at the cost of understanding and tackling the psychological underpinnings of disordered eating. Crucially, this was experienced throughout the service experience: from accessing services, through treatment and at discharge. This minimisation of the psychological impact of the ED was described to increase risk of relapse or engrain the ED further. We can draw parallels again to Graham et al. (2020)'s meta-ethnography, who offer an explanation for ED healthcare professional's dependence on using safe and certain measures such as weight restoration via the safe-certainty model proposed by Mason (1993). ED healthcare professionals may seek a position of safe-certainty (Fox et al., 2012) – that is, the intervention used will be safe (e.g. prevent death) and will certainly work (i.e. re-feeding will lead to weight restoration), confirming the healthcare professionals' status as experts that know what they are doing. However, Mason (1993) calls for a position of safe-uncertainty to be adopted within therapeutic settings. The safe-certain approach tends to be fixed and constrained, subsequently limiting healthcare professionals' expertise due to seeking certainty and not being open to novel ideas. In contrast, the safe-uncertain position allows healthcare professionals to take a more flexible, collaborative approach to treatment that follows an evolving narrative with the service user and promotes individualised care through a more investigational process. For example, it is well documented that early intervention in ED treatment is paramount for a more successful prognosis (Nazar et al., 2017; Treasure & Russell, 2011; Treasure, Stein, & Maguire, 2015), yet the current findings suggest there are still significant gaps in access to treatment. This was reported to be partly due to the rigid, weight-dependent protocol dictating access to and discharge from services. Taking a safe-uncertain position across services may allow for a more individualised, holistic approach, rather than relying on body-mass index targets. This safe-uncertain approach also mirrors aspects of care, such as collaboration and individualisation, that service users held in high regard in the current findings. In practice, it may be that adopting a more flexible approach, such as the one described above, is currently unachievable due to the lack of available funding and resources reported by those working within ED services (Koskina et al., 2012) This support is described as being essential in order for services to improve their practice and implement this kind of approach effectively (Koskina et al., 2012).

The role of control in ED services was a dominant theme within the results. Perception of control is a significant but complex phenomenon that both drives and maintains an ED (Fairburn, Shafran, & Cooper, 1999; Froreich, Vartanian, Grisham, & Touyz, 2016; Schmidt & Treasure, 2006; Slade, 1982) and this can extend into treatment settings and negatively affect prognosis (Jarman, Smith, & Walsh, 1997). These findings build a complex and conflicting picture of the relief of letting go of and the importance of gradually regaining control, together with control being perceived as punishment within treatment settings. It appeared that some service users retrospectively gained insight into their experiences and recognised the necessity of taking away control at the time of treatment. However, this gaining of insight was not the case for all participants, as some still reported perceiving the control imposed on them as punitive regardless of whether their experiences were current or retrospective.

These findings reinforce the importance of individualised care within ED services, as we can theorise that some individuals are more affected by perceived shifts in control during their treatment and less able to cope with these changes. While the data did not explicitly tell us where these individual differences lie, we can hypothesise where some of these might be from existing literature. For example, vulnerability to Obsessive-Compulsive Disorder, which is highly prevalent in ED populations (Kaye et al., 2004), has been linked to perceived control, exhibiting similar patterns to those with disordered eating behaviours (Froreich et al., 2016). Furthermore, qualitative accounts from autistic women with AN suggest that a need for control was a significant maintaining factor for their ED and affected their ability to engage with treatment (Brede et al., 2020). For these individuals, handing over control could be particularly distressing and perceived more negatively, and this should be considered in service provision.

There are important clinical implications relating to the role of control within treatment settings. Research suggests that the sense of control an ED provides can be a strong maintaining factor, leading individuals to value their ED (Schmidt & Treasure, 2006) and become resistant to change in treatment settings (Abbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2013). Motivational Interviewing techniques (Rollnick & Allison, 2004) have been utilised in ED services to challenge treatment resistance (Macdonald, Hibbs, Corfield, & Treasure, 2012). Crucially, the technique of ‘rolling with’ resistance, rather than opposing it, may be particularly helpful where the service user is feeling ambivalent about change and the perceived loss of control. Opposing resistance could be counter-therapeutic as it is likely to reinforce resistance and decrease likelihood of behaviour change (W. R. Miller & Moyers, 2006). It could be hypothesised that using these techniques may be particularly applicable for individuals demonstrating ambivalence relating to control recognised in the results.

Motivational Interviewing endorses a collaborative approach between service user and clinician (W. R. Miller & Rollnick, 2012). Collaboration was described as empowering in service users’ treatment experiences, yielding further endorsement for using these techniques. These findings suggest that perceptions of control vary across individuals, and some may be more susceptible to treatment resistance due to perceived loss of control than others. For those exhibiting resistance to treatment, Motivational Interviewing could facilitate the process of change. Some studies have suggested that motivational-based interventions are not effective at enhancing motivation or ED treatment outcomes (G. Waller, 2012). However, other studies have reported value and benefit in the delivery of brief motivational sessions, when compared to clearly non-motivational approaches such as psychoeducation (Denison-Day, Appleton, Newell, & Muir, 2018). Moreover, evidence-based therapeutic approaches for EDs such as enhanced Cognitive Behavioural Therapy (CBT-E) and the Maudsley Model for Treatment of Adults with AN (MANTRA) incorporate a clear, motivational component, implicating its importance as an element of the full treatment model for EDs (Denison-Day et al., 2018). Taking this research into consideration, it could be hypothesised that a brief motivational session or a therapeutic approach that incorporates these principles could be particularly beneficial for individuals exhibiting treatment ambivalence.

The influence of peers with an ED was a salient theme within service users' narratives, and these experiences were often conflicting. 'Peer contagion' is a term used to describe the adverse social learning processes of imitation, identification and competition observed in ED inpatient services. There has previously been a particular focus on adolescent service users (Vandereycken, 2011). This meta-synthesis found similar narratives in adults as well as adolescents. Contrary to the peer contagion concept, recent developments stress the potential effectiveness of peer mentoring within ED treatment settings, whereby recovered individuals become mentors for individuals receiving ED treatment (Hanly et al., 2020; Ramjan, Hay, & Fogarty, 2017). The results support the notion that peer influence can have a positive impact on recovery, and it could be that providing a wider spectrum of peers (including those recovered from an ED) within a service is key to a more successful prognosis.

Within the results, many participants reported similar ED service experiences. However, there seemed to be an additional layer of difficulty or complexity for certain participant samples. For example, male samples reported a lack of understanding about the male experience of EDs, describing the isolation felt by often being the only male in the service. This is supported by a recent synthesis which reported a lack of understanding about subtle gender differences in ED presentations (e.g. a drive for muscularity rather than thinness), which may require different treatment approaches (Murray et al., 2017). Moreover, participants with a chronic AN presentation seemed to have a particular emphasis on their perceptions of staff feeling hopeless about their ED. Research indicates that by instilling hope, clinicians can enhance therapeutic alliance and treatment outcomes in individuals with severe and enduring presentations of AN (Stiles-Shields et al., 2016). Finally, it was observed that some adolescent service users highlighted a perceived interruption in their development when transitioning back into the community after an inpatient admission. These additional reported difficulties for certain groups of service users emphasise the running theme of a need for an individualised approach. Research suggests that some populations have unique treatment needs relating to their ED, e.g. autistic individuals (Babb et al., 2021; Brede et al., 2020), those with diabetes (Macdonald et al., 2018) and ethnic minorities (Kronenfeld, Reba-Harrelson, Von Holle, Reyes, & Bulik, 2010). Adopting an individualised approach could help to overcome and meet these treatment needs. Poignantly, given the tendency for staff to stereotype service users (Graham et al., 2020), it may be that these service users are actually at most need of individualised support and care.

2.4.1 Limitations

There were some biases in demographics across selected papers for the meta-synthesis. For example, a large proportion focused solely on inpatient experiences (45% of papers, compared to 9% of papers focusing solely on outpatient experiences), included service users with a primary diagnosis of AN (at least 41% of participants; possibly higher as some papers did not report exact figures), and were female (97% of participants). Subsequently, the experiences reported by these participants may not represent the general ED population. There was also a lack of reporting some demographics, such as ethnic background and sexuality in the papers. Whilst our understanding of EDs within ethnic and sexual/gender minorities is expanding, this is still under-researched (Calzo, Blashill, Brown, & Argenal, 2017; McClain & Peebles, 2016; Perez, Ramirez, & Trujillo-ChiVacuán, 2019; Rodgers, Berry, & Franko, 2018) and reporting these demographics in ED research can help us to understand these populations further.

A limitation of the review is that the majority of data screening and analysis was completed by one researcher. This was somewhat addressed by utilising independent researchers to undertake quality checks during the screening process and quality appraisals. There was also involvement from the wider research team later in the analysis process. However, due to the subjective nature of the review, the meta-synthesis could have been improved by involving more than one researcher throughout the analysis process to avoid reliance on a single analyst driving the development of the themes.

It is also important to note that not all papers stated the diagnostic manual used to define the EDs received by participants, and in some cases, the type of ED was not defined at all (e.g., Escobar-Koch et al., 2010). For consistency and validity, it may have been appropriate to exclude papers that did not include this information. However, for this review I decided to take a more inclusive stance to represent a range of different ED diagnoses and presentations.

2.4.2 Conclusion

This is the first meta-synthesis to focus solely on service user experiences of ED services. I identified 22 papers spanning eight countries and involving 712 ED service users. I developed four overarching themes depicting service user experiences of ED services. These included: 'Treatment: Focus on physical vs. psychological symptoms'; 'Service Environment: The role of control within services'; 'Staff: Experiences with staff and the value of rapport'; and 'Peer Influence: Camaraderie vs. comparison'. The results portray the conflicts and complexities that service users encounter in ED services. I also highlight some important clinical implications for ED services to consider. For example, a running theme throughout the results emphasises the importance of adopting an individualised, collaborative approach within these services to ensure that individuals are receiving appropriate and tailored care.

Chapter 3: "It's not that they don't want to access the support… it's the impact of the autism": The Experience of ED Services from the Perspective of Autistic Women, Parents and Healthcare Professionals

3.1 Introduction

In Chapter 2, the qualitative accounts of service users were synthesised to understand their experiences and perspectives on ED services. Service users were often critical of the overfocus on physical symptoms and subsequent neglect of the psychological impact of their ED. The role of control was a complex and fluctuating construct that played a significant role within ED services. Finally, there was an emphasis on the importance of the clinician-service user relationship and the impact of peers also in treatment for an ED. We know that AN has the highest mortality rate of all psychiatric conditions (Arcelus et al., 2011), so access to effective treatment is paramount. However, high relapse rates in AN suggests that, long-term, treatment is often unsuccessful (Khalsa, Portnoff, McCurdy-McKinnon, & Feusner, 2017), and this meta-synthesis suggests that effective and appropriate treatment is often not achieved. There was also a suggestion in Chapter 2 that those with additional individual needs such as a co-occurring autism diagnosis may require a more individualised approach.

As outlined in Chapter 1, research suggests there is a need for better autism understanding within healthcare services (Tint & Weiss, 2017). Indeed, autistic adults face many barriers when accessing mental health services (Crane, Adams, Harper, Welch, & Pellicano, 2019). Qualitative evidence suggests that autistic women have autism-specific factors underpinning their AN (Brede et al., 2020; Kinnaird, Norton, Stewart, et al., 2019), so their service needs will likely differ from those who are not autistic. For example, common treatment approaches addressing body image and weight concerns, e.g. CBT-E (Fairburn, 2008) may be unsuitable for autistic women, as they report these factors play less of a role in their AN (Brede et al., 2020).

One qualitative study has investigated ED service experiences from the perspective of autistic individuals, with a focus on treatment adaptations. Kinnaird, Norton, Stewart, et al. (2019) interviewed thirteen participants in treatment for AN with an autism diagnosis (N=9) or presenting with high levels of autistic traits (N=4). Participants reported that current

ED treatments did not meet their needs and that adaptations were required to provide adequate care. Kinnaird, Norton, and Tchanturia (2017) also interviewed nine clinicians from the same ED service about their experiences working with autistic individuals. Clinicians reported lacking experience and confidence treating autistic individuals with AN. Finally, carers of autistic women with AN reported a lack of support for co-occurrence of autism and AN in ED services and emphasised the importance of treatment adaptations (Adamson, Kinnaird, Glennon, Oakley, & Tchanturia, 2020).

Whilst Brede et al. (2020) explored the theoretical underpinnings of the development of AN in autistic women, the current study aims to explore autistic women's experiences of ED services. It therefore builds on the fundamental groundwork laid down by Kinnaird, Norton, Stewart, et al. (2019), Adamson et al. (2020) and Kinnaird et al. (2017) by using a multi-perspective approach to further investigate autistic women's experiences in a larger, independent sample from across the UK. I expand on their findings in three key ways: first, by including the perspectives of three stakeholders – namely autistic women themselves, parents of autistic women and healthcare professionals (HCPs) with experience working with autistic individuals in ED services – in one analysis, thereby utilising an efficient and streamlined approach; second, by ensuring the autistic women interviewed all have a formal autism diagnosis, differing from Kinnaird, Norton, Stewart, et al. (2019)'s sample; and third, by utilising more extensive, in-depth interviews.

Data source triangulation (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014) was utilised to achieve a more rounded understanding of autistic women's ED service experiences. Given that the overarching aim was to understand the experience of the autistic women, I positioned the autistic women with AN as the central thematic voice in the analysis. In doing so, the aim is to substantially add to an evidence base that can inform service provision for autistic women. This research takes a participatory approach (Cornwall & Jewkes, 1995) via collaboration with two autistic advisors with lived experience of AN throughout the research process. A participatory approach is advocated particularly in autism research to ensure relevance to the affected community, sensitive and ethical conduct of the research, and to enhance the quality of data collected, analysis and communication of findings (Fletcher-Watson et al., 2019).

3.2 Methods

3.2.1 Participants

I recruited three participant groups from across the UK: autistic women with experience of AN; parents of autistic women with experience of AN; and ED HCPs. Data collection was intended to serve two different but related studies, and all participants in this study overlap with the sample in Brede et al. (2020). Two autistic women and one parent were excluded from the final analysis as they/their daughter scored below the cut-off on the 10-item Autism Spectrum-Quotient (AQ-10; Allison et al., 2012). Researchers regularly reflected on the emerging data and recruitment stopped once estimated that data saturation had been reached (Guest, Bunce, & Johnson, 2006). The final sample included 15 autistic women, 13 parents and 11 HCPs. Participants were recruited via social media (Twitter and Facebook), Autistica's Discover network, our online blog (www.sedaf18.blogspot.com) and via existing contacts.

3.2.1.1 Autistic women

The inclusion criteria for autistic women were: (1) above the age of 18; (2) clinical diagnosis of an autism spectrum disorder; (3) past or current experience of AN. Participants were asked to confirm that they met these criteria prior to being recruited to the study. Participants were asked for more details on their autism and AN diagnostic experience during the interviews, and all participants accounts were consistent, giving researchers no reason to doubt the authenticity of their diagnostic status. Demographics are in Table 3.1. Notably, the average age of autism diagnosis was 12 years higher than the average age of AN diagnosis. ED status was varied at the time of study – some considered themselves recovered, whilst others reported that they were still living with an ED.

Table 3.1. Demographics for autistic women with experience of AN (N=15).

Demographics	Mean	Standard deviation	Range
Age (years)	32.60	10.32	23-58
Age at AN diagnosis (years)	17.40	6.07	10-34
Age at autism diagnosis (years)	29.40	11.34	14-56
AQ-10 score	8.73	1.10	7-10
EDE-QS score	11.53	6.49	0-26
BMI (N=7*)	18.17	3.19	15-23

Note: *AN=anorexia nervosa; AQ-10=Autism Quotient-10; EDE-QS=ED Examination-short form; BMI=Body mass index. *Not all women were willing to provide their height and weight.*

All women reported having received ED treatment. Reported service types accessed and therapeutic approaches received are in Table 3.2.

Table 3.2. Type of services accessed, and therapy approaches received by autistic women (N=15).

Type of service accessed	Number of participants (/15)	Percentage (%)
Inpatient	9	60
Outpatient	10	67
Day patient	2	13
Type of therapy received		
Cognitive Behavioural Therapy (CBT)	11	73
Dialectical Behaviour Therapy (DBT)	7	47
Occupational Therapy (OT)	4	27
Group therapy	12	80
Other (e.g., mindfulness, art therapy)	5	33

3.2.1.2 Parents

The inclusion criteria for parents were: a daughter with both (1) a clinical diagnosis of autism spectrum disorder and (2) current or past experience of AN. Parents with a daughter under 18 years old were included. Five parents' daughters participated in the autistic women group of this study. All parents interviewed were mothers, except for one interview where both mother and father were interviewed together. See Table 3.3 for demographics.

Table 3.3. Demographics for parents of an autistic daughter with experience of AN (N=13).

Demographics	**Mean**	**Standard deviation**	**Range**
Daughter's age (years)	24.75	6.36	15-31
Daughter's age at AN diagnosis (years)	15.50	4.17	10-25
Daughter's age at autism diagnosis (years)	21.17	7.15	9-31

Note: *AN =anorexia nervosa*

3.2.1.3 Healthcare professionals

The inclusion criteria for HCPs were that they worked in ED services in a clinical capacity and had experience working with autistic individuals in this setting. Professions included clinical psychology (N=6), psychiatry (N=4), and counselling psychology (N=1). Two HCPs worked across both ED and autism services. The mean length of time working in their role was 9.6 years (SD = 5.8 years; range = 4-23 years). All HCPs reported working with individuals with a formal autism diagnosis in ED services. Many also reported working with girls and women whom they suspected were autistic but did not have a formal diagnosis.

3.2.2 Materials

3.2.2.1 AQ-10 (Allison et al., 2012)

The 10-item AQ-10 was administered to all autistic women to measure autistic traits and supplemented a self-reported clinical diagnosis of autism. Scores range from 0-10, with scores of 6 or above being indicative of autism. The AQ-10 has excellent predictive validity (>90%), comparable to the full 50-item AQ (T. Booth et al., 2013). Internal consistency for the autistic women in this sample was low ($\alpha = 0.29$).

3.2.2.2 ED Examination Questionnaire- short form (EDE-QS; (Gideon et al., 2016)

The 12-item EDE-QS measured autistic women's current ED symptomatology. Scores range from 0-36, with higher scores indicating more severe ED symptomology. The EDE-QS can successfully distinguish individuals with and without a clinical ED (Gideon et al., 2016). Internal consistency for the autistic women in this sample was acceptable (α = 0.77).

3.2.3 Interview Schedules

Two autistic advisors consulted on the interview schedule development to ensure that participation was accessible. The autistic women's interview covered their experience and diagnosis of autism and AN, how their AN and autism may interact, and the ED services they had encountered. This interview schedule was adapted for the parent group to be applicable to their daughter's and family's experience. The HCP interview schedule covered their experiences and knowledge of autistic women in ED services. Prompts were used to expand on the answers given, where necessary. Full interview schedules can be found as supplementary material in Brede et al. (2020).

3.2.4 Procedure

All autistic women and parents completed a demographic questionnaire, and autistic women additionally completed the AQ-10 and EDE-QS. Interviews were conducted by one of two non-autistic female researchers (CB and JB) either face-to-face, via Skype, or over the phone. They lasted on average for 1h 23min (range: 43min–2h 26min) with autistic women, 1h 27min (range: 43min–1h 54min) with parents, and 1h (range: 53min-1h 15min) with HCPs. Participants were offered £10 to thank them for participation. All interviews were audio-recorded with participant consent.

3.2.5 Analysis

Interviews were transcribed verbatim and entered into the qualitative data analysis program NVivo 12 (QSR International Pty Ltd., 2018) for analysis.

Thematic Analysis (TA; Braun & Clarke, 2006) identified patterns and themes across the data. TA was chosen for its flexibility and because it allowed generation of new ideas and insights from the data. An inductive, essentialist approach to TA was adopted when analysing the data, with theme development driven by the participants' experiences, insights and the overarching research aim.

CB and JB coded transcripts in reverse order to one another, so that different insights and perspectives could be utilised when emerging themes were discussed. Discussions about coding occurred regularly between CB and JB, and with the wider research team. All transcripts were double-coded. At two points during analysis, two autistic advisors provided feedback on the clarity of emerging themes and whether themes accurately reflected the autistic voice. These insights were taken into consideration when finalising the themes.

Themes were initially generated from the codes in the autistic women datasets. These initial themes were used to synthesise the codes in the parent and HCP datasets. Themes were refined to establish the final themes and sub-themes.

3.3 Results

Analysis of the three datasets resulted in three interrelated themes: Misunderstanding autism and autistic traits; One treatment does not fit all; Improving accessibility and engagement within services (Table 3.4). Participant quotes are labelled as ‘AW’ (autistic women), ‘HCP’ (healthcare professional) or ‘P’ (parent) followed by a number to represent individual participants anonymously.

Table 3.4. Main themes and subthemes.

Main theme	Subtheme	Example quote
Misunderstanding autism and autistic traits	Pre-autism diagnosis	"When I was in hospital, I kept getting told off for walking on tip toes and for fidgeting a lot… they thought I was doing these things to burn more calories, except I'd been doing them for as long as I could remember."
	Post-autism diagnosis	"I think the co-existence of [autism] as well as the ED is something that just makes some adults teams feel, "It's just too complicated, we just don't really want to know"."
One treatment does not fit all	Challenges of CBT	"With the CBT, maybe the problem is that they assume you have lot of these skills already… Therefore, I couldn't even begin to make changes, because I don't have any of those foundational skills."
	Challenges of group therapy	"I'm largely silent in any sort of group situation because I don't know

		what's expected of me. I'm worried of saying the wrong thing or I worry about misinterpreting people”
	Alternative therapeutic approaches	“DBT was really helpful… we spent a long, long time talking through emotions, identifying them and trying to think about how to regulate, how to manage them… DBT was about [emotion regulation] skills, and that was really important.”
Improving accessibility and engagement within services	Adapting communication styles	“It’s all about changing perceptions, it’s all about putting an autistic lens on and saying, how could I explain this differently?”
	Adapting service environments	“Noise… is something that has got to two patients and they’ve found that really difficult… we made allowances, in terms of music therapy taking place as far away from her as possible.”

Note: CBT=Cognitive Behavioural Therapy; DBT=Dialectical Behaviour Therapy; ED=eating disorder.

Theme 1. Misunderstanding autism and autistic traits

None of the autistic women had an autism diagnosis when they were first seen by ED services. They noted that some of the autistic traits and behaviours that they displayed were misconstrued. Contact with ED services varied for the women; some only encountered services for a few months, but the majority described multiple referrals across many years. Some autistic women received an autism diagnosis during this time period and consequently experienced ED services with and without a diagnosis of autism. Even with a diagnosis, some women still felt that their autistic traits were dismissed.

Sub-theme: Pre-autism diagnosis

This sub-theme relates to autistic women's experiences in ED services before they received an autism diagnosis. Many women felt that their autistic behaviours and traits were misjudged by some staff as driven by their ED. This led to these women being labelled as "resistant" or "naughty", which in turn made them feel unheard. In particular, coping mechanisms the autistic women adopted to appease sensory sensitivities were misinterpreted by staff:

> ***"When I was in hospital, I kept getting told off for walking on tip toes and for fidgeting a lot… they thought I was doing these things to burn more calories, except I'd been doing them for as long as I could remember."*** **AW09**

Other autism-related traits, such as communication difficulties or a lack of flexibility, were often misinterpreted as disengagement from treatment:

> ***"I felt… very criticised. I was being very resistant – or labelled as being very resistant. I don't think they took into account how… difficult I found it seeing lots of different people."*** **AW08**

Although they did not realise that they were autistic at the time, the autistic women expressed that they *were* aware that many of the traits they displayed were not driven by their ED. These misinterpretations of behaviours were noted by some HCPs, who described the difficulties of disentangling ED-fuelled behaviours and behaviours that might be related to autism:

> ***“For example, she would want to put a pea on each of the prongs of the fork, but [staff] said ‘oh no you can’t be doing that, you shouldn’t be doing that’ and corrected her when she was doing it, because they thought it was being driven by the ED.”*** **HCP03**

Some HCPs expressed their concerns around distinguishing autistic traits from being in a state of starvation:

> ***“One of the interesting things with people with particularly low weight is that the cognitive inflexibility that comes with it may sometimes be mistaken... Whether it is something that is a developmental condition or whether it’s something that is caused by the effect of starvation.”*** **HCP05**

Recognising the overlap in AN and autistic presentations was described by HCPs as “murky” and a “grey area”, which makes it “difficult to separate them all out”.

Sub-theme: Post-autism diagnosis

Some autistic women spoke about their experiences of ED services once they had received their autism diagnosis. In some cases, they felt that their diagnosis was still not taken into consideration in their treatment:

> ***“It felt like they didn’t care… I used to like to sit in the same seat, just because I knew where it was, and every day a different staff member would go and sit there. And they wouldn’t understand why I was getting upset.”*** **AW18**

Indeed, some HCPs reflected on the challenges for other staff in understanding autism in their workplace:

> ***“People who are interested in working with EDs don’t necessarily have an interest in, or a great deal of knowledge, working with autism.”*** **HCP05**

Furthermore, some HCPs emphasised that ED services, which were described as stretched for time and resources, may feel unable to support these individuals:

> ***"I think the co-existence of [autism] as well as the ED is something that just makes some adults teams feel, "It's just too complicated, we just don't really want to know"."*** **HCP01**

Indeed, some autistic women highlighted their experiences of being "too complex a case" for individual clinicians that they had encountered.

It is important to note that not all the autistic women had negative experiences with clinicians understanding their autism. Once a diagnosis had been given, this did in some cases lead to a better understanding of the individual and their needs:

> ***"When I explained about needing the food separate, they were very good about accommodating that. And they would separate out the food, and they didn't necessarily challenge that… but they also gave me the opportunity to try it differently if I wanted to."*** **AW03**

However, this understanding tended to reflect a minority of autistic women's experiences in ED services, with adaptations being dependent on individual clinician's experiences.

In summary, many of the autistic women stressed the importance of feeling heard and validated within services, as often their needs would differ to those of other service users. This particularly related to social communication and sensory sensitivities. However, an understanding of autism tended to depend on staff's personal experience and knowledge. For some HCPs, there seem to be difficulties understanding the overlap between AN and autism.

Theme 2. One treatment does not fit all

This theme relates to different treatments that autistic women had received and the challenges they experienced.

Sub-theme: Challenges of CBT

Most autistic women said they received CBT as part of their treatment, but nearly all described negative experiences of it. Some expressed that CBT was not accessible or effective for them:

> ***"With the CBT, maybe the problem is that they assume you have lot of these skills already… Therefore, I couldn't even begin to make changes, because I don't have any of those foundational skills."*** **AW17**

> ***"Interviewer: Is that something you found difficult, to transfer the skills [learnt in CBT]?***
> ***AW03: I didn't realise anybody would need me to. I wasn't realising that I was being taught a general technique rather than to alleviate a particular problem."***
> **AW03**

These women believed they did not benefit from CBT as they did not have the skills needed to fully engage with the therapy, e.g., the ability to transfer learnt information to real-life situations. In contrast, a couple of autistic women felt that they did benefit from CBT, noting that they found it to be helpful:

> ***"[CBT] helped me to understand why I thought and felt the way I did… that understanding helps you to kind of… restructure your thoughts and made me realise what wasn't true." AW14***

HCPs also reflected on difficulties that autistic women might face with CBT treatment:

> ***"In theory, they can demonstrate that they can switch between one way of thinking to another. When you put that dynamically into a daily life situation, they can't generalise it, it becomes different. So, they look as if they're making progress, but they're not."*** **HCP02**

Parents tended to echo the negative view held by autistic women, describing the CBT their daughter received as a "one size fits all" approach, overlooking individual differences. They felt that their daughters, who did not fit the treatment “mould”, were left behind:

> ***“[Daughter has] not been able to go through the sausage machine of evidenced-based care… [she] keeps falling off the conveyor belt.”*** **P03**

Sub-theme: Challenges of group therapy

Many autistic women were offered group therapy and described how the social demands impacted their ability to engage with the treatment:

> ***“I'm largely silent in any sort of group situation because I don’t know what's expected of me. I'm worried of saying the wrong thing or I worry about misinterpreting people”*** **AW08**

This links with the theme of ‘Misunderstanding autism and autistic traits’, in which autistic women and HCPs described how HCPs can misconstrue social difficulties as reflecting lack of engagement or “rudeness”, which further exaggerated their anxiety in this setting. Some HCPs acknowledged the social information-processing difficulties for autistic individuals within groups:

> ***“Processing information from others can be very arduous anyway… bring in a dozen more people into that room, it becomes impossible… a lot of people I see just go into shutdown in these groups, become silent, become withdrawn and find it hard to properly engage”*** **HCP03**

Similarly to the theme of ‘Misunderstanding autism and autistic traits’, this recognition typically reflected the HCP’s own experience of autism, rather than representing a service-wide awareness.

Some autistic women noted that a lack of structure in a group setting affected their ability to engage with therapy:

> ***"They had other groups as well, one which was just a general talking group, which I found was really unhelpful because they had no structure to it"* AW11**

Similarly, HCPs highlighted the importance of structure, and suggested that specific types of group may still be beneficial for autistic individuals:

> ***"Groups differ… if they were in a [dialectical behaviour therapy] group that's highly structured, they know exactly what to expect, it's all done from handouts, it's all teaching sessions, so that might be more tolerable or comfortable than say our contemplation groups, which are more of the social interaction"* HCP14**

These sentiments were echoed by one autistic woman who shared her experience of group therapy for her ED. Adjustments were made so that handouts were given to her in advance and she met with a staff member outside beforehand to reduce her anxiety.

Sub-theme: Alternative therapeutic approaches

Alternatives to common ED treatment options, such as CBT, were discussed by many autistic women. For example, dialectical behaviour therapy (DBT) (Linehan, 1993) was often described as helpful:

> ***"DBT was really helpful… we spent a long, long time talking through emotions, identifying them and trying to think about how to regulate, how to manage them… DBT was about [emotion regulation] skills, and that was really important."* AW17**

> ***"Emotion regulation was really important to me… when I was in distress, I would just self-harm, just become very unwell. But after that, I actually started to think what was going on... I think that's what really helped to improve my eating at the time."* AW01**

Therapy emphasising developing skills in recognising, managing and regulating emotions was perceived by many autistic women as particularly beneficial. Additionally, occupational therapy was positively received due to its practical focus:

> ***"[The occupational therapist] helped me get a volunteer placement at my old primary school… that was the best therapy I ever got, because it was practical and gave me something to do."*** **AW09**

Moreover, autistic women seemed to prefer a therapeutic focus away from food, weight and body image. For many, these were not as relevant as other underlying issues relating to the AN:

> ***"She basically didn't believe me when I said this is not about [body image]… she wanted to do body image therapies with me and I… found it humiliating, and also irritating and condescending that I was being not listened to."*** **AW13**

> ***"We didn't really focus on my eating... They made me focus on emotion regulation, and just mindfulness really, and social aspects, and that really helped me."*** **AW01**

In the first quote, feeling unheard is recurrent from the theme of 'Misunderstanding autism and autistic traits', whereby women felt their difficulties were being misconstrued by some staff as classic ED behaviours. In contrast, the second quote illustrates the benefits of focusing away from typical therapeutic content and towards issues that are more relevant to autistic difficulties.

To summarise, many autistic women felt they did not benefit from the typical therapeutic approaches. Engagement in group therapy was difficult due to social demands. Therapeutic models such as DBT and occupational therapy were favoured by many women due to the focus on regulating emotions and practical aspects, respectively. Moreover, focusing therapy away from food and body image was described as beneficial. A clear therapeutic structure seemed to be an important element for successful engagement, regardless of the type of treatment received.

Theme 3. Improving accessibility and engagement within services

The final theme relates to adjustments that can be made within services to accommodate autistic individuals. This theme links to the sub-theme of 'Post-autism diagnosis' in the 'Misunderstanding of autism and autistic traits' theme, where HCPs who adjusted usual practice to accommodate autistic needs were praised.

Sub-theme: Adapting communication styles

Communication with HCPs appeared key to the autistic women's engagement with services. Autistic women spoke highly of HCPs who adapted their usual communication style to meet their needs:

> ***"She understood how best to communicate with me, so she gave me written summaries after my appointments, she gave me written information and we used goal setting to help plan my care."*** **AW11**

Moreover, some HCPs identified communication barriers with autistic clients and suggested how to overcome these:

> ***"It's all about changing perceptions, it's all about putting an autistic lens on and saying, how could I explain this differently?"*** **HCP02**

Despite these insights, the autistic women's experiences tended to reflect that effective communication was not typical of the whole multidisciplinary team – a common thread seen throughout the results.

Parents were also aware of communication difficulties that their daughter may have with staff, including the importance of language used to start a conversation and build rapport:

> ***"'How are you?' is a very annoying question to my younger daughter. What on earth does that mean? If it's something more specific, like, 'What have you been doing this morning?',*** **[it]** ***is likely to make you feel comfortable and start a conversation."*** **P09**

This relates to the narrative seen in the first theme, whereby autistic women describe their social communication difficulties being misunderstood by some staff.

Sub-theme: Adapting service environments

Many autistic women talked about the service-level adaptations that were, or could have been, made to accommodate their autism, particularly relating to sensory sensitives and their need for predictability and routine. This relates to the 'Misunderstanding of autism and autistic traits' theme, in which some staff's understanding of autism allowed for adjustments to be made.

Relating to the ward environment, more routine and structure was desirable, such as a more rigid daily timetable:

> ***"Although I found the groups more challenging, I knew what I had to do during my day. I found unstructured time difficult, and I used to spend my time making my own structure."*** **AW08**

This relates to the 'One treatment does not fit all' theme - although group therapy was difficult, the structure it gave was helpful. Routine and structure resonated as an important factor for many autistic women in their ability to engage with treatment. Moreover, small adjustments to support the unpredictability of a new environment helped autistic women to engage with services:

> ***"The adjustments they agreed were… agreeing a time and day for key work sessions, giving me plenty of notice of change… and I could bring my soft duvet cover in and that then meant that I was comfortable and I could sleep and it's just minor things like that that can make a really big difference."*** **AW11**

Furthermore, many HCPs reflected on practical adjustments made to better accommodate autistic traits within therapeutic settings:

> ***"Noise… is something that has got to two patients and they've found that really difficult… we made allowances, in terms of music therapy taking place as far away from her as possible."*** **HCP08**

To summarise, autistic women's engagement with services was facilitated by staff adapting way they communicate with autistic clients. Additionally, the implementation of environmental adjustments to accommodate needs, e.g., sensory sensitivities, were praised by those who received them. This ties in with the previous themes, highlighting the need for an adaptive, individualised and autism-informed approach to treatment.

3.4 Discussion

This study aimed to deepen our understanding of autistic women's experiences of ED services by synthesising the views of autistic women with experience of AN, parents and HCPs working in ED services. One of the strengths of this study was the triangulation of the three stakeholder perspectives recruited from across the UK, representing a wide range of service experiences. Parent interviews enabled us to explore the extent to which the service experiences of autistic women with AN was reflected in close family members and gain insight into periods of time when autistic women with AN were severely ill in ED services, which autistic women themselves may be unable to recall. HCP interviews allowed us to gain insight into the treatment of autistic women with AN from the perspective of relevant services. Another strength of this study was its participatory approach, which ensured that questions asked were considerate, relevant and clear to participants. This research was enhanced by the advisors' lived experience and their understanding of the experiences of others within the community. Using TA (Braun & Clarke, 2006), three interrelated themes were generated: 'Misunderstanding autism and autistic traits'; 'One treatment does not fit all'; and 'Improving accessibility and engagement within services'. The overriding message emerging was that the ability to recognise autistic traits and understand autism in ED services is paramount to allowing autistic women to engage effectively, whether they have an autism diagnosis at the time or not.

These findings broadly support previous research with autistic women and women with high autistic traits (Adamson et al., 2020; Kinnaird, Norton, Stewart, et al., 2019; Kinnaird et al., 2017), strengthening claims for the need to adapt current therapeutic approaches, with an emphasis on a better understanding of the cooccurrence of AN and autism, through validation in a large independent sample. Additionally, by having a sample of clinically diagnosed autistic women, the current study adds insight into how the women's autism diagnosis in particular affected their experience in ED services. The participants in the current study described that common therapeutic approaches for AN may be less accessible to them. Moreover, the close overlap in the way that autistic traits and the symptoms of AN manifest often led to misinterpretations of behaviour by staff. Taken together, these experiences endorse a need to adjust and adapt current service provision to meet autistic women's needs.

There are similarities in the current findings to the ED service experiences of non-autistic individuals with AN, suggesting some findings reflect service-wide issues, as explored in Chapter 2. ED service-users in other qualitative studies reflected that staff treated them as an 'anorexic', without taking into account their individual differences (Offord et al., 2006; V. Smith et al., 2016). This is comparative to the current finding that women's autistic traits were misinterpreted as ED-related behaviours, i.e., viewing the individual as a stereotypical anorexic patient and interpreting behaviours through this lens. However, it is important to note that although autistic and non-autistic women with AN may superficially report similar experiences, the reasons for their dissatisfaction may be distinct. For example, women with AN described a desire for therapeutic focus away from food and weight, as it reinforced ED-related ideas and behaviours that were of critical importance to them (Rance et al., 2017). For the autistic participants, this was due to the insignificance of weight concerns to their AN (Brede et al., 2020). Moreover, Rance and colleagues noted that CBT was unpopular for women with AN due to its rigid structure. However, for many participants, a rigid structure was endorsed, and it was the requirement for abstract thinking abilities within CBT that held them back. The impact of other ED service-users on an inpatient ward was not as pertinent in the autistic women's narratives in this study, as is seen in other qualitative research (Colton & Pistrang, 2004; V. Smith et al., 2016), further emphasising their need for individualised care.

An unexpected finding in the data was that all the autistic women, and most of the autistic daughters of parents, had received their autism diagnosis after they were first seen by ED services. For many, their autism was not recognised until years after their ED was recognised, and there are a couple of potential explanations for this. First, this could be explained by the presence of autism merely being an epiphenomenon arising from the ED alone, rather than being present prior to the ED onset (Dinkler et al., 2020) – that is, autistic traits are exacerbated due to the consequences of the ED, and not indicative of 'true' autism. For an autism diagnosis to be given, traits must be present in early childhood (American Psychiatric Association, 2013), yet recent findings have suggested that this does not seem to always be the case with those who present with autistic traits after the onset of their ED (Dinkler et al., 2020). Alternatively, and in line with participants' narratives, it could reinforce findings that, particularly for women, mental health diagnoses act as a barrier to an autism diagnosis, known as diagnostic overshadowing (Bargiela et al., 2016; Leedham, Thompson, Smith, & Freeth, 2020). Recent thinking suggests that a dimensional, heterogeneous characterisation of autism is warranted, rather than relying on a categorical autism definition (Happé & Frith, 2020). Recognising and accommodating the presence of autistic traits, rather than relying on formal diagnosis, could allow those without (as well as those with) a diagnosis to be supported more appropriately. Indeed, autistic women and parents in this study reported that consideration of autistic traits would have helped them to access more appropriate care when being treated for AN.

The results imply a culture within some ED service teams that may lack capacity to accommodate autism and recognise autistic traits. We can draw parallels from previous qualitative research conducted with HCPs working in ED services (Graham et al., 2020). HCPs described working in ED services as emotionally draining, which lead them to form negative and stereotyped judgements of patients. To avoid these negative feelings, HCPs described shutting off and becoming task-oriented, subsequently overlooking patient's individual differences. Relating to the current study, both stereotyped judgements and neglect of individual differences meant that autistic traits were often attributed as ED-fuelled behaviours. This suggests a need for a culture shift towards an individualised, holistic approach to care.

3.4.1 Clinical Implications

While the scope of the current study did not focus on the mechanisms underlying anorexic behaviours in autistic women (see Brede et al., 2020), autistic women still reported a lack of concern about body image, reflecting that anorexic behaviours in autism may have unconventional antecedents or maintaining factors for some individuals. Research suggests that treatments for autism-related anxiety should be developed that are distinct from those for 'common' anxiety, although both can occur in autism (Lau et al., 2019). Similarly, there may be autism-related mechanisms driving at least some anorexic behaviours in autistic women or those with high levels of autistic traits (e.g., selecting food based on sensory properties) which would require different treatments to 'common' anorexic behaviours (e.g., selecting food based on calorific content).

The results suggested that AN treatment recommended by the UK's National Institute for Health and Care Excellence (NICE, 2017) like traditional CBT tended to be unsuccessful for autistic women. However, CBT has been successfully modified to treat autistic individuals for other mental health disorders such as anxiety (R. Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2010), depression (A. Russell et al., 2019) and obsessive-compulsive disorder (Kose, Fox, & Storch, 2018), suggesting there may be scope for modifications to CBT-ED (Fairburn, 2008). Furthermore, the findings highlight the potential value of other treatment options, such as DBT (Linehan, 1993). Other therapeutic approaches are being trialed for autistic individuals with AN, such as Cognitive Remediation Therapy which aims to address specific cognitive difficulties, rather than directly addressing the ED (Y Dandil, Smith, Kinnaird, Toloza, & Tchanturia, 2020).

The results highlight the need for more understanding and recognition of autism within ED services to provide effective treatment for autistic service users. We know that autistic traits are overrepresented within AN populations (Westwood, Eisler, et al., 2016), and this should be considered when offering treatment for AN. Moreover, considering the high number of women who have a late autism diagnosis, an understanding of how autistic traits might present in ED services will allow these women to seek advice and a diagnosis, if appropriate. Indeed, some of this work is currently being piloted through the implementation of the Pathway for EDs and Autism developed from Clinical Experience (PEACE) at the South London and Maudsley NHS Trust, which aims to address autism and AN comorbidity clinically through better autism identification and staff training, treatment adaptations and improved service experiences (Tchanturia, Smith, Glennon, & Burhouse, 2020).

3.4.2 Limitations

A limitation to this study was the sampling of participants. The online recruitment technique implemented excluded those who did not use social media. There is also potential for a volunteer bias whereby autistic women who were particularly dissatisfied with their care may have been more inclined to participate. Furthermore, I did not collect any measures of intelligence quotient (IQ), but the autistic women's reported education levels suggest generally high levels of intelligence. A meta-analysis found that individuals with AN have higher average IQ scores compared to the average of normative data (Lopez, Stahl, & Tchanturia, 2010). This suggests that there may be a subconscious recruitment bias to exclude those with lower intellectual abilities, which should be addressed in future research. Moreover, because of the bias in recruitment towards HCPs with experience working with autism and AN, their reflections may be different to HCPs with less experience with this client group or those who did not resonate with the aim of this study. A strength of the recruitment technique, however, was the ability to recruit participants from across the country, and therefore investigate a broad range of experiences and expertise.

Given the interpretive nature of qualitative research, it is acknowledged that researcher bias may shape the results to some extent. Whilst techniques were put in place to control for this, e.g., having two coders to analyse data and involving the wider research team with a range of backgrounds in theme development, it is recognised that our own beliefs, values, and experiences can shape the analysis, and this should be taken into consideration when interpreting the findings.

While the AQ-10 is recommended as an autism screening tool (NICE, 2016) and endorsed in its use in AN populations (Westwood et al., 2016), other research has suggested that the measure may not be an effective tool to use in a clinical population, with particular concern being raised with its use in AN populations (Kerr-Gaffney, Harrison, & Tchanturia, 2020; Sedgewick et al., 2019), which has implications for the validity of the AQ-10 used within the current study. Moreover, the sample's low internal consistency contrasts with that reported by the developers of the AQ-10 (Allison et al., 2012), who reported a Cronbach alpha of 0.85. It has been suggested by other authors who also found low internal consistency (Lundin, Kosidou, & Dalman, 2019) that this contrast may be due to differences in sample characteristics across studies. To combat this, future research should implement a more robust, reliable measure of autistic traits, such as the Autism Diagnostic Observation Schedule-2 (ADOS-2; C Lord et al., 2012).

Future studies could also consider including a control group of non-autistic women with AN. This would allow researchers to tease out where difficulties experienced are autism-specific, and where these are more universally experienced, e.g., whether difficulties with generalising CBT techniques, as stipulated by participant AW03, is specific to autistic individuals, or whether there are other factors influencing this, such as therapist characteristics or competency. Moreover, to improve the veracity of self-reported clinical diagnosis of autism, future studies should contemplate using more stringent checks to validate this, e.g., validating via health records.

While this study focused on autistic women with experience of AN, further research should consider the views of autistic men, non-binary and transgender individuals to understand any discrepancies in their experiences of ED services. In the general population, there are gender-specific issues that men face in ED services (Robinson, Mountford, & Sperlinger, 2013), and transgender clients in ED services face their own difficulties, with many clinicians being unequipped to appropriately treat them (Duffy, Henkel, & Earnshaw, 2016). It is unknown whether this study's findings would translate to the experiences of these individuals and future research is needed.

3.4.3 Conclusion

This study explored the experiences of autistic women in ED services, from the perspectives of autistic women themselves, their parents, and HCPs. These findings, combined with other research, emphasise that autistic women's needs are not being met in ED services and better awareness and understanding of autism is needed within these services, including recognising women without a formal diagnosis.

The following chapters will aim to expand on the current findings and address some of the limitations outlined above. For example, Chapter 4-6 will introduce comparison groups to help us to understand whether the difficulties expressed by autistic women are unique to them, or whether they are more universally experienced. This chapter also highlighted limitations with the measures used to determine levels of autistic traits. Chapter 4 will introduce more robust, reliable measures to improve on this.

Chapter 4: An exploration of disordered eating characteristics in autistic and non-autistic women with and without a restrictive eating disorder

4.1 Introduction

We learnt in Chapter 3 through qualitative methodology that autistic women's ED treatment needs are often directly related to their autism, and it was reported that these needs are rarely met in their experiences of ED services. This may relate to differences in the factors influencing their ED. For example, other qualitative findings suggest that some autism-related factors, such as sensory sensitivities and rigid thinking, directly and indirectly influence autistic women's eating behaviours (Brede et al., 2020). Moreover, other factors that are more traditionally associated with disordered eating are reported to be less important to them (Brede et al., 2020). Three factors that have been traditionally associated with the development and maintenance of a RED include pride in restrictive eating behaviours (Kenneth Goss & Gilbert, 2002), body dissatisfaction (Stice & Shaw, 2002) and internalisation of the thin ideal (ITI) (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999).

The self-conscious emotions of pride and shame have been implicated in the development and maintenance of REDs (Allan & Goss, 2012). Much research has focused on the role of shame within EDs (e.g. A. C. Kelly, Carter, & Borairi, 2014; Troop, Allan, Serpell, & Treasure, 2008), and less attention has been given to the role of pride. However, early anecdotal accounts of AN suggest that feelings of pride relating to restriction and control may play an important role particularly in the maintenance of AN (e.g. Bruch, 1974; MacLeod, 1982). Pride in disordered eating behaviours, such as the ability to control food intake or over-exercise, are theorised to regulate negative feelings of shame, and facilitate feelings of being successful and in control (Kenneth Goss & Gilbert, 2002; Skårderud, 2007). This may partly account for the reported lack of motivation to change during treatment (Skårderud, 2007). More recent research has suggested that feelings of pride in eating evolve over the period of the illness, and play a key role in the development, maintenance and treatment of AN (Faija, Fox, Tierney, Peters, & Gooding, 2017).

Despite a plethora of research into the expression and recognition of basic emotions (e.g., Trevisan, Hoskyn, & Birmingham, 2018; Uljarevic & Hamilton, 2013), there is little research exploring the complex emotion of pride in autism. Of the few studies that do exist, they often focus on children, and findings relating to the expression and recognition of pride are mixed. For example, early reports observed deficits in the expression of pride in autistic children (Kasari, Sigman, Baumgartner, & Stipek, 1993). On the other hand, autistic children were found to be just as accurate at recognising facial expressions of pride as neurotypical children (Tracy, Robins, Schriber, & Solomon, 2011). In adults, it has been found that those with high autistic traits expressed lower levels of both hubristic and authentic pride than neurotypical adults (Davidson, Vanegas, & Hilvert, 2017). Based on previous literature and given the social and emotional difficulties observed in autistic individuals, it could be hypothesised that the expression of pride may present differently in autistic women with a RED, compared to those who are not autistic. Supporting this, Brede et al. (2020) found that healthcare professionals with experience working with autistic individuals with an ED reported observing less competition and pride in weight loss in autistic service users than non-autistic service users. Overall, despite a lack of research into pride in autism, there are some suggestions that there are deficits particularly in the expression of pride in autistic individuals.

Body image disturbance is a multi-faceted paradigm, which involves: (i) an internalisation of Western sociocultural body image ideals, known in the literature as the ITI, and; (ii) a negative evaluation of one's own body, i.e. body dissatisfaction (Stice, 2002). Models of REDs such as AN show that ITI predicts body dissatisfaction, which in turn predicts disordered eating symptoms, suggesting both constructs are risk factors for the development of an ED (Stice, Nemeroff, & Shaw, 1996; Urvelyte & Perminas, 2015). There is also some evidence to suggest that body dissatisfaction plays a role in the maintenance of AN (e.g. Calugi, El Ghoch, Conti, & Dalle Grave, 2018). However other studies have found no association (e.g. Fichter, Quadflieg, Crosby, & Koch, 2017). Research suggests that maintaining factors of AN may differ between those in the early stages (e.g. <3 years) and later stages (e.g. >3 years) of illness (Treasure et al., 2015), which may partly explain the differences in the role of body dissatisfaction in the maintenance of AN found across studies (Glashouwer, van der Veer, Adipatria, de Jong, & Vocks, 2019). Fewer studies have looked at ITI in the maintenance of AN, however there is some evidence to suggest that ITI persists into recovery (Bardone-Cone et al., 2010) and may be a potential target for ED treatment (Heinberg et al., 2008).

There is little research looking at body dissatisfaction and ITI in autism. Through a series of two studies, (Asada et al., 2018) found that autistic individuals were less accurate at estimating their own body size – specifically their shoulder width - than a neurotypical control group. Body size overestimation is a core component of body image disturbance observed in individuals with AN (Moelbert et al., 2017), but the findings across the two studies were opposing: in Study 1, autistic participants overestimated their shoulder width, and in Study 2, they underestimated their shoulder width (Asada et al., 2018). Moreover, inaccurate body size estimation was attributed to sensory differences in autistic individuals, rather than a disturbance in body image (Asada et al., 2018). A qualitative study of eleven autistic adults (ranging in BMI categories from normal to obese) explored perceptions of weight management, body weight, and body image, with a specific aim to aid the prevention and treatment of obesity in autistic adults (Healy, Pacanowski, Kennedy, & Obrusnikova, 2021). They reported that body dissatisfaction was a recurrent theme for these adults, but suggest the origins of the dissatisfaction may be specific to autistic individuals, relating to distorted perceptions of the body and camouflaging to fit in. They also suggested that social influences impact their body dissatisfaction, but this suggestion was only endorsed by a minority of the sample (Healy et al., 2021). Conversely, in a qualitative study of fifteen autistic women with experience of AN, body weight and shape concerns were not a dominant driver in the development of their ED (Brede et al., 2020). For these women, where weight and/or shape were described to be a concern, this tended to be related to a sense of wanting to fit in with others or to sensory aversions to the feeling of weight (Brede et al., 2020). This is supported by findings in Chapter 3 in which autistic women reported to lack body image concern and found this focus within their ED treatment inappropriate. Taken together, the current research suggests an overall lack of endorsement of ITI and body dissatisfaction in autistic individuals. Furthermore, where some autistic individuals may present with body dissatisfaction and endorsement of ITI, the origins of this may be specific to autism-related factors, such as camouflaging to fit in or sensory sensitivities relating to weight.

To explore pride in restricted eating, body dissatisfaction and ITI in autistic women, we can make hypotheses derived from the findings from Chapter 3, drawing on previous qualitative research, and test these using quantitative methodology to allow for more generalisability of findings. This process reflects an exploratory sequential mixed methods design, which utilises a qualitative method to inform theory-generating, and the testing of this in a subsequent quantitative investigation (Creswell, 2021; Edmonds & Kennedy, 2016). Adopting this approach allows us to benefit from the richness of data collected in qualitative methods and the more generalisable nature of data collected in quantitative research methods.

An unanswered question from the previous chapter to be explored further is whether these findings are unique to autistic women with a RED or whether some of these extend to non-autistic women with a RED. We can address this by testing hypotheses derived from our qualitative findings via a comparison of autistic women with a RED, non-autistic women with a RED and autistic women without an ED. It is important to understand whether there are differences in ED profiles of autistic and non-autistic women as this can have implications for the treatment of their eating difficulties. For example, nationally recommended psychological interventions for EDs such as CBT-E (Fairburn, 2008) tend to involve work around body image (National Institute for Health and Care Excellence, 2017). If our qualitative research that illustrates the lack of importance of body image concerns for autistic women is generalisable to other autistic women with a RED, then this treatment may be ineffective for a significant proportion of individuals being treated for an ED. Moreover, including a comparison group of autistic women without an ED allows us to understand the differences in profiles between those who do and do not have a RED.

4.1.1 Aims and Hypotheses

I had two main aims for this study. The first aim of this study was to explore traditional ED profiles in: (1) autistic women with a RED, (2) non-autistic women with a RED and (3) autistic women without a RED. I did this by using a battery of questionnaires and experimental measures. For this aim, I had three primary hypotheses:

1. The non-autistic women with a RED will show higher levels of pride in eating than the autistic women with a RED. The autistic women without a RED will show the lowest levels of pride in eating.

2. The non-autistic women with a RED will present with more body dissatisfaction than the autistic women with a RED. The autistic women without a RED will show the least body dissatisfaction.
3. The non-autistic women with a RED will show greater endorsement of the ITI than the autistic women with a RED. The autistic women without a RED will show the least endorsement of the ITI.

The second aim was to investigate whether traditional ED characteristics (pride in eating, body dissatisfaction and ITI) or autistic traits were better predictors of ED psychopathology for the three participant groups described above. My hypotheses were:

1. Traditional ED characteristics will be a better predictor of ED psychopathology for non-autistic women with a RED.
2. Autistic traits will be a better predictor of ED psychopathology for autistic women with a RED and autistic women without a RED.

4.2 Method

4.2.1 Participants

Participants were recruited into three distinct groups: those who are autistic with a RED (Autism+REDs); those who are not autistic with a RED (REDs only); and those who are autistic and do not have a RED (Autism only). The full inclusion criteria are detailed in Table 4.1.

Table 4.1. Inclusion criteria for the three participant groups.

Autism+REDs	REDs only	Autism only
• Female • Aged 18+ • Must have a clinical autism diagnosis (including autism spectrum disorder, autism, Asperger's syndrome, high functioning autism, and pervasive developmental disorder) • Must be clinically diagnosed and currently living with a restrictive eating disorder (including anorexia nervosa, atypical anorexia and ARFID)	• Female • Aged 18+ • No autism diagnosis • Must be clinically diagnosed and currently living with a restrictive eating disorder (including anorexia nervosa, atypical anorexia and ARFID)	• Female • Aged 18+ • Must have a clinical autism diagnosis (including autism spectrum disorder, autism, Asperger's syndrome, high functioning autism, and pervasive developmental disorder) • No (current or past) restrictive eating disorder

Note: *RED=restrictive eating disorder.*

Study recruitment began in August 2019. The COVID-19 pandemic interrupted the study progression and therefore steps were taken to adapt the study from an in-person procedure to an online procedure. Therefore, this study was carried out in two stages: (1) pre-COVID-19, in which participants were seen in-person to complete the study, and (2) during COVID-19, whereby participants completed an adapted version of the study online.

Participants were recruited via social media (Twitter, Facebook, and our blog (http://sedaf18.blogspot.com/)), relevant charity networks (Autistica and Beat), NHS Eating Disorder services and Autism services. In total, 222 participants completed the study. Removal of participants that did not meet the inclusion criteria resulted in a final sample of

209 participants (Autism+REDs=51, REDs only=110, Autism only=48). See Table 4.2 for demographics.

Table 4.2. Participant demographics and statistical tests.

		Autism+REDs (n=51)	**REDs only (n=110)**	**Autism only (n=48)**	**Statistical test**
Testing location	*In-person*	35.3% (n=18)	<1% (n=1)	58.3% (n=28)	
	Online	64.7% (n=33)	99% (n=109)	41.7% (n=20)	
Gender identity	*Female*	88.2% (n=45)	100% (n=110)	91.7% (n=44)	
	Non-binary	9.8% (n=5)	N/A	6.3% (n=3)	
	Prefer not to say	2% (n=1)		2% (n=1)	
Age (years)	*Mean*	30.9	29.99	38.6	*F*(2,206)=11.87, *p*<.01, η^2 =.103
	SD	11.5	9.28	11.6	
	Range	18-61	18-63	18-69	
Age at autism diagnosis	*Mean*	27.7	N/A	34.9	*t*(94)=-2.85, *p*<.01, 95% CI [-12.21, -2.18], Hedges' g_s=.58
	SD	11.8		13	
	Range	11-58		9-59	
Age at eating disorder diagnosis	*Mean*	18.9	22.06	N/A	*t*(156)=-2.11, *p*>.05, 95% CI [-6.15, -.2], Hedges' g_s=.36
	SD	7.7	9.22		
	Range	9-54	11-59		
Current BMI	*Mean*	18.32	17.35	28.92	*Welch's F*(2,80.5)=62.77, *p*<.01, η^2 =.57
	SD	3.17	2.72	6.41	
	Range	13.11-30.04	11.76-26.2	15.24-42.77	
BMI missing		9.8% (n=5)	7.3% (n=8)	2.1% (n=1)	

Note: *BMI=Body Mass Index; SD=standard deviation; RED=restrictive eating disorder.*

Statistical tests revealed that the Autism only group were significantly older and had a significantly higher BMI than the Autism+REDs and REDs only group. The Autism only group were also significantly older than the Autism+REDs group when they received their autism diagnosis. The Autism+REDs group were significantly younger than the REDs only group when they received their ED diagnosis. Table 4.3 shows a breakdown of BMI by the type of ED reported by the Autism+REDs and REDs only groups. Participants in the two ED groups included those in recovery and/or who were weight-restored but still struggled with disordered eating cognitions and behaviours, which is reflected in the range of BMIs.

Table 4.3. BMIs for Autism+REDs and REDs only participant group per reported eating disorder diagnosis.

Eating disorder diagnosis		**Autism+REDs (n=51)**	**REDs only (n=110)**
Anorexia Nervosa	*Frequency*	74.5% (n=38)	80.91% (n=89)
	BMI mean	17.74	16.84
	BMI SD	2.37	2.4
	BMI range	13.11-22.34	11.76-26.2
Atypical Anorexia	*Frequency*	7.8% (n=4)	9.1% (n=10)
	BMI mean	19	21.06
	BMI SD	1.59	1.97
	BMI range	17.85-21.22	17.72-24.14
Avoidant-Restrictive Food Intake Disorder (ARFID)	*Frequency*	7.8% (n=4)	N/A
	BMI mean	23.08	
	BMI SD	6.7	
	BMI range	17.21-30.04	
Other	*Frequency*	N/A	2.73% (n=3)
	BMI mean		20.06
	BMI SD		3.66
	BMI range		15.84-22.32
BMI and/or eating disorder diagnosis missing		9.8% (n=5)	7.27% (n=8)

Note: *BMI=Body Mass Index; SD=standard deviation; RED=restrictive eating disorder.*

4.2.2 Materials

Materials included a demographic questionnaire and a battery of eighteen standardised questionnaires. Additionally, for participants who were seen in-person, we completed the ADOS-2, a structured, observational autism assessment. The relevant materials for the current chapter are outlined in Table 4.4 and described in more detail below. Other measures that were collected that will be discussed further in the successive chapter include two implicit association tests (IATs): a picture-based IAT and a questionnaire-based IAT. Not all materials were used as part of this PhD, but a complete list of materials can be found in Appendix A.

Table 4.4. Overview of relevant measures.

Measure	Type	What is it measuring?	Who completed the measure?
Demographic questionnaire	Self-report questionnaire	Questionnaire used to collect data relating to age, education level, occupation, eating disorder diagnosis and background, autism diagnosis and background, family eating disorder and autism history, mental health, height and weight. The online participants also answered questions relating to COVID-19 and how it has impacted them.	All participants (additional COVID-19 questions for online participants)
Ritvo Autism Asperger Diagnostic Scale – 14 (RAADS-14; Eriksson et al. (2013)	Self-report questionnaire	A fourteen-item screening measure of autistic traits for adults.	All participants
Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Hus & Lord, 2014)	Observational schedule	Gold-standard, semi-structured autism assessment tool used to support autism diagnosis (or lack thereof) in a research capacity.	In-person participants
Autism-Quotient (AQ; Baron-Cohen et al., 2001)	Self-report questionnaire	A fifty-item questionnaire to measure autistic traits.	Online participants
Eating Disorder Evaluation -	Self-report questionnaire	A thirty-two-item questionnaire to measure	All participants

Questionnaire (EDE-Q, Fairburn & Beglin, 1994)		eating disordered behaviours and cognitions.	
SWedish Eating Assessment for Autism spectrum disorders (SWEAA; Karlsson, Råstam, & Wentz, 2013)	Self-report questionnaire	A sixty-item questionnaire to measure eating disturbances in autism.	All participants
Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)	Self-report questionnaire	A fourteen-item questionnaire to measure symptoms relating to depression and anxiety	All participants
Pride in Eating Pathology Scale (PEP-S; Faija et al., 2017)	Self-report questionnaire	A sixty-item questionnaire to measure pride in relation to disordered eating behaviours and cognitions.	All participants
Body Shape Questionnaire (BSQ; Cooper et al., 1987)	Self-report questionnaire	A thirty-four-item questionnaire to measure the cognitive and attitudinal aspects of body shape dissatisfaction.	All participants
Sociocultural Attitudes Towards Appearance Scale (SATAQ-3; Thompson, van den Berg, Roehrig, Guarda & Heinberg, 2004)	Self-report questionnaire	A thirty-item questionnaire to measure endorsement of societal appearance ideals.	All participants

4.2.2.1 Measures of Autistic Traits

Ritvo Autism & Asperger's Diagnostic Scale (RAADS-14; Eriksson, Andersen, & Bejerot, 2013)

The RAADS-14 is a 14-item screening tool which reflects the autism diagnostic criteria, developed to screen for autism in psychiatric populations. Items are rated as 'never true' (0), 'true only when I was younger than 16' (1), 'true only now' (2), and 'true now and when I was young' (3). An example statement is 'I often don't know how to act in social situations.' Scores from 0-3 for each item are summed to achieve a total score, ranging from 0-42, with higher scores indicating greater endorsement of autistic traits. The measure consists of three subscales: 'Mentalising', 'Social anxiety', and 'Sensory reactivity'. A cut-off score of 14 reached a sensitivity of 97% and a specificity of 95% for non-psychiatric controls and 64% for those with psychiatric disorders, including psychotic disorder, mood disorder, anxiety disorder, obsessive-compulsive disorder and borderline personality disorder (Eriksson et al., 2013). The measure has good internal consistency (Cronbach's Alpha (α)>0.7), and adequate construct and convergent validity (Eriksson et al., 2013).

Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2; Catherine Lord et al., 2012)

The ADOS-2 is a structured observational assessment used to measure the presence of autistic traits. It takes approximately 30-60 minutes to administer by a trained examiner. The ADOS-2 consists of a range of questions and activities intended to elicit observable autistic traits. Items are scored, generally ranging from 0-3, with higher scores reflecting more autistic traits. The algorithm used to compute scores consists of two subscales: 'Social affect' and 'Restrictive and repetitive behaviours'. A score of 8 or above in the sum of the two subscales is suggestive of reaching criteria for an autism diagnosis. The ADOS-2 is often referred to as a 'gold-standard' autism assessment tool and its use is recommended by NICE guidelines as part of the diagnostic process for autism in adults (National Institute for Health and Care Excellence, 2012). The measure has been shown to have good specificity and sensitivity (both above 80%; Hus & Lord, 2014) and these findings have generally been replicated in studies of clinical populations, although specificity is somewhat lower for those with psychosis (Maddox et al., 2017) and schizophrenia (de Bildt, Sytema, Meffert, & Bastiaansen, 2016). Inter-rater reliability for ADOS-2 scoring is generally good (Zander et al., 2016) but it has been advised that reliability should be monitored by video-recording and double coding a proportion of ADOS-2 administrations (Kamp-Becker et al., 2018).

Autism-Spectrum Quotient (AQ; Baron-Cohen et al., 2001)

The AQ was only completed by those participating online to replace the in-person ADOS-2 measure. The AQ is a widely used, 50-item self-report questionnaire used to measure autistic traits. The AQ items are rated on a 4-point Likert scale, from ‘definitely agree’ to ‘definitely disagree’ and these are then collapsed dichotomously to score either 0 or 1, with scores ranging from 0-50. Higher scores are indicative of greater endorsement of autistic traits. An example statement includes ‘I often notice small sounds when others do not.’ A clinical cut-off of 32 is recommended by the original authors (Baron-Cohen et al., 2001). Internal consistency for the overall AQ scale is generally found to be good (e.g. α=0.82; Austin, 2005), although the internal consistency for the five AQ subscales (‘Social skill’, ‘Attention switching’, ‘Attention to detail’, ‘Communication’, and ‘Imagination’) are reported to be lower, with α’s ranging from 0.36-0.77 across studies (Stevenson & Hart, 2017). Some studies have successfully used the AQ to examine autistic traits within clinical populations, with autistic individuals scoring considerably higher than those with obsessive-compulsive disorder or social anxiety disorder (Hoekstra, Bartels, Cath, & Boomsma, 2008). Ashwood et al. (2016) found the AQ to have high sensitivity of 0.77 and a positive predictive value of 0.76. However, they also found it to have a low specificity of 0.29 and a negative predictive value of 0.36, meaning that 64% of those scoring below the AQ cut-off were ‘false negatives’. There is a lack of reliable self-report measures of autistic traits, so despite its drawbacks, the AQ was chosen as a second measure of autistic traits to be used in the online study, alongside the RAADS-14, in the absence of the ADOS-2.

4.2.2.2 Measures of Disordered Eating

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

The EDE-Q was developed as a self-report alternative to the Eating Disorder Examination (Fairburn, Cooper, & O'Connor, 1993), a clinical interview used to assess the core behavioural and cognitive symptoms of disordered eating over the past 28 days. It consists of: (i) 22 items rated on a 7-point Likert scale (ranging from 0–6), with higher scores reflecting either greater severity or frequency; (ii) 6 items measuring frequency of ED behaviours and cognitions; (iii) an estimate of current height and weight and; (iv) for females, regularity of menstrual periods and whether they take a contraceptive pill. It is widely used as a clinical and research tool. An example item includes, ‘Have you had a definite fear that you might gain weight?’. The questionnaire comprises of four subscales each consisting of 5–8 items: ‘Restraint’, ‘Eating concerns’, ‘Weight concerns’, and ‘Shape concerns’. Scores are averaged to gain an overall global score, which ranges from 0-6. The measure boasts good internal consistency (α=0.7-0.93; Berg, Peterson, Frazier, & Crow, 2012), discriminative validity (J. M. Mond, Hay, Rodgers, Owen, & Beumont, 2004) and convergent validity (Berg, Peterson, Frazier, & Crow, 2011).

Swedish Eating Assessment for Autism Spectrum Disorders (SWEAA; Karlsson, Råstam, & Wentz, 2013)

The SWEAA is a 60-item self-report questionnaire developed to measure eating disturbances in autistic individuals. This measure was chosen to identify autism-specific eating difficulties that may not be picked up by standard ED measures such as the EDE-Q, e.g., relating to sensory sensitivities to food items. It includes eight subscales (‘Perception’, ‘Motor control’, ‘Purchase of food’, ‘Eating behaviour’, ‘Mealtime surroundings’, ‘Social situation at mealtime’, ‘Other behaviour associated with disturbed eating’, ‘Hunger/ satiety’) and two single items (‘Pica’, ‘Simultaneous capacity’), as well as some demographic and medical history items. Questionnaire items are scored on a scale from 1 (never) to 5 (always). An example of one of the items is ‘I eat the same food every day’. As reported in the original validation paper (Karlsson et al., 2013), the means of the items for each subscale are calculated and transformed into a scale from 0-100 to create a more easily interpretable scale. The measure and its individual subscales show good reliability (α=0.73-0.92), good test-retest reliability (intra-class correlation coefficient (ICC)=0.86), and good convergent validity (0.34-0.62) (Karlsson et al., 2013).

4.2.2.3 Measures of Anxiety and Depression

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

The HADS is a brief self-report questionnaire used to measure anxiety and depression over the past week. It consists of 14 items, with 7 items measuring depressive symptoms and the remaining 7 items measuring anxiety symptoms. An example depression item includes ‘I feel as if I am slowed down’ and an example anxiety item includes ‘Worrying thoughts go through my mind’. Items are scored on a scale from 0-3, with higher scores indicating greater depression/anxiety severity. Scores for each subscale range from 0-21, with scores of 8-10 indicating a mild/borderline condition and scores of 11+ indicating clinical significance (Zigmond & Snaith, 1983). Internal consistency for the two subscales has shown to be good (HADS-anxiety mean α=.83; HADS-depression mean α=.82), and the sensitivity and specificity for both subscales are approximately 0.8 (Bjelland, Dahl, Haug, & Neckelmann, 2002).

4.2.2.4 Measures of Pride in Eating, Body Dissatisfaction and Internalisation of the Thin Ideal

Pride in Eating Pathology Scale (PEP-S; Faija et al., 2017)

The PEP-S is a 60-item self-report questionnaire that measures levels of pride towards ED symptoms such as food restriction and weight loss. An example statement includes ‘I feel pride when I experience having an empty stomach’. The scale consists of four subscales: ‘Pride in weight loss, food control and thinness’; ‘Pride in healthy weight and healthy eating’; ‘Pride in outperforming others and social recognition; and ‘Pride in capturing other people’s attention due to extreme thinness’. Items are rated on a 7-point Likert scale from ‘Strongly Disagree’ to ‘Strongly Agree’. A global score is obtained by summing and averaging all subscales except the ‘Pride in healthy weight and healthy eating’ subscale. The subscale excluded from the global PEP-S score is thought to be a measure of a protective factor which could counter disordered eating. The authors found internal consistency for the measure to be very good (α=0.98) and the subscales ranged from 0.88-0.98. It also showed excellent convergent validity with the EDE-Q, very good test-retest reliability (*r*=0.92) and excellent discriminant validity, successfully distinguishing between women with higher and lower levels of eating psychopathology (Faija et al., 2017). As the tool is relatively novel, it is yet to be utilised and validated in other studies and clinical populations.

Body Shape Questionnaire (BSQ; Cooper, Taylor, Cooper, & Fairbum, 1987)

The BSQ is a 34-item self-report questionnaire that measures cognitive and attitudinal aspects of body dissatisfaction (e.g., how one feels about their own body) over the past four weeks. An example item includes ‘Have you been so worried about your shape that you have been feeling you ought to diet?’. It uses a 6-point Likert scale ranging from ‘Rarely’ through to ‘Always’. The BSQ is a widely-used self-report questionnaire and is used frequently in AN populations (Guardia et al., 2012; Keizer et al., 2011). The BSQ has good criterion and convergent validity (particularly for women) and test-retest reliability (r=.88; Rosen, Jones, Ramirez, & Waxman, 1996). The measure also boasts very good internal consistency (α=0.97; Pook, Tuschen-Caffier, & Brähler, 2008). A total BSQ score of less than 81 suggest little or no worry about body shape, whereas scores of more than 140 suggest extreme worry about body shape, with a total possible score range from 34 to 204 (Cooper & Taylor, 1988).

Sociocultural Attitudes Towards Appearance (SATAQ-3; Thompson, Van Den Berg, Roehrig, Guarda, & Heinberg, 2004)

The SATAQ-3 is a 30-item self-report questionnaire that measures an individual's endorsement of societal appearance ideals, known as the internalisation of the thin ideal (ITI). ITI has been linked to body dissatisfaction and a distorted body image (Blowers, Loxton, Grady-Flesser, Occhipinti, & Dawe, 2003; Clark & Tiggemann, 2008). An example item includes 'I've felt pressure from TV or magazines to lose weight'. The SATAQ-3 is completed on a 5-point Likert scale ranging from 'Definitely Disagree' to 'Definitely Agree'. Higher total scores reflect stronger endorsement of the ITI, with scores ranging from 30-150. The questionnaire has four subscales: 'Internalization-General', which measures media influence related to TV, magazines and movies; 'Internalization-Athlete', which reflects influences related to athletic and sports figures; 'Pressure', which measures pressure to adhere to societal appearance ideals felt from the media; and 'Information', which reflects a measure of media as an information source for societal ideals of appearance. Internal consistency for the SATAQ-3 total and all subscales were high (α=.89-.96) and the measure has excellent convergent validity with the Eating Disorders Inventory (Thompson et al., 2004). Validity has also been tested in a large clinical sample of individuals with AN and bulimia nervosa, and α's remained high (Calogero, Davis, & Thompson, 2004).

4.2.3 Procedure

4.2.3.1 Pre-COVID-19 (In-person)

Participants completed the study either at the University (UCL or Cardiff) or in their own home. Once participants had read the information sheet and given written consent to participate, the ADOS-2 assessment was carried out. Next, participants would complete the questionnaire-based Implicit Association Test (Q-IAT) and experimental interoception task in a randomised order. Participants would then be asked to complete approximately 30 minutes of self-report questionnaires on a laptop and have their weight and height measured by the researcher for the demographic questionnaire. The demographic questionnaire was always presented first to participants, but the order of standardised questionnaires was randomised. Participants had the option to complete these questionnaires on paper if they would prefer. Next, participants would complete the picture-based Implicit Association Test (P-IAT), Test of Premorbid Functioning (ToPF; Wechsler, 2011) and experimental sensory sensitivities task in a randomised order. If self-report questionnaires were not finished in the 30-minute period, participants were given the option to complete these towards the end of the study with the researcher present or at home in their own time through a secure weblink. The majority of participants chose the option to complete these in their own time. In total, participants spent approximately 2-2.5 hours completing the study with the researcher and were offered breaks throughout. At the end of the study, participants were debriefed and offered a £30 voucher to thank them for their time.

4.2.3.2 During COVID-19 (online)

Participants were sent a secure link to the online study once they had read the information sheet. On opening this link, they were presented with the consent form which they had to read and complete in order to continue with the study. The demographic questionnaire, which also included questions about the frequency and impact of hardships experienced during COVID-19, was presented first. The battery of questionnaires was then presented to participants in a randomised order. In the absence of the in-person ADOS assessment, participants also completed the AQ as part of the questionnaire battery. Participants had the option to complete all questionnaires in one or multiple sittings. A second link was sent to participants to complete the P-IAT online. In total, participants took approximately 1-1.5 hours to complete the study. Once the study was completed, participants were presented with an online debrief and offered a £15 voucher to thank them for their time.

4.2.4 Data Analysis

4.2.4.1 Data cleaning

Little’s Missing Completely At Random (MCAR) tests were run for all raw questionnaire data. All MCAR tests indicated that data was missing completely at random, and amount of missing data was low across all questionnaires (<1%). This percentage may be low due to prompts given at the end of each questionnaire if any items were missing (although participants still had the option to bypass this prompt). Any missing data were replaced using Multiple Imputation (MI). In line with recommendations outlined in Rubin (1996), five imputations per missing observation were used. For each questionnaire, where data missing for a participant was <10%, MI was used to replace the individual item(s) and a new total score was calculated based on this imputation. Where data missing for a participant was >10%, MI was used to replace the total and subscale scores for the questionnaire.

Distribution of data was assessed using the Kolmogorov-Smirnov test and by calculating z-scores to detect skewness and kurtosis. For non-normally distributed variables, logarithmic transformations and square root transformations were performed separately on the raw data to attempt to improve distribution. Overall, neither transformations improved the distribution of data across groups. To improve distribution and reduce the risk of Type I and Type II errors, outliers were identified using the outlier labelling method (Hoaglin & Iglewicz, 1987) and any outliers identified were corrected using the Winsorizing procedure (e.g. Field, 2013; Wainer, 1976). This procedure was chosen over other outlier correcting procedures, such as trimming means, as there is evidence to suggest that this is a more robust technique (Dixon, 1980; Tukey, 1962). When analysing the data, statistical tests were run with and without outlier corrections. We found no differences in the outcome of the analysis when using either the data with or without outliers, and so the original data with outliers has been reported.

4.2.4.2 Exclusion

Our inclusion criteria for the two ED groups (Autism+REDs and REDs only) was to include those who considered themselves to be currently living with a RED. Due to the subjective nature of this inclusion, we used a secondary criteria post-data collection to confirm the presence of ED behaviours and cognitions. Participants in these two groups must either (1) score above a cut-off of 2.5 on their EDE-Q global score (J. M. Mond et al., 2004; Rø, Reas, & Stedal, 2015); (2) score +1 standard deviation above the means of an autism (clinical) group on the subscale ‘Eating behaviour’ or ‘Other behaviour associated with disturbed eating’ on the SWEAA questionnaire (Karlsson et al., 2013). This conservative cut-off for the SWEAA questionnaire subscales was used to take into account more autism-specific eating behaviours which might not be picked up by the EDE-Q, but still indicate disordered eating behaviours. Using this criteria, we excluded ten participants (REDs only group = 6; Autism+REDs group = 4). Additionally, we excluded one participant from the Autism only group who reported previous experience of an ED, and two participants from the Autism+REDs group who did not have a formal autism diagnosis.

4.2.4.3 Statistical analysis

To test the primary hypotheses and investigate differences across our measures of EDs, autism, anxiety and depression, one-way ANOVAs and post-hoc tests were carried out using IBM SPSS Statistics for Windows, Version 26.0. Due to uneven group sizes, a Hochberg's GT2 test was used as a post-hoc test when the assumption of homogeneity of variance was met. When the assumption of homogeneity of variance was not met, a Games-Howell post-hoc test (Field, 2013) and a Welch's F-Test was carried out and reported as an alternative to the ANOVA, as a more robust measure that takes into account these violations (Tomarken & Serlin, 1986). Homogeneity of variance was tested using Levene's test. Where only two groups were compared (e.g., for the ADOS-2), an independent samples t-test was carried out. Pearson's *r* correlations were also carried out to understand relationships between the relevant measures. A mixed-model ANOVA was also performed to further explore individual questionnaire subscales. For the mixed-model ANOVA, where Mauchly's test of sphericity was significant, Greenhouse-Geisser correction were reported when estimates of sphericity (ε) < 0.75, and Huynh-Feldt correction was reported when ε >0.75. Bonferroni corrections were applied when comparing main effects.

Follow-up analyses were carried out using Pearson's *r* correlations followed by multiple regressions. For multiple regressions, the assumption of no multicollinearity was tested using variance inflation factor (VIF) and the tolerance statistic, the assumption of independent errors was tested using the Durbin-Watson test, and the assumptions of homoscedasticity and linearity were tested using regression plots (Field, 2013). To determine pairwise effect sizes, Hedges' g was calculated. This type of effect size was chosen to correct for biases that can sometimes result from calculating Cohen's d effect sizes (Lakens, 2013). For ANOVAs, eta-squared (η^2) is also reported. Confidence intervals (CI) are reported for transparency.

4.3 Results

4.3.1 Measures Relating to Autism, Disordered Eating and Mental Health

One-way ANOVAs and appropriate post-hoc tests were carried out to understand the differences between measures for the three participant groups. An overview of the means, standard deviations and statistical tests for the relevant measures can be found in Table 4.5. Pearson's *r* correlations to explore relationships between measures can be found in Appendix B.

Table 4.5. Means, standard deviations and statistical tests for measures relating to autism, disordered eating, depression, and anxiety for the three participant groups.

Measure	Group	N	Mean	Standard deviation	Statistical test	Post-hoc comparisons
RAADS-14	Autism+REDs	51	35.06	5.83	*Welch's F*(2,119.4)=97.56, *p*<.01, η^2 =.46	REDs only < Autism+REDs
	REDs only	110	17.2	10.88		REDs only < Autism only
	Autism only	48	32.83	7.6		
AQ	Autism+REDs	33	38.45	4.15	*Welch's F*(2,49.219)=78.5, *p*<.01 η^2 =.373.	REDs only < Autism+REDs
	REDs only	109	24.85	8.46		REDs only < Autism only
	Autism only	20	35	7.48		
ADOS-2	Autism+REDs	20	14.6	4.11	*t*(51)=2.74, *p*<.01, 95% CI [.87, 5.66], Hedges' g_s=.77	Autism only < Autism+REDs
	REDs only	N/A	N/A	N/A		
	Autism only	33	11.33	4.26		
EDE-Q	Autism+REDs	51	3.46	1.43	*F*(2,206)=67, *p*<.01, η^2=.394	REDs only > Autism+REDs > Autism only
	REDs only	110	4.27	1.15		
	Autism only	48	1.75	1.3		
SWEAA	Autism+REDs	51	50.47	11.48	*F*(2,206)=26.52, *p*<.01, η^2=.205.	Autism+REDs > REDs only > Autism only
	REDs only	110	41.08	13.5		
	Autism only	48	31.8	14.23		
HADS-Anxiety	Autism+REDs	51	14.88	4.26	*F*(2,206)=14.83, *p*<.01, η^2 =.126	Autism only < Autism+REDs

	REDs only	110	14.45	3.54		Autism only < REDs only
	Autism only	48	11.06	4.53		
HADS-Depression	Autism+REDs	51	10.18	5.54	*Welch's F*(2,94.23)=17.52, *p*<.01 η^2 =.134	Autism only < Autism+REDs
	REDs only	110	10.73	4.03		Autism only < REDs only
	Autism only	48	6.4	4.34		

Note: *ADOS=Autism Diagnostic Observation Schedule; AQ=Autism-Spectrum Quotient; EDE-Q=Eating Disorder Examination Questionnaire; HADS=Hospital Anxiety and Depression Scale; RAADS=Ritvo Autism & Asperger's Diagnostic Scale; RED=restrictive eating disorder; SWEAA= Swedish Eating Assessment for Autism Spectrum Disorders*

4.3.1.1 Ritvo Autism & Asperger's Diagnostic Scale (RAADS-14)

A Welch's F-test revealed a significant effect of RAADS-14 score for the three groups. Post-hoc comparisons using the Games-Howell test indicated that the mean score for the REDs only group was significantly lower than both the Autism+REDs group (*p*<.01, 95% CI [14.74, 20.98], Hedges' g_s=1.86) and the Autism only group (*p*>.01, 95% CI [12.05, 19.21], Hedges' g_s=1.55). The mean RAADS-14 score did not significantly differ for the Autism+REDs and Autism only groups (p>.05, 95% CI [-1.03, 5.49], Hedges' g_s=.33).

4.3.1.2 Autism-Spectrum Quotient (AQ)

This measure was only administered to those completing the study online. A Welch's F-test revealed a significant effect of AQ score for the three groups. Post-hoc comparisons using the Games-Howell test indicated that the mean score for the REDs only group was significantly lower than both the Autism+REDs group (*p*<.01, 95% CI [11.02, 16.18], Hedges' g_s=1.76) and the Autism only group (*p*<.01, 95% CI [5.56, 14.74], Hedges' g_s=1.21). The mean AQ score did not significantly differ for the Autism+REDs and Autism only groups (p>.05, 95% CI [-1.78, 8.69], Hedges' g_s=.6).

4.3.1.3 Autism Diagnostic Observation Schedule (ADOS-2)

This measure was only administered to those completing the study in-person. Due to time constraints, there is one ADOS assessment missing from the Autism only group. We were also able to obtain ADOS-2 scores from those in the Autism+REDs (n=2) and Autism only (n=6) groups who were recruited from NHS services. Because we only saw one participant in-person from the REDs only group, data presented are from the Autism+REDs (n=20) and Autism only (n=33) groups.

An independent-samples t-test revealed that the mean total ADOS-2 score for the Autism+REDs group was significantly higher than the Autism only group.

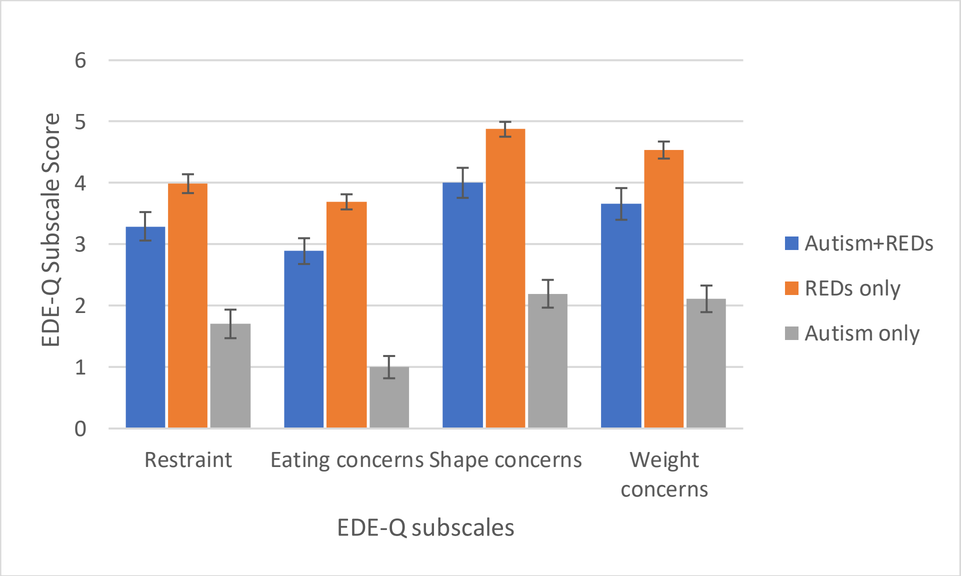
4.3.1.4 Eating Disorder Examination-Questionnaire (EDE-Q)

A one-way ANOVA revealed a significant effect of EDE-Q global score for the three groups. Post-hoc comparisons using the Hochberg's GT2 test indicated that the mean score for the REDs only group was significantly higher than the mean score for the Autism+REDs group (*p*<.01, 95% CI [.30, 1.33], Hedges' g_s=.65) and the Autism only group (*p*<.01, 95% CI [2.0, 3.04], Hedges' g_s=2.09). The Autism+REDs group mean score was also significantly higher than the Autism only group mean score (*p*<.01, 95% CI [1.10, 2.32], Hedges' g_s=1.24).

EDE-Q subscales

A 3 (Group) x 4 (Subscales) mixed-model ANOVA was conducted to compare EDE-Q subscale scores across groups. Figure 4.1 depicts the subscale means and standard errors for each group. The assumption of sphericity was violated and so the Huynh-Feldt correction was used. The ANOVA revealed a significant main effect of EDE-Q subscales, *F*(2.7,555.7)=52.91, *p*<.01, η^2=.204, suggesting an overall significant difference between subscales regardless of group. A significant main effect of group was also revealed, *F*(2,206)=67, *p*<.01, η^2=.394, indicative of significant differences between groups regardless of subscale differences. There was not a significant interaction effect of Group x Subscale, *F*(5.4,555.7)=.851, *p*>.05.

Figure 4.1. Mean EDE-Q subscale scores for participant groups. Error bars show +/-1 standard error.



Note: *EDE-Q=Eating Disorder Examination-Questionnaire; RED=restrictive eating disorder.*

4.3.1.5 Swedish Eating Assessment for Autism Spectrum Disorders (SWEAA)

A one-way ANOVA revealed a significant effect of SWEAA score for the three groups. Post-hoc comparisons using the Hochberg's GT2 test indicated that the mean score for the Autism+REDs group was significantly higher than the mean score for the REDs only group (*p*<.01, 95% CI [4.18, 14.58], Hedges' g_s=.72) and the Autism only group (*p*<.01, 95% CI [12.50, 24.84], Hedges' g_s=1.56). The REDs only group mean score was also significantly higher than the Autism only group mean score (*p*<.01, 95% CI [3.98, 14.59], Hedges' g_s=.7).

4.3.1.6 Hospital Anxiety and Depression Scale (HADS)

A one-way ANOVA revealed a significant effect of HADS-anxiety score for the three groups. Post-hoc comparisons using the Hochberg's GT2 test indicated that the mean score the Autism only group was significantly lower than the mean score for the Autism+REDs group (*p*<.01, 95% CI [1.9, 5.74], Hedges' g_s=.86) and the REDs only group (*p*<.01, 95% CI [1.74, 5.04], Hedges' g_s=.87). There was no significant difference between the Autism+REDs and REDs only groups (p>.05, 95% CI [-2.39, 1.29], Hedges' g_s=.11).

A Welch's F-test revealed a significant effect of HADS-depression score for the three groups. Post-hoc comparisons using the Games-Howell test indicated that the mean score for the Autism only group was significantly lower than the mean score for the Autism+REDs group (*p*<.01, 95% CI [1.41, 6.16], Hedges' g_s=.75) and the REDs only group (*p*<.01, 95% CI [2.58, 6.09], Hedges' g_s=1.04). There was no significant difference between the Autism+REDs and REDs only groups (p>.05, 95% CI [-1.21, 2.06], Hedges' g_s=.12).

4.3.2 Measures of Pride in Eating, Body Shape Concern and Internalisation of the Thin Ideal

One-way ANOVAs and appropriate post-hoc tests were carried out to test the three primary hypotheses. An overview of the means, standard deviations and statistical tests for the PEP-S, BSQ and SATAQ-3 can be found in Table 4.6.

Table 4.6. Means, standard deviations and statistical tests for measures relating to pride in eating, body shape concerns and thin-ideal internalisation for the three participant groups.

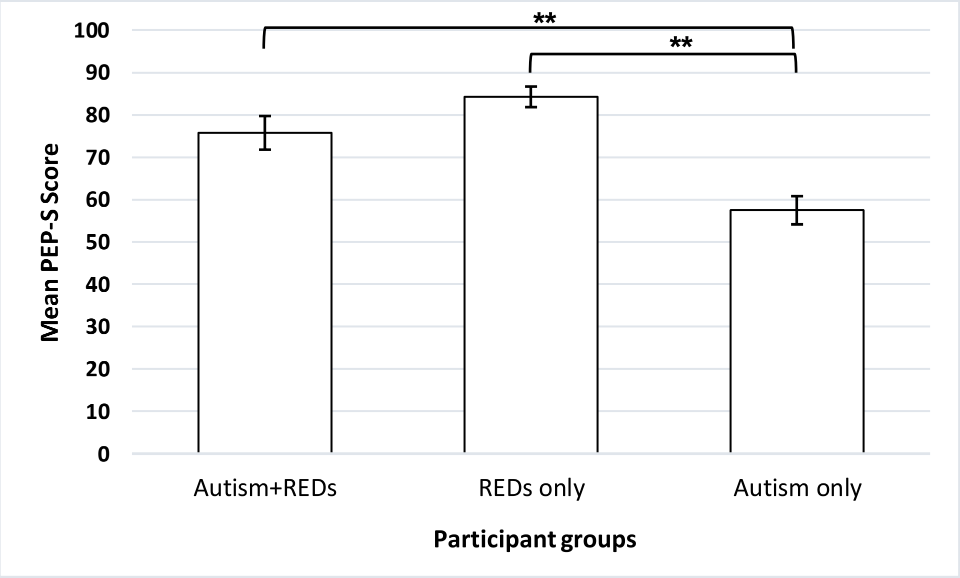
Measure	Group	N	Mean	Standard deviation	Statistical test	Post-hoc comparisons
PEP-S	Autism+REDs REDs only Autism only	51 110 48	75.73 84.22 57.47	28.41 25.39 23.03	*F*(2, 206)=18.185, *p*<0.01, η^2=.15	Autism only < Autism+REDs Autism only < REDs only
BSQ	Autism+REDs REDs only Autism only	51 110 48	125.94 146.91 88.81	36.89 34.15 33.3	*F*(2, 206)=47.164, *p*<0.01, η^2=.314	Autism only < Autism+REDs < REDs only
SATAQ-3	Autism+REDs REDs only Autism only	51 110 48	88.67 102.29 74.9	29.52 27.25 26.65	*F*(2, 206)=17.071, *p*<.01, η^2=.142	Autism only < Autism+REDs < REDs only

Note: *BSQ=Body Shape Questionnaire; PEP-S=Pride in Eating Pathology Scale; RED=restrictive eating disorder; SATAQ=Sociocultural Attitudes Towards Appearance Questionnaire.*

4.3.2.1 Profile for Pride in Disordered Eating Behaviours

A one-way ANOVA revealed a significant effect of total PEP-S score for the three groups. Post-hoc comparisons using the Hochberg's GT2 test indicated that the mean score for the Autism only group was significantly lower than the mean scores for the Autism+REDs group (*p*<.01, 95% CI [5.85, 30.67], Hedges' g_s=.70), and the REDs only group (*p*<.01, 95% CI [16.08, 37.43], Hedges' g_s=1.09). The mean scores for the Autism+REDs group and the REDs only group were not significantly different (p>.05, 95% CI [-18.95, 1.96], Hedges' g_s=.34). Means, standard errors and significance between groups are depicted in Figure 4.2.

Figure 4.2. Mean PEP-S scores for participant groups. Error bars show +/-1 standard error.



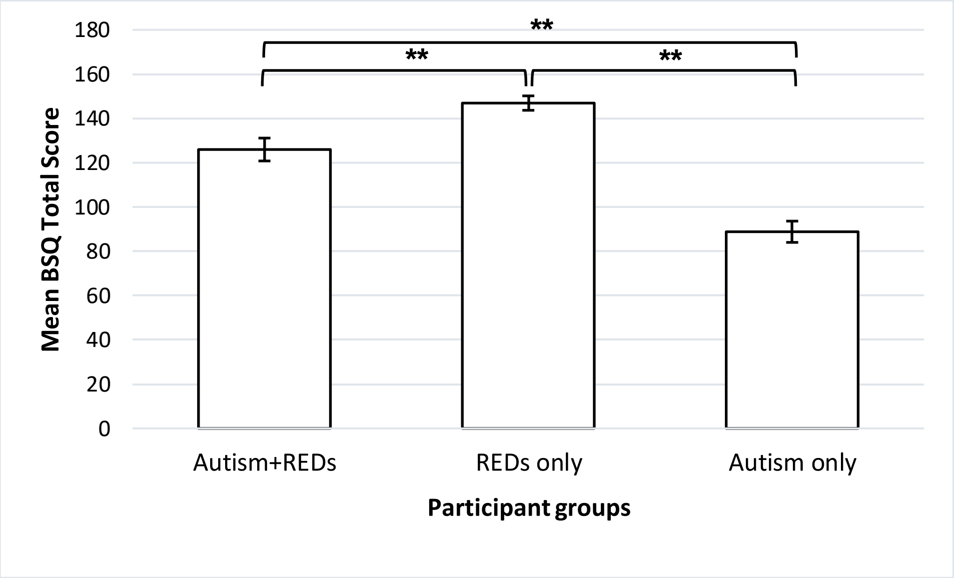
Note: *PEP-S=Pride in Eating Pathology Scale; RED=restrictive eating disorder. **=p<.01.*

The ANOVA findings did not support my hypothesis that the REDs only group would show more pride in eating than the Autism+REDs group.

4.3.2.2 Profile for Body Dissatisfaction

A one-way ANOVA revealed a significant effect of BSQ score for three groups. Post-hoc comparisons using the Hochberg's GT2 test indicated that the mean score for the REDs only group was significantly higher than the mean score for the Autism+REDs group (*p*<.01, 95% CI [6.84, 35.09], Hedges' g_s=.60) and the Autism only group (*p*<.01, 95% CI [43.67, 72.52], Hedges' g_s=1.71). The Autism+REDs group mean score was also significantly higher than the Autism only group mean score (*p*<.01, 95% CI [20.36, 53.90], Hedges' g_s=1.05). Means, standard errors and significance between groups are depicted in Figure 4.3.

Figure 4.3. Mean BSQ scores for participant groups. Error bars show +/-1 standard error.



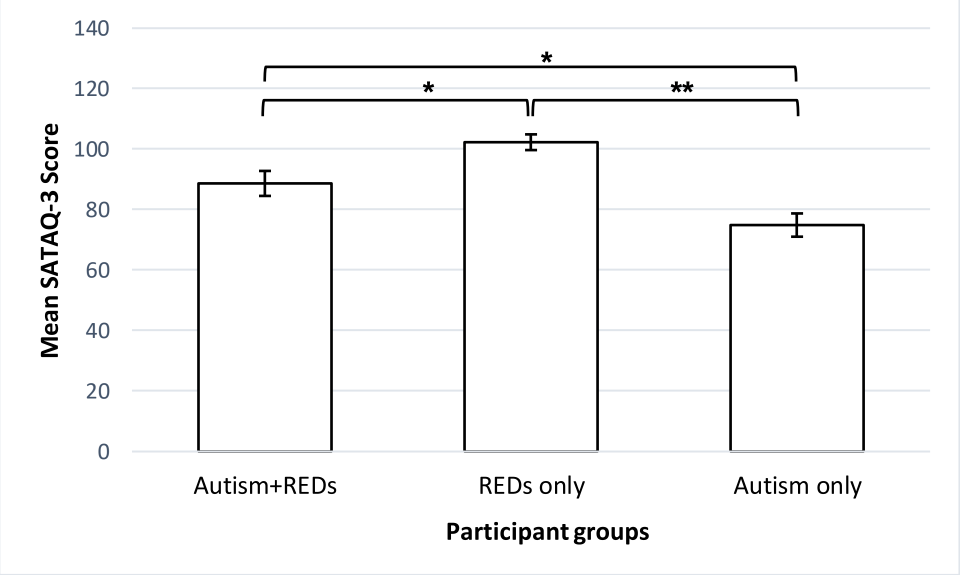
Note: *BSQ=Body Shape Questionnaire; RED=restrictive eating disorder. ** = p<.01.*

The results of the ANOVA support my hypothesis that the REDs only group would present with significantly more body dissatisfaction than the Autism+REDs group, and the Autism only group will show the lowest levels of body dissatisfaction.

4.3.2.3 Profile for Internalisation of the Thin Ideal (ITI)

A one-way ANOVA revealed a significant effect of SATAQ-3 score for three groups. Post-hoc comparisons using the Hochberg’s GT2 test indicated that the mean score for the REDs only group was significantly higher than the mean score for the Autism+REDs group (*p*=.01, 95% CI [2.34, 24.91], Hedges’ g_s=.48) and the Autism only group (*p*<.01, 95% CI [15.87, 38.92], Hedges’ g_s=1.0). The Autism+REDs group mean score was also significantly higher than the Autism only group mean score (*p*=.04, 95% CI [.37, 27.17], Hedges’ g_s=.49). Means, standard errors and significance between groups are depicted in Figure 4.4.

Figure 4.4. Mean SATAQ-3 scores for participant groups. Error bars show +/-1 standard error.



Note: *SATAQ-3=Sociocultural Attitudes Towards Appearance Scale-3; RED=restrictive eating disorder. * = p<.05. ** = p<.01.*

The ANOVA results support my hypothesis that the REDs only group will present with higher levels of thin-ideal internalisation than the Autism+REDs group, and that the Autism only groups will show the lowest levels.

4.3.3 Aim 2: Traditional ED characteristics and autistic traits as predictors of ED psychopathology

I investigated whether measures of traditional ED behaviours and cognitions (PEP-S, BSQ, SATAQ-3) or measures of autistic traits (RAADS-14 subscales) were better predictors of ED psychopathology, as measured by EDE-Q global scores, for the three participant groups. First, Pearson's r correlations were carried out to understand the relationship between the EDE-Q, PEP-S, BSQ, SATAQ-3 and RAADS-14 subscales (see Table 4.7). The pattern of correlations is somewhat complex, but some similar patterns can be identified across groups. For example, strong correlations were found across the three traditional ED characteristic measures for all three groups and across the RAADS-14 subscales for all three groups.

Due to the conceptual overlap between the BSQ and the EDE-Q Shape Concerns subscale, the correlations were run both with and without the inclusion of the Shape

Concern subscale within the EDE-Q-global score. There were no differences in the outcome of the correlations, and so the correlations with the full EDE-Q-global score are presented.

Table 4.7. Correlation matrices to show relationships between EDE-Q, PEP-S, BSQ, SATAQ-3 and RAADS subscales for each participant group.

Autism+REDs (n=51)		**EDE-Q-global**	**PEP-S**	**BSQ**	**SATAQ-3**	**RAADS-mentalising deficit**	**RAADS-social anxiety**
	PEP-S	.551**					
	BSQ	.704**	.645**				
	SATAQ-3	.327*	.352*	.59**			
	RAADS-mentalising deficit	.072	.071	.085	.056		
	RAADS-social anxiety	.305*	.325*	.316*	.143	.416**	
	RAADS-sensory reactivity	.142	.056	.157	.096	.483**	.324*
REDs only (n=110)		**EDE-Q-global**	**PEP-S**	**BSQ**	**SATAQ-3**	**RAADS-mentalising deficit**	**RAADS-social anxiety**
	PEP-S	.563**					
	BSQ	.683**	.513**				
	SATAQ-3	.223*	.366*	.447**			
	RAADS-mentalising deficit	.134	-.001	.273**	-.037		

	RAADS-social anxiety	.226*	.121	.174	-.035	.606**	
	RAADS-sensory reactivity	.265**	.12	.331**	-.075	.651**	.451**
Autism only (n=48)		**EDE-Q-global**	**PEP-S**	**BSQ**	**SATAQ-3**	**RAADS-mentalising deficit**	**RAADS-social anxiety**
	PEP-S	.613**					
	BSQ	.844**	.61**				
	SATAQ-3	.287*	.46**	.463**			
	RAADS-mentalising deficit	.313*	.223	.269	-.086		
	RAADS-social anxiety	.192	.142	.115	-.294*	.506**	
	RAADS-sensory reactivity	.25	.067	.217	.146	.616**	.308*

Note: *BSQ=Body Shape Questionnaire; EDE-Q=Eating Disorder Examination Questionnaire; PEP-S=Pride in Eating Pathology Scale; RAADS=Ritvo Autism & Asperger's Diagnostic Scale; RED=restrictive eating disorder; SATAQ-3=Sociocultural Attitudes Towards Appearance Questionnaire-3.*

Second, multiple regression analyses were performed to understand whether autistic traits (RAADS-14 subscales) or traditional ED measures (PEP-S, BSQ and SATAQ-3) are better predictors of ED psychopathology (EDE-Q). Variables that were significantly, positively correlated with EDE-Q global scores were entered into a regression for each participant group. Regression outcomes for each group can be seen in Table 4.8. Similarly to the correlations above, the multiple regressions were run with and without the inclusion of the Shape Concerns subscale within the EDE-Q global score. There were no differences in the outcome of the regressions, and so the analyses with the full EDE-Q-global score are presented.

Table 4.8. Multiple linear regression analyses predicting EDE-Q global scores as a function of autistic traits (RAADS-14 subscales) and traditional eating disorder measures (PEP-S, BSQ and SATAQ-3).

	R^2	**Predictor variable**	***B***	***SE B***	**β**	***t***	***p***
Autism+REDs	.526	RAADS-social anxiety	.043	.072	.066	.603	.549
		PEP-S	.007	.007	.145	1.077	.287
		BSQ	***.026***	***.006***	***.663***	***4.25***	***.000***
		SATAQ-3	-.006	.006	-.124	-.986	.329
REDs only	.554	RAADS-social anxiety	.028	.023	.09	1.218	.226
		RAADS-sensory reactivity	-.007	.032	-.016	-.206	.837
		PEP-S	***.014***	***.004***	***.311***	***4.003***	***.000***
		BSQ	***.02***	***.003***	***.58***	***6.64***	***.000***
		SATAQ-3	-.006	.003	-.149	-1.928	.057
Autism only	.753	RAADS-mentalising deficit	.013	.025	.042	.517	.608
		PEP-S	.011	.006	.199	1.993	.053
		BSQ	***.031***	***.004***	***.788***	***7.717***	***.000***
		SATAQ-3	-.008	.004	-.165	-1.799	.079

Note: *BSQ=Body Shape Questionnaire; EDE-Q=Eating Disorder Examination Questionnaire; PEP-S=Pride in Eating Pathology Scale; RAADS=Ritvo Autism & Asperger's Diagnostic Scale; RED=restrictive eating disorder; SATAQ-3=Sociocultural Attitudes Towards Appearance Questionnaire-3.*

The multiple regressions suggest that, for all three groups, BSQ scores were a significant predictor of EDE-Q global scores. Additionally, for the REDs only group, PEP-S scores were also a significant predictor of EDE-Q global scores.

4.4 Discussion

The current study compared the typical ED profiles of autistic women with a RED, non-autistic women with a RED, and autistic women without an ED. Specifically, we focused on levels of body dissatisfaction, ITI and pride in eating, which have all been associated with the presence of a RED in previous research. Contrary to one of our primary hypotheses, we found that both autistic women and non-autistic women with a RED presented with similar levels of pride in eating. However, in line with the remaining two primary hypotheses, autistic women with a RED showed significantly lower levels of ITI and body dissatisfaction than non-autistic women with a RED. Autistic women without an ED, as predicted, showed the lowest levels of pride in eating, ITI and body dissatisfaction. In our follow-up analyses, we found that, for all three groups, EDE-Q global scores were significantly predicted by measures of body dissatisfaction, over and above measures of autistic traits. Additionally, for the REDs only group, EDE-Q global scores were also significantly predicted by measures of pride in eating.

Our hypotheses relating to body dissatisfaction and ITI were supported by the findings that autistic women with a RED reported significantly less body dissatisfaction and less endorsement of the ITI than non-autistic women with a RED. This is in line with Chapter 3 and other qualitative research in which autistic women with an ED described experiencing fewer concerns relating to their weight and shape (Brede et al., 2020). Moreover, this view is supported by healthcare professionals with experience working with autistic individuals with an ED, who understood autistic women's difficulties to be distinct from those without an autism diagnosis, with an emphasis on a lack of body image issues (Brede et al., 2020). These findings directly oppose the understanding of EDs as primarily being driven by an overevaluation of weight and shape, which is considered to be the core psychopathology across all EDs, according to the transdiagnostic cognitive-behavioural model (Fairburn et al., 2003). While this might be the case for a proportion of individuals with an ED, for some autistic women with an ED, this does not seem to be a core feature of their ED psychopathology.

Our findings did not support our hypothesis that the Autism+REDs group would show significantly lower levels of pride in eating than the REDs only group. We found that autistic and non-autistic women with a RED reported similar levels of pride in eating. The findings add to the limited literature base relating to autism and feelings of pride, suggesting that in the context of an ED, autistic women's reported feelings of pride in disordered eating behaviours are similar to those found in non-autistic women. It is important to note that the current study relied on self-reported pride in eating which could be subjective, and therefore future studies could build on these findings and explore other aspects of pride as an emotion, such as its expression and recognition. The developers of the PEP-S highlighted its distinction from global pride (Faija et al., 2017), so future studies could benefit from including a global measure of pride (e.g. the 7-item Authentic and Hubristic Pride Scales; Tracy & Robins, 2007) as well as the PEP-S to understand the role of disordered eating-related pride and global pride in autism further. It is important to note that the PEP-S is a relatively novel measure which is yet to be validated in clinical populations. Our findings can add to the current evidence base for the use of the PEP-S, suggesting that levels of pride in eating are elevated in individuals with a RED (regardless of whether they have an autism diagnosis or not) compared to those without an ED. However, these findings should be interpreted with caution as further research with clinical populations is needed to validate this novel measure.

The second part of the analysis sought to understand whether autistic traits or traditional ED traits predicted ED psychopathology, as measured with the EDE-Q. We found that for all three participant groups, autistic traits were not significant predictors of ED psychopathology. Body dissatisfaction was a significant predictor for all three participant groups. For the REDs only group, pride in eating was also a significant predictor of ED psychopathology. These findings could suggest that the REDs only group present with a more traditional ED profile than the two autism groups. It may be that the strongest associations for ED psychopathology were with traditional ED characteristics rather than autistic traits because many of the EDE-Q items are conceptually similar to more traditional ED traits, such as body dissatisfaction, than disordered eating difficulties that are more closely related to autistic traits, such as sensory aversions to food (Brede et al., 2020). Overall, autistic women with a RED reported significantly lower ED psychopathology as measured using the EDE-Q, suggesting that this measure, which is used widely in clinical environments, may not necessarily be reflective of autistic women's ED experiences.

Previous research has found correlations between autistic traits and eating disorder symptomology measured using the EDE-Q in those with AN (Kerr-Gaffney et al., 2020; Tchanturia et al., 2019). However, we found that those in the Autism+REDs group scored significantly lower than those in the REDs only group on the EDE-Q measure. Moreover, in our exploration of the relationship between measures, while we found significant correlations between EDE-Q scores and measures of autistic traits for the REDs only group, for the Autism+REDs group, the correlations were not significant, and even slightly negative for the relationship between EDE-Q and AQ scores, and EDE-Q and ADOS scores. Our findings support, but also extend on, results from previous research that have found positive correlations between autistic traits and disordered eating symptoms in AN populations (Kerr-Gaffney et al., 2020; Tchanturia et al., 2019). Previous research has not included participants with a RED diagnosis and a formal autism diagnosis, and these findings suggest that the relationship between disordered eating behaviours and autistic traits may be more nuanced than previously suggested, as it seems to be different for those with and without an autism diagnosis. The correlation found in the REDs only group can be explained by the cognitive interpersonal maintenance model of AN (Treasure & Schmidt, 2013), which implies that autistic-like traits such as cognitive rigidity and increased attention to detail may exacerbate typical disordered eating psychopathology that is measured by the EDE-Q. This does not seem to be the case for autistic individuals. As suggested previously, it could be hypothesised that the EDE-Q is less accurate at detecting the ED psychopathology that is more typical of autistic individuals, possibly due to the EDE-Q items' focus on weight and shape concerns, of which the autistic women in this study and other studies (Brede et al., 2020) tended to report fewer.

4.4.1 Limitations

With the exception of the ADOS-2, all the measures utilised in the current study rely on self-report to explore different concepts. Self-report measures can be useful to an extent, as they can be distributed widely, which became particularly salient when adapting the study to an online format due to the unexpected restrictions placed on the research during the COVID-19 pandemic. However, self-report methods rely on the self-insight and questionnaire interpretation of the individual, which may vary across participants, potentially affecting the validity of the results (Paulhus & Vazire, 2007). Future research would benefit from exploring other methods for measuring concepts of interests that do not rely on self-report, such as experimental measures. There is also a risk of social desirability bias, particularly when concepts of interest are socially sensitive (King & Bruner, 2000), and so this may be particularly relevant for the current study which measured mental health difficulties. This could be controlled for in future studies by including a scale to estimate levels of social desirability responding (Van de Mortel, 2008) or using measures that aim to address social desirability biases such as implicit measures (Greenwald, McGhee, & Schwartz, 1998). This will be explored further in Chapter 5 with the development and use of experimental, implicit methods to measure traditional ED characteristics.

4.4.2 Service implications and future directions

The findings of this study have some implications for service provision for the treatment of EDs. For example, given the similarly high levels of pride in eating reported by both autistic and non-autistic women with a RED, it could be suggested that this would be a potential target for intervention. Nevertheless, it should be noted that the PEP-S measure is in its infancy, and more research is needed to validate its use in clinical populations. The use of body image-focussed interventions, however, may be less effective – or even ineffective – for autistic individuals with a RED. These interventions should be offered on a more individualised level, perhaps aided by the utilisation of body image-related self-report questionnaires such as the BSQ and SATAQ-3, to explore levels of body dissatisfaction and ITI, to deem whether this kind of intervention would be appropriate or not.

Future research should explore other factors that we know from previous research (e.g. Brede et al., 2020) are more relevant for autistic individuals, such as sensory sensitivities, interoception and intolerance of uncertainty. These parameters may subsequently aid the design of autism-specific interventions for EDs that are more appropriate than the treatments currently offered that have a focus on body image disturbance.

4.4.3 Conclusion

The results from Chapter 3, along with other research (e.g., Brede et al., 2020), have suggested that autistic women have different factors driving their ED and that they do not always fit a more traditional RED profile. The study in this chapter supports these findings, as autistic women with a RED reported significantly less body dissatisfaction and less endorsement of the thin ideal internalisation than non-autistic women with a RED. Contrary to my hypothesis, autistic and non-autistic women with a RED reported similar levels of pride in disordered eating. We also found that for autistic women, their ED psychopathology is predicted by fewer traditional ED-related traits than non-autistic women, suggesting there are differences in their ED profiles. These findings add to the growing literature base exploring autism in EDs and have clinical implications for the treatment of REDs for autistic and non-autistic women.

In Chapter 5, I will continue to explore the role of traditional ED characteristics across the three participant groups whilst addressing some of the limitations identified in this chapter. Through using a more experimental approach that relies on implicit, rather than explicit, reporting, I hope to overcome the limitations associated with self-report measures, such as the risk of social desirability bias.

Chapter 5: Implicit measures of disordered eating characteristics and their relationship to explicit measures

5.1 Introduction

In Chapter 4, autistic women with a RED reported significantly less body dissatisfaction and less endorsement of the internalisation of the thin ideal (ITI) than non-autistic women with a RED. Moreover, for autistic women with a RED, only one of the traditional ED measures was a significant predictor of current ED psychopathology, whereas for non-autistic women with a RED, their current ED psychopathology was predicted by two of the traditional ED measures. These findings suggest that autistic and non-autistic women with a RED may present with different ED profiles, which has implications for their ED treatment. The ED profile constructs were measured using self-report questionnaires. Self-report methods are often chosen due to their widespread availability and ease of distribution (Paulhus & Vazire, 2007). However, as discussed within the limitations of Chapter 4, there are some drawbacks associated with using self-report measures.

For example, self-report methods are often susceptible to biased responses from participants in order to manage impressions of themselves, known as a social desirability bias (Paulhus & Vazire, 2007). This is thought to be particularly relevant to measurements of body image disturbance (Heider, Spruyt, & De Houwer, 2018). It has been observed clinically that those with AN often under-report the true extent of their body image disturbance and fear of weight gain, either deliberately (Bruch, 1988; as cited in Thomas, Hartmann, & Killgore, 2013) or due to a lack of self-insight or conscious awareness of their underlying weight and shape concerns (Thomas et al., 2013). To overcome some of the limitations associated with the self-report of body image disturbance, alternative methods that do not involve conscious reporting are needed.

Implicit methods are widely used in research to overcome the limitations of explicit measures, such as self-report biases. One of the most popular measures is the Implicit Association Test (IAT) developed by Greenwald, McGhee, and Schwartz (1998). The IAT is a computer-based measure that uses reaction time to detect the strength of an individual’s automatic or underlying association between two concepts. The paradigm relies on the theory that concepts that are more strongly related to one another in an individual’s memory will lead to faster pairings on the IAT than those that are less strongly related (Greenwald et al., 1998). This theory is based on the idea posed by Markus (1977), that individuals should be faster at processing information that is congruent with their own beliefs and/or attitudes (i.e., schema-congruent information) than information that is incongruent with their beliefs and/or attitudes (i.e., schema-incongruent information).

The concept examples used in the original IAT was that of insects/flowers and unpleasant/pleasant words. Participants were instructed to press a keyboard key on the left with their left forefinger when the target word matched a category on the left (e.g., if the category 'Flower' appeared on the left and the target word was 'Rose'). Similarly, they were instructed to press a keyboard key on the right with their right forefinger when the target word matched a category on the right (e.g., if the category was 'Unpleasant words' appeared on the right and the target word was 'Evil'). These examples can be seen in Figure 5.1 and 5.2. Figure 5.1 represents a schema-congruent pairing, and Figure 5.2 represents a schema-incongruent pairing.

Figure 5.1. Example of a schema-congruent IAT pairing (Greenwald et al., 1998).

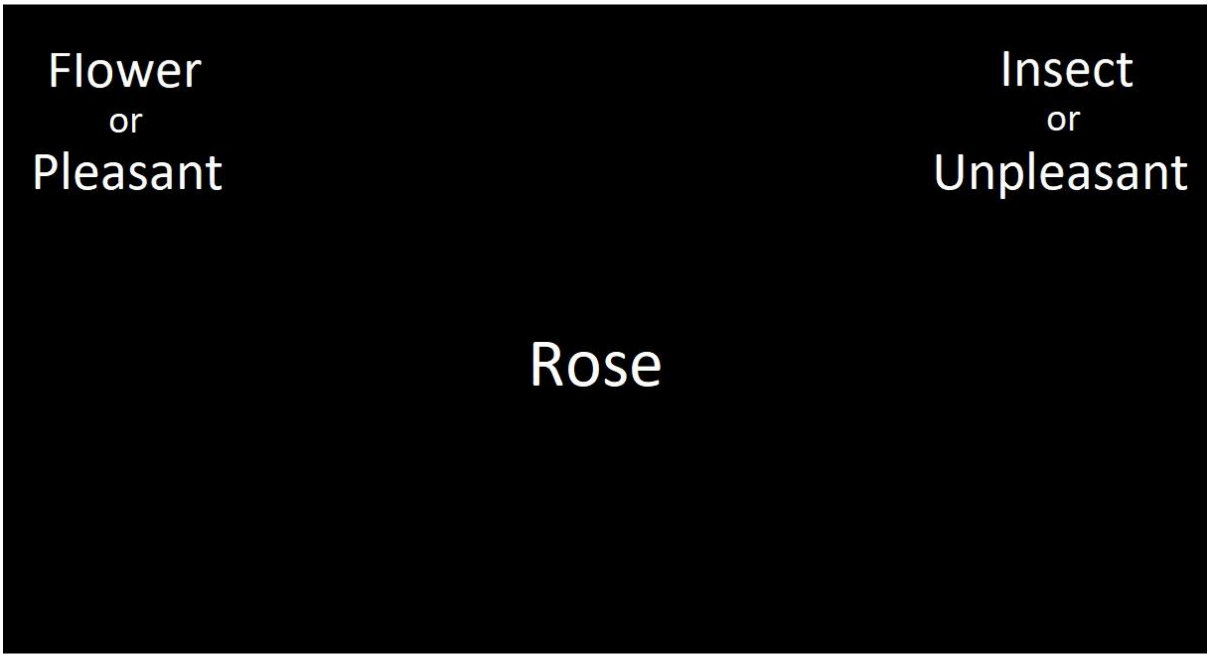


Figure 5.2. Example of a schema-incongruent IAT pairing (Greenwald et al., 1998).

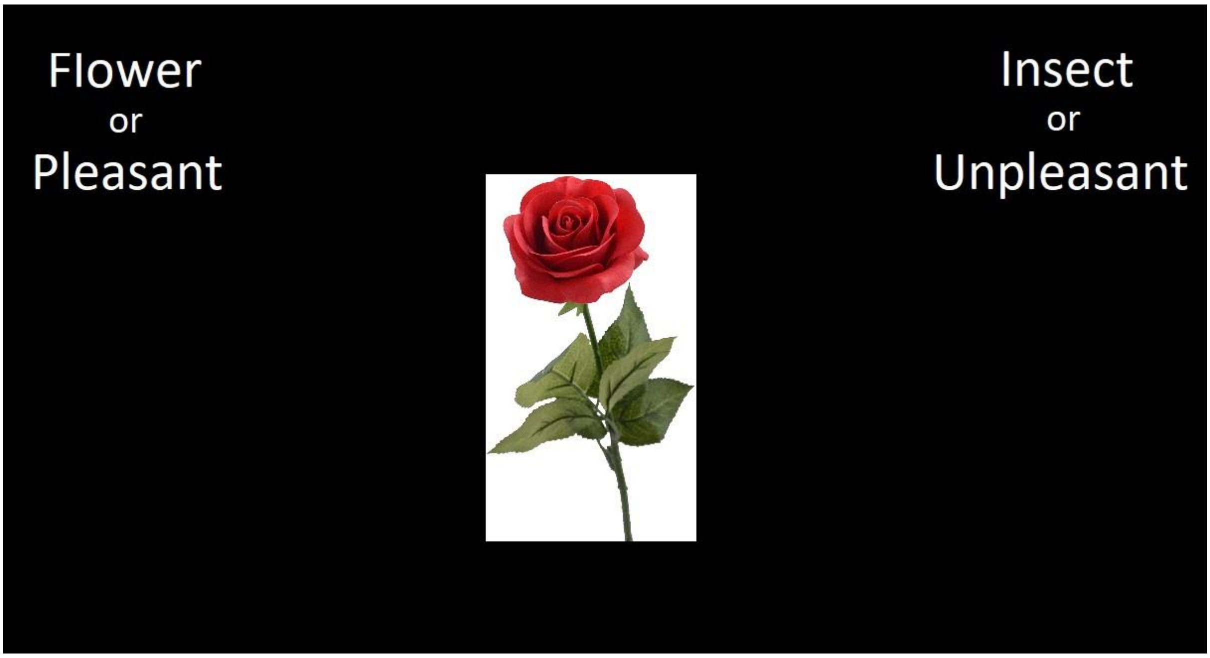
When insects and unpleasant words shared the same response key, the response was faster than when insects and pleasant words shared the same response key. Similarly, when flowers and pleasant words shared the same response key, the response was faster than when flowers and unpleasant words shared the same response key. Psychometric investigations of the IAT suggest it has good internal consistency and reasonable test-retest reliability (Nosek, Greenwald, & Banaji, 2005). The IAT has been deemed to be particularly useful for detecting attitudes towards concepts that may be socially undesirable (Baron & Banaji, 2006). For example, IATs have been used to measure sexual interest in convicted paedophiles (Gray & Snowden, 2009).

The IAT paradigm has been used in previous research to explore implicit attitudes towards weight, food and dieting behaviours in non-clinical samples. For example, research has consistently reported finding more negative implicit attitudes towards overweight or obese stimuli than normal weight stimuli in non-clinical samples (Ahern & Hetherington, 2006; Phelan et al., 2014; T. Waller, Lampman, & Lupfer-Johnson, 2012). Ahern, Bennett, and Hetherington (2008) explored weight biases using normal weight and underweight stimuli and found more negative implicit attitudes towards underweight stimuli than normal weight stimuli in a sample of students. Another study found an implicit bias towards associating shame with high-fat foods, compared to low-fat foods (Werntz, Steinman, Glenn, Nock, & Teachman, 2016). Furthermore, Vartanian, Polivy, and Herman (2004) found that chronic dieters, of whom they report have similar cognitions to ED populations, had negative implicit attitudes towards high-fat foods and body fat. Interestingly, almost all the studies that included an explicit version of their implicit measure found only a weak correlation between the two measures, with the exception of Vartanian et al. (2004) who reported parallels between explicit and implicit attitudes. Some have attempted to explain this discrepancy as occurring due to concern in relation to self-presentation (Werntz et al., 2016) or the considerable strength of the attitude as a societal norm (Ahern & Hetherington, 2006).

IATs have also been used to measure implicit ED-related attitudes in those with an ED. For example, Izquierdo et al. (2019) measured implicit attitudes towards dieting across four participant groups – those with AN who reported a fear of weight gain (fat-phobic AN), those with AN who reported no fear of weight gain (non-fat-phobic AN), those with ARFID, and a healthy control group. They found that both AN groups (fat-phobic and non-fat-phobic) endorsed attitudes indicative of pro-dieting, whereas the ARFID and healthy control group did not. Explicit measures of dieting attitudes were consistent with implicit measures for all groups except the non-fat-phobic AN group, who explicitly reported significantly fewer pro-dieting attitudes than the fat-phobic AN group. This study also replicated the IAT developed by Ahern et al. (2008) described above across their four participant groups. Similarly to Ahern et al. (2008), they found that all four groups exhibited more negative implicit attitudes towards underweight stimuli than normal weight stimuli, with this association being the strongest in the healthy control group, indicative of a large effect size, and weakest in the two AN groups, indicative of a small effect size.

Despite the widespread use of the IAT, it still poses some limitations. For example, it has been indicated that complex categories cannot be represented effectively using a single word (Dionne, Gainforth, O'Malley, & Latimer-Cheung, 2013). Therefore, rather than using single words to represent a category, e.g., 'Rose' to represent the category 'Flower' in Figure 5.1, IATs have been developed using pictures instead (see Figure 5.3 for a picture-based IAT (P-IAT) alternative to the IAT depicted in Figure 5.1). The limitations associated with using single words is thought to be of particular relevance for implicit investigations relating to weight due to inherently negative connotations associated with words used to describe overweightness, which may act as a confounding variable to the effects of the IAT (Ahern & Hetherington, 2006; Govan & Williams, 2004).

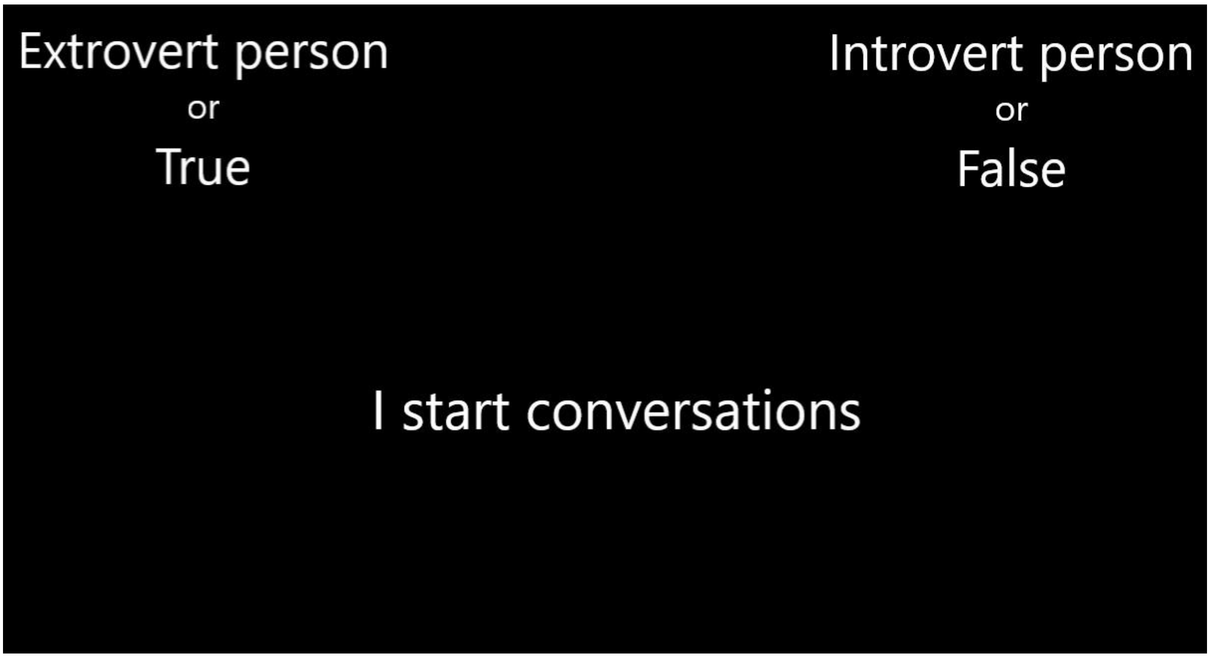
Figure 5.3. P-IAT representation of Greenwald et al. (1998)'s IAT paradigm.



Note: *P-IAT=Picture-based Implicit Association Test.*

A second limitation associated with the IAT paradigm is the risk that it may lack construct validity, i.e., the measure does not measure what it is intending to. For example, it has been suggested that IATs may be measuring societal norms rather than own attitudes (De Houwer, 2002). The questionnaire-based IAT (Q-IAT) has been developed to overcome said limitation (Yovel & Friedman, 2013). Instead of relying on individual words to represent a concept, the Q-IAT uses standardised, self-related statements developed from validated self-report questionnaires which more closely resemble the complex concepts under investigation. Positive/negative words are replaced with self-related statements that must be categorised as true or false, e.g. “I am sat at a computer”, which would be a self-related true statement for someone performing the task, whereas “I am playing football” would be a self-related false statement. Using such self-related statements addresses the limitation of the IAT being purely about the schematic association of two concepts, as instead these concepts are directed towards the self (Yovel & Friedman, 2013). The Q-IAT developers sought to implicitly measure extraversion using self-related statements adapted from the Extraversion scale of the 50-item International Personality Item Pool questionnaire (Goldberg et al., 2006). Figure 5.4 depicts an example of a congruent Q-IAT trial for someone who is an extrovert used by Yovel and Friedman (2013).

Figure 5.4. Example of a Q-IAT test trial (Yovel & Friedman, 2013).



Extrovert person
or
True

Introvert person
or
False

I start conversations

Note: *Q-IAT=Questionnaire-based Implicit Association Test.*

For the current study, I wanted to measure implicit attitudes towards ITI and implicit attitudes towards body dissatisfaction across the three participant groups: Autism+REDs, REDs only and Autism only. In order to overcome the limitations described above, I decided to use a P-IAT to implicitly measure ITI and a Q-IAT to implicitly measure body dissatisfaction.

Due to the novelty of the IATs in the current study, which have been adapted from previous studies (Ahern et al., 2008; Izquierdo et al., 2019), a pilot study of university students was carried out first to test their feasibility. This included ratings of attractiveness and size of the body image stimuli used in the P-IAT to confirm whether the stimuli have face validity as members of their respective categories (normal weight and underweight). Moreover, if the IATs are considered feasible from the pilot study, this gives us a dataset from a sample of university students to reflect normative data.

The aim of the pilot study was to assess the feasibility of the IAT tasks and associated body image stimuli in a student population for use in future studies. The aim of the main study was to explore implicit attitudes towards ITI and body dissatisfaction in: (1) autistic women with a RED, (2) non-autistic women with a RED and (3) autistic women without a RED.

My hypotheses for this study show a similar pattern to the hypotheses in Chapter 4. For the P-IAT, we hypothesised that non-autistic women with a RED would show stronger implicit endorsement of ITI than autistic women with a RED. Autistic women without an ED were hypothesised to show the lowest levels of implicit ITI endorsement. For the Q-IAT, we hypothesised that non-autistic women with a RED would show higher levels of implicit body dissatisfaction than autistic women with a RED. Autistic women without an ED were hypothesised to show the lowest levels of implicit body dissatisfaction. Due to restrictions relating to COVID-19 and having limited time to move the study online, we were unable to collect any Q-IAT data from non-autistic women with a RED. Therefore, we could not test the hypothesis relating to non-autistic women with a RED, only that autistic women without a RED would show lower levels of body dissatisfaction than autistic women with a RED.

5.2 Pilot study

5.2.1 Method

5.2.1.1 Participants

105 female Psychology undergraduate students participated in the study in exchange for course credits. Participants ranged in age from 18 to 40 years old (*M*=19.7, *SD*=2.45). Males were not included in this pilot due to the focus on females throughout the PhD project (see Chapter 1).

5.2.1.2 Materials

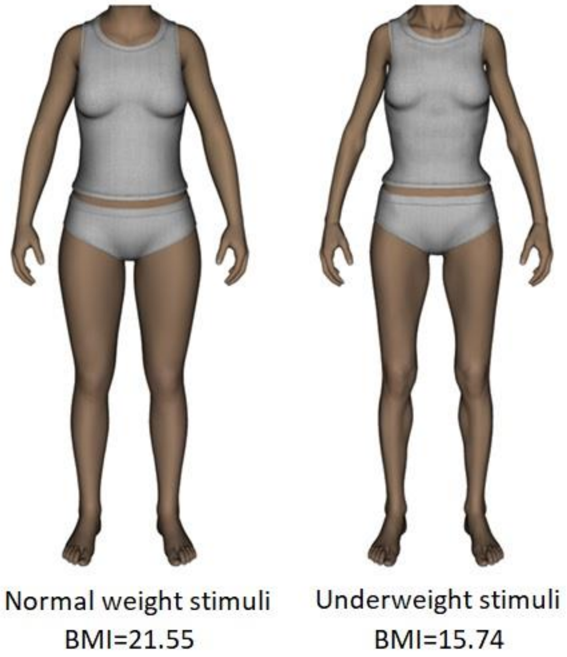
Picture-based implicit association test (P-IAT)

The P-IAT was used as an implicit measure of ITI by measuring subconscious attitudes towards normal weight and underweight bodies (as stipulated by BMI categorisations). The four categories for the P-IAT were ‘Normal weight’, ‘Underweight’, ‘Positive words’ (happy, pleasure, laughter, glorious and peace) and ‘Negative words’ (awful, terrible, nasty, horrible and failure). The IAT was created by modifying an existing, open source IAT programme (https://github.com/ianhussey/ImplicitAssociationTest) written in PsychoPy (Peirce et al., 2019).

The P-IAT paradigm was based on those used in previous studies (Ahern et al., 2008; Izquierdo et al., 2019). Ahern et al. (2008) acknowledged that their pilot data suggested that participants had difficulties distinguishing between underweight and normal weight stimuli. Therefore, the current IAT used body image stimuli from a database developed by Moussally, Rochat, Posada, and Van der Linden (2017) for use in body image studies. These systematically manipulated body image stimuli were chosen over other stimuli for a number of reasons. First, these stimuli include no faces which, according to previous studies (e.g. Gardner, Jappe, & Gardner, 2009), may distract away from the target. Second the stimuli are all based on the same body with only the shape/Body Mass Index (BMI) being manipulated, minimising confounding factors. The stimuli all have the same skin tone, pose and clothing, so that all bodies are easily comparable. Third, the stimuli have good ecological validity compared to drawn, silhouette or caricature body shape stimuli that have been used in previous body image research (e.g. Khan & Petróczi, 2015) as they look more realistic. Finally, these body shape stimuli have been pilot-studied and validated by the authors to examine their feasibility for use in body image research (Moussally, Grynberg, Goffinet, Simon, & Van der Linden, 2017; Moussally, Rochat, et al., 2017).

For my P-IAT paradigm, I chose body shapes for the normal weight category to range in BMI from approximately 19-21.5, and the underweight models to range in BMI from approximately 14-16.5. In order to match the underweight/normal weight categories as closely as possible, they both have a BMI range of 2.5. An example of the underweight and normal weight stimuli can be seen in Figure 5.5. All ten body image stimuli used in the P-IAT can be found in Appendix C.

Figure 5.5. Examples of the normal weight and underweight stimuli used in the P-IAT.



Normal weight stimuli
BMI=21.55

Underweight stimuli
BMI=15.74

Note: *BMI=body mass index; P-IAT=Picture-based Implicit Association Test.*

The P-IAT followed the seven-block IAT structure described by Nosek, Greenwald, and Banaji (2007). Table 5.1 shows the IAT block design for the P-IAT. To eliminate any order effects, Block order 1 and Block order 2 were counterbalanced across participants.

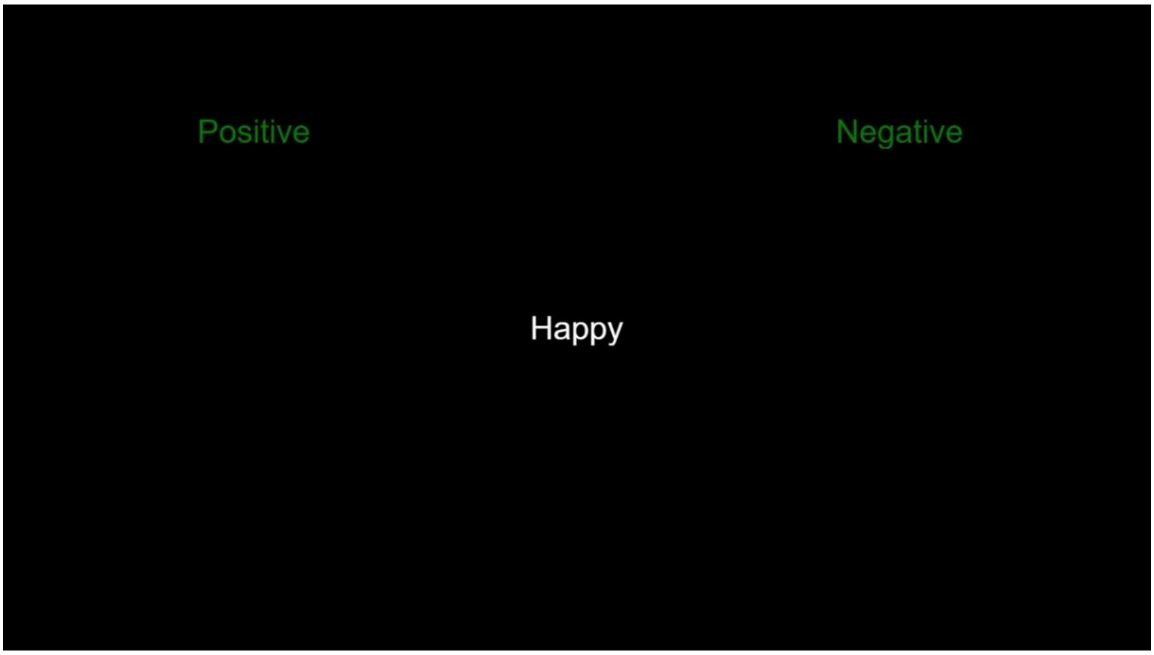
Table 5.1. Block designs for the P-IAT. Participants completed either Order 1 or Order 2 (counterbalanced).

	Block	Number of trials	Item(s) assigned to 'A' key	Item(s) assigned to 'L' key
Order 1	1 (practice)	20	Normal weight stimuli	Underweight stimuli
	2 (practice)	20	Positive words	Negative words
	3 (practice)	20	Normal weight stimuli + positive words	Underweight stimuli + negative words
	4 (test)	40	Normal weight stimuli + positive words	Underweight stimuli + negative words
	5 (practice)	40	Underweight stimuli	Normal weight stimuli
	6 (practice)	20	Underweight stimuli + positive words	Normal weight stimuli + negative words
	7 (test)	40	Underweight stimuli + positive words	Normal weight stimuli + negative words
Order 2	1 (practice)	20	Underweight stimuli	Normal weight stimuli
	2 (practice)	20	Positive words	Negative words
	3 (practice)	20	Underweight stimuli + positive words	Normal weight stimuli + negative words
	4 (test)	40	Underweight stimuli + positive words	Normal weight stimuli + negative words
	5 (practice)	40	Normal weight stimuli	Underweight stimuli
	6 (practice)	20	Normal weight stimuli + positive words	Underweight stimuli + negative words
	7 (test)	40	Normal weight stimuli + positive words	Underweight stimuli + negative words

Note: P-IAT=Picture-based Implicit Association Test.

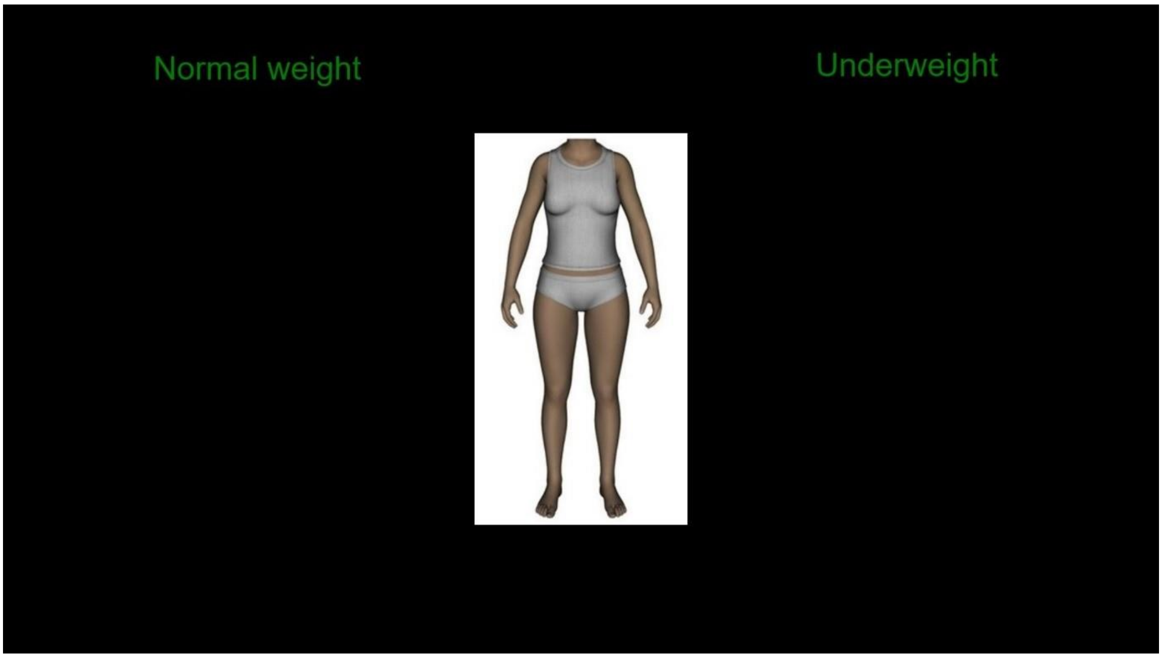
The instructions to participants were to categorise the words/images that appeared in the centre screen to the appropriate label either in the top-left or top-right corner of the screen. Participants responded on their keyboard by clicking ‘A’ to categorise stimuli as belonging to the left category and ‘L’ to categorise stimuli as belonging to the right category. If participants clicked the incorrect category, a red cross would appear in the middle of the screen and participants would have to click the correct category to move onto the next trial. Figures 5.6 and 5.7 represent examples of a P-IAT practice trial. Figure 5.8 depicts an example of a P-IAT test trial.

Figure 5.6. An example of a P-IAT practice trial within the block that familiarised participants with their response options ('positive' or 'negative') for a target word. In this example, the participant should categorise the target word ('Happy') with the correct category ('Positive') by selecting the appropriate key ('A' key).



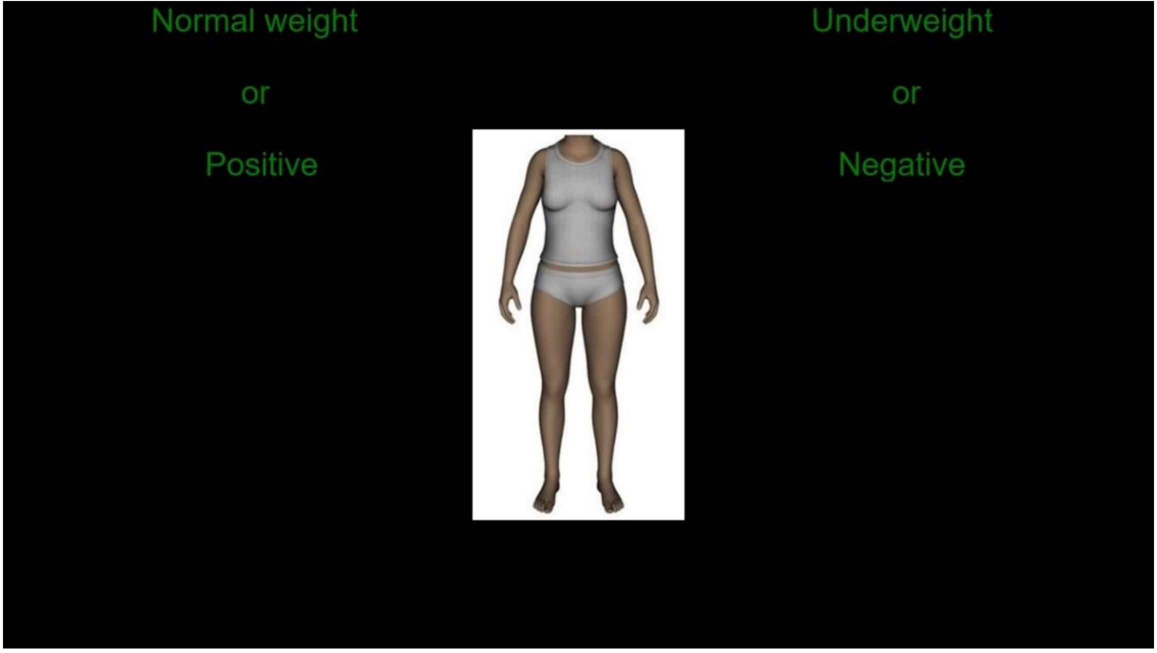
Note: *P-IAT=Picture-based Implicit Association Test.*

Figure 5.7. An example of a P-IAT practice trial within the block that familiarised participants with their response options ('Normal weight' or 'Underweight') for a target picture. In this example, the participant should categorise the target picture of the normal weight stimuli with the correct category ('Normal weight') by selecting the appropriate key ('A' key).



Note: *P-IAT=Picture-based Implicit Association Test.*

Figure 5.8. An example of a P-IAT test trial. In this example, the participant should categorise the target picture with the correct category ('Normal weight') by selecting the appropriate key ('A' key).



Note: *P-IAT=Picture-based Implicit Association Test.*

The P-IAT was scored following the improved IAT scoring algorithm detailed by Greenwald, Nosek, and Banaji (2003). When scoring the P-IAT, a positive score was indicative of stronger endorsement of the thin-ideal internalisation as there was faster association of underweight body image stimuli and positive words and/or normal weight body image stimuli and negative words. Conversely, a negative score was indicative of a lack of endorsement of the thin-ideal internalisation as there was faster association of normal weight body image stimuli and positive words and/or underweight body image stimuli and negative words.

Body image stimuli size and valence ratings

To assess the validity of the body image stimuli used, ratings of body size and attractiveness for each of the stimuli were recorded, consistent with two of the four ratings utilised by the developers of the stimuli (Moussally, Rochat, et al., 2017). Specifically, each of the ten body image stimuli used were rated on a 9-point Likert scale on body size (1=fat to 9=thin) and attractiveness (1=repulsive to 9=attractive). This was used to aid validation of the stimuli (i.e., ensure the body image stimuli were representative of their category).

Questionnaire-based implicit association task (Q-IAT)

The Q-IAT, based on the paradigm developed by Yovel and Friedman (2013), was used to measure implicit levels of body dissatisfaction. This paradigm was also created using the PsychoPy software (Peirce et al., 2019). The four categories for the Q-IAT were ‘Body satisfaction’, ‘Body dissatisfaction’, ‘True statements’ and ‘False statements’. For the current study, we used the same self-related true/false statements as Izquierdo et al. (2019), altered only to reflect the current participants’ environments. The body dissatisfaction statements were created based on the ‘Weight concerns’ and ‘Shape concerns’ subscale items of the EDE-Q (Fairburn & Beglin, 1994). Body satisfaction statements were reversed versions of the body dissatisfaction statements. To control for extraneous variables, the statements were matched for readability using the Dale-Chall readability index (Dale & Chall, 1948). The mean Dale-Chall readability score for the categories of statements (M=7.6, SD=2.4) is regarded as being easily understood by a 9th-10th grade student (Dale & Chall, 1948), i.e. 14-16 years old. A full list of statements can be found in Table 5.2.

Table 5.2. Statements used in the Q-IAT to assess implicit attitudes towards body dissatisfaction.

Body satisfaction statements	Body dissatisfaction statements
I am satisfied with my weight	I am dissatisfied with my weight
I have little desire to lose weight	I have a strong desire to lose weight
I rarely feel fat	I regularly feel fat
I am okay with gaining weight	I fear gaining weight
I am satisfied with my shape	I am dissatisfied with my shape
True statements	**False statements**
I am currently in the UK	I am currently in the Philippines
I am currently sat in a chair	I am currently sat on the beach
I am reading words on a laptop screen	I am playing a song on the guitar
I am pressing buttons on a keyboard	I am playing rugby outside
I am participating in a research study	I am climbing a steep mountain

Note: *Q-IAT=Questionnaire-based Implicit Association Test.*

Similarly to the P-IAT, the Q-IAT followed the seven-block IAT structure described by Nosek et al. (2007). Table 5.3 shows the IAT block design for the Q-IAT. To eliminate any order effects, Block order 1 and Block order 2 were counterbalanced across participants.

Table 5.3. Block designs for the Q- IAT. Participants completed either Order 1 or Order 2 (counterbalanced).

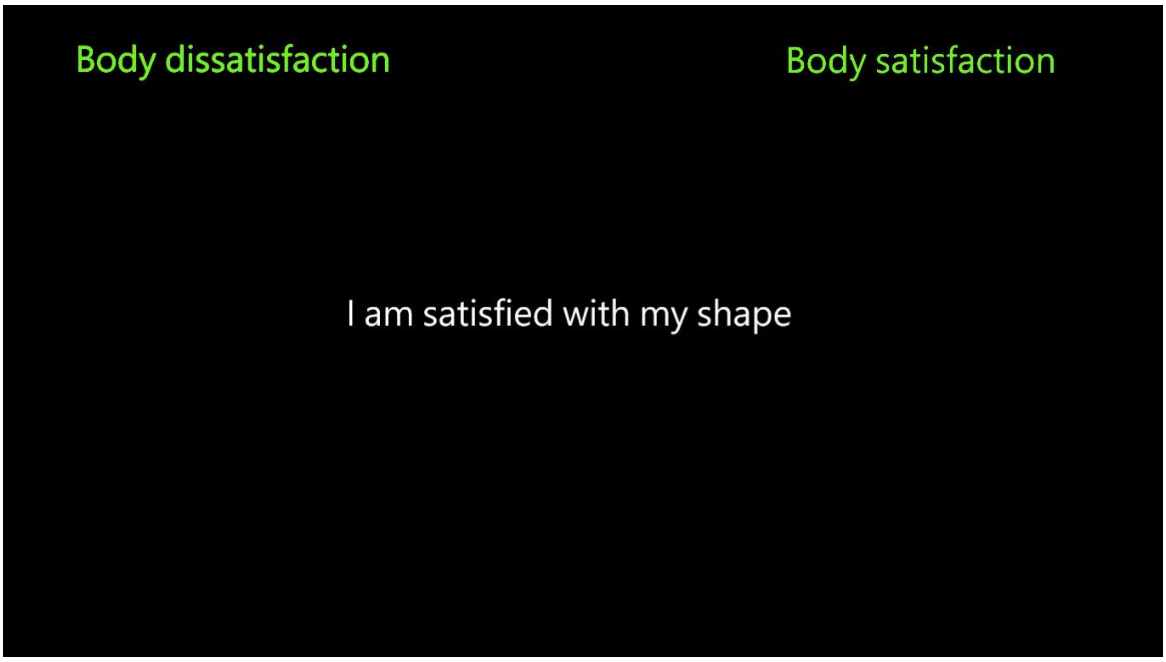
	Block	Number of trials	Item(s) assigned to ‘A’ key	Item(s) assigned to ‘L’ key
Order 1	1 (practice)	20	Body satisfaction statements	Body dissatisfaction statements
	2 (practice)	20	True statements	False statements
	3 (practice)	20	Body satisfaction + true statements	Body dissatisfaction + false statements
	4 (test)	40	Body satisfaction + true statements	Body dissatisfaction + false statements
	5 (practice)	40	Body dissatisfaction statements	Body satisfaction statements
	6 (practice)	20	Body dissatisfaction + true statements	Body satisfaction + false statements
	7 (test)	40	Body dissatisfaction + true statements	Body satisfaction + false statements
Order 2	1 (practice)	20	Body dissatisfaction statements	Body satisfaction statements
	2 (practice)	20	True statements	False statements
	3 (practice)	20	Body dissatisfaction + true statements	Body satisfaction + false statements
	4 (test)	40	Body dissatisfaction + true statements	Body satisfaction + false statements
	5 (practice)	40	Body satisfaction statements	Body dissatisfaction statements
	6 (practice)	20	Body satisfaction + true statements	Body dissatisfaction + false statements

7 (test)	40	Body satisfaction + true statements	Body dissatisfaction + false statements

Note: *Q-IAT=Questionnaire-based Implicit Association Test.*

The instructions to the participants were to categorise the statements that appeared on the screen to the appropriate label either in the top-left or top-right corner of the screen. Participants responded on their keyboard by clicking ‘A’ to categorise stimuli to the left category and ‘L’ to categorise stimuli to the right category. If participants clicked the incorrect category, a red cross would appear in the middle of the screen and participants would have to click the correct category to move onto the next trial. Figures 5.9 and 5.10 represent examples of a Q-IAT practice trial. Figure 5.11 depicts an example of a Q-IAT test trial.

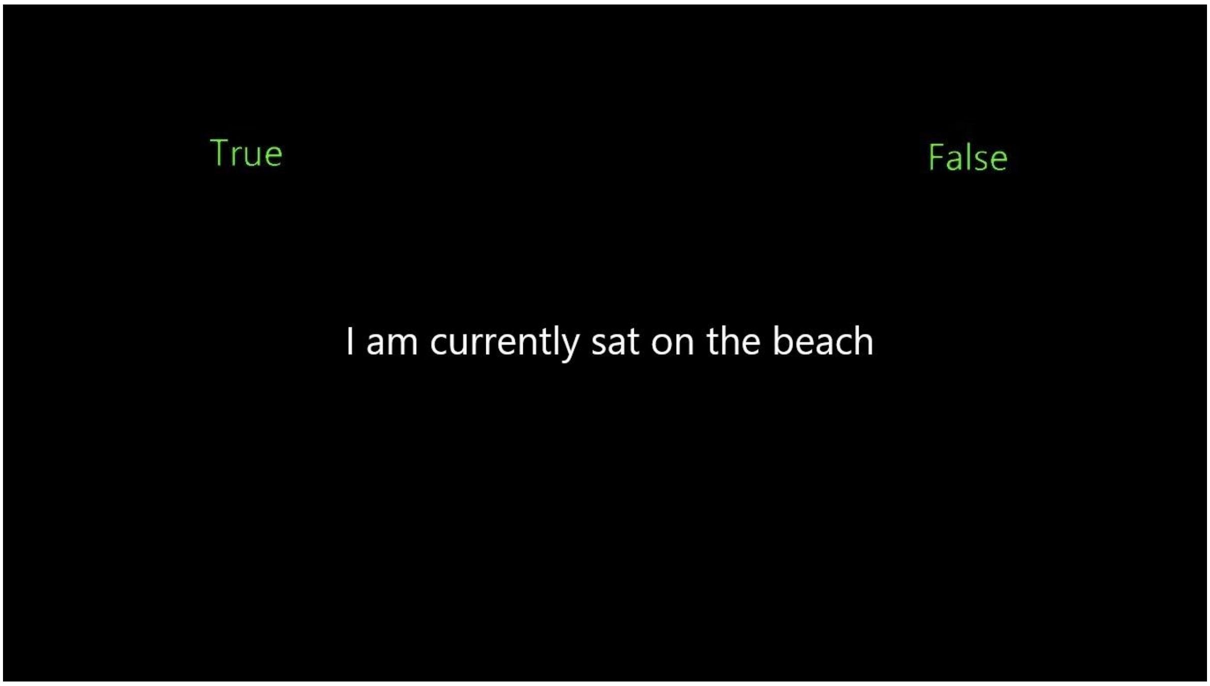
Figure 5.9. **An example of a Q-IAT practice trial within the block that familiarised participants with their response options ('Body dissatisfaction' or 'Body satisfaction') for a target statement. In this example, the participant should categorise the target statement ('I am satisfied with my shape') with the correct category ('Body satisfaction') by selecting the appropriate key ('L' key).**



I am satisfied with my shape

Note: *Q-IAT=Questionnaire-based Implicit Association Test.*

Figure 5.10. An example of a Q-IAT practice trial within the block that familiarised participants with their response options ('True' or 'False') for a target statement. In this example, the participant should categorise the target statement ('I am currently sat on the beach') with the correct category ('False') by selecting the appropriate key ('L' key).



I am currently sat on the beach

Note: *Q-IAT=Questionnaire-based Implicit Association Test.*

Figure 5.11. An example of a Q-IAT test trial. In this example, the participant should categorise the target statement with the correct category (‘Body dissatisfaction’) by selecting the appropriate key (‘A’ key).

I fear I might gain weight

Note*: Q-IAT=Questionnaire-based Implicit Association Test.*

The Q-IAT was scored following the improved IAT scoring algorithm detailed by Greenwald et al. (2003). When scoring the Q-IAT, a positive score was indicative of higher levels of body dissatisfaction as there was a faster association of body dissatisfaction statements and true self-statements and/or body satisfaction statements and false self-statements. Conversely, a negative score was indicative of lower levels of body dissatisfaction as there was faster association of body satisfaction statements and true self-statements and/or body dissatisfaction statements and false self-statements.

Self-report measures

Self-report measures included the Eating Disorder Examination Questionnaire (EDE-Q), the Body Shape Questionnaire (BSQ) and the Sociocultural Attitudes Towards Appearance Questionnaire (SATAQ-3). See Chapter 4 for full details on these measures.

5.2.1.3 Procedure

After reading the information sheet and giving informed consent, participants were asked to complete the two IAT tasks. Counterbalancing was used by alternating the IAT task that was completed first. Directly after completing the P-IAT, participants also rated the attractiveness and size of the computerised body shapes used in the task. Participants were then presented with the self-report questionnaires which were completed on a computer. The order of questionnaires was randomised. Once the tasks and questionnaires were completed, participants were debriefed and had time to ask any questions. In total, the tasks and questionnaires took approximately 45 minutes to complete.

5.2.1.4 Analysis

Data Cleaning

As in Chapter 4, to reduce the risk of Type I and Type II errors and improve the distribution of non-normal data, outliers were identified using the outlier labelling method (Hoaglin & Iglewicz, 1987) and any outliers identified were corrected using the Winsorizing procedure (e.g. Field, 2013; Wainer, 1976). When analysing the data, statistical tests were run with and without outlier corrections. We found no differences in the outcome of the analysis when using either the data with or without outliers, and so the original data with outliers has been reported.

Statistical Analysis

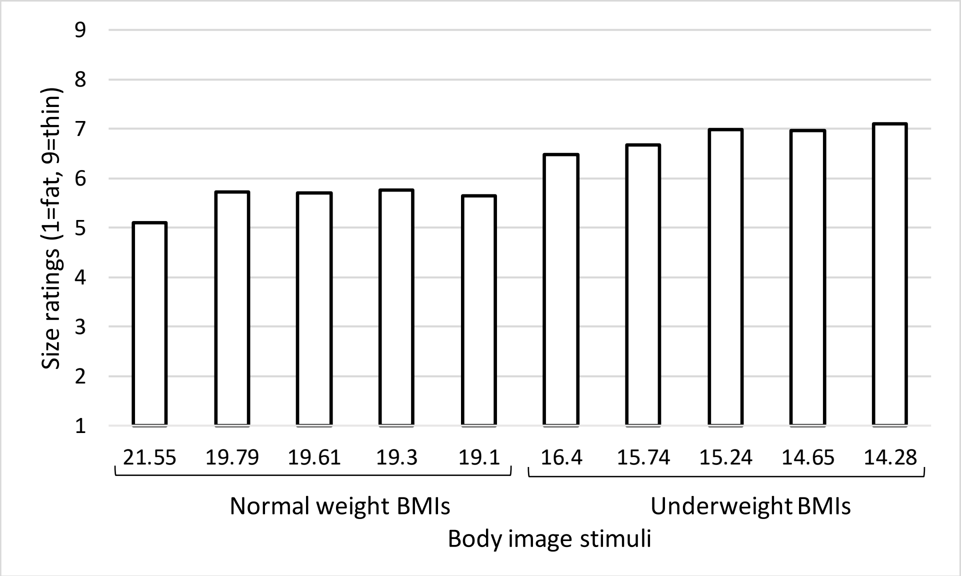
Paired-samples t-tests, one-samples t-tests and Pearson's *r* correlations were carried out to explore the pilot data using IBM SPSS Statistics for Windows, Version 26.0. As in Chapter 4, a Hedges' g effect size was calculated, and confidence intervals (CI) are reported.

5.2.2 Results

5.2.2.1 P-IAT body image stimuli ratings

For the body image stimuli ratings, sizes were estimated relatively accurately, in that smaller BMIs were rated as thinner (see Figure 5.12). Similarly, when comparing average ratings for the categories (underweight stimuli and normal weight stimuli), a paired samples t-test revealed a significant difference ($t(104)=-5.04$, $p<.01$, 95% CI [.76, 1.75], Hedges' $g_{av}=.63$), with the underweight BMI body shapes ($M=6.84$, $SD=2.6$) being rated significantly higher (i.e. thinner) than normal weight BMI body shapes ($M=5.59$, $SD=1.09$). These findings suggest that on average, the body shapes are being correctly identified in relation to their size.

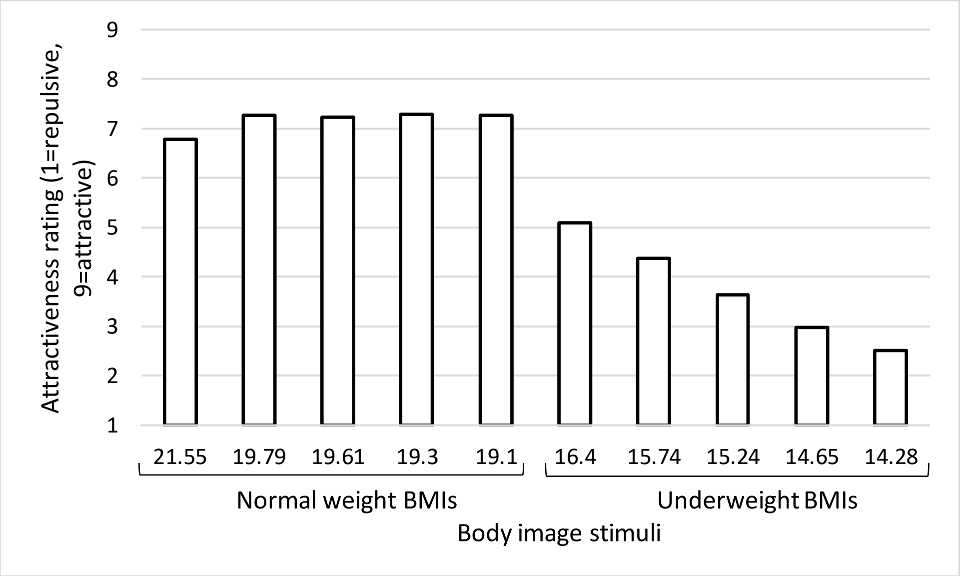
Figure 5.12. Mean size ratings of body image stimuli for the P-IAT.



Note: *BMI=Body mass index; P-IAT=Picture-based Implicit Association Test.*

For the attractiveness ratings, the normal weight stimuli were rated as similarly attractive, whereas attractiveness decreased as BMIs decreased for the underweight stimuli (see Figure 5.13). When comparing average ratings for the categories (underweight stimuli and normal weight stimuli), a paired samples t-test revealed a significant difference ($t(104)=14.82$, $p<.01$, 95% CI [2.99, 3.92], Hedges' $g_{av}=2.13$), with the underweight stimuli ($M=3.72$, $SD=1.58$) being rated significantly lower (i.e., less attractive) than normal weight stimuli ($M=7.17$, $SD=1.64$). These findings are similar to the valence ratings obtained by the researchers that developed the body shapes for research use (Moussally, Rochat, et al., 2017).

Figure 5.13. Mean attractiveness ratings of body image stimuli for the P-IAT.



Note: *BMI=Body mass index; P-IAT=Picture-based Implicit Association Test.*

In summary, assessment of the Likert scales for size and attractiveness of the body image stimuli indicate they have face validity as representatives of the categories of ‘normal weight’ and ‘underweight’.

5.2.2.2 Implicit and explicit measures of body dissatisfaction, internalisation of the thin ideal and eating disorder pathology

Table 5.4 shows means, standard deviations and range for the participants for each measure. The negative mean for the P-IAT suggests that there is a stronger association towards underweight stimuli and negative words and/or normal weight stimuli and positive words, suggestive of a lack of endorsement of ITI. Moreover, a one-sample t-test revealed that this mean is significantly different from 0, *t*(104)=-11.915, *p*<.01, CI [-.45, -.32]. Similarly, the Q-IAT mean, which is also negative, suggests a stronger association towards body satisfaction and true statements and/or body dissatisfaction and false statements, suggestive of a lack of body dissatisfaction. A one-sample t-test revealed that the mean for the Q-IAT is also significantly different from 0, *t*(104)=-6.018, *p*<.01, CI [-.29, -.15].

Table 5.4. Means, standard deviations and ranges for implicit and explicit measures.

	Mean	Standard deviation	Range
P-IAT	-.39	.34	-1.25-0.68
Q-IAT	-.22	.37	-0.98-0.83
EDE-Q global	2.03	1.41	0-5.55
Restraint	1.66	1.5	0-6
Eating concerns	1.31	1.35	0-5.2
Shape concerns	2.66	1.66	0-6
Weight concerns	2.49	1.66	0-6
BSQ	101.3	35.47	39-176
SATAQ-3 Total	95.8	19.89	31-141
Internalisation-General	30.98	6.64	9-44
Internalisation-Athlete	16.16	4.23	5-25
Pressures	23.39	5.99	7-35
Information	25.27	7.09	9-39

Note: *BSQ=Body Shape Questionnaire; EDE-Q=Eating Disorder Examination Questionnaire; P-IAT=Picture-based Implicit Association Test; Q-IAT=Questionnaire-based Implicit Association Test; SATAQ-3=Sociocultural Attitudes Towards Appearance Questionnaire.*

Pearson's correlations were carried out to explore the relationship between the implicit measures, explicit measures, and explicit evaluations of body image stimuli (see Table 5.5). The explicit measures (EDE-Q, BSQ, SATAQ) show significant, positive correlations between each other. The Q-IAT shows significant, positive correlations with explicit measures, suggesting that the higher the Q-IAT score (i.e., more implicit body dissatisfaction), the higher the scores on the explicit measures of disordered eating, ITI and body shape concern. For the P-IAT there are no significant associations with the explicit measures. For the explicit evaluations of body image stimuli, there are few significant correlations with ratings for underweight stimuli, but ratings of normal weight stimuli tend to have significant, negative correlations with explicit measures of disordered eating and body shape concern and the P-IAT, suggesting that lower ratings (i.e., stimuli rated as fatter or less attractive) are associated with more disordered eating, body shape concerns and implicit ITI).

Table 5.5. Pearson's r correlation matrices for implicit and explicit measures.

	P-IAT	Q-IAT	EDE-Q	BSQ	SATAQ	UW size	UW attract.	NW size
P-IAT	-	-	-	-	-	-	-	-
Q-IAT	.249*	-	-	-	-	-	-	-
EDE-Q	.159	.369**	-	-	-	-	-	-
BSQ	.183	.379**	.886**	-	-	-	-	-
SATAQ	.109	.217*	.467**	.534**	-	-	-	-
UW size	.047	-.101	-.107	-.163	-.039	-	-	-
UW attract.	-.02	.212*	.112	.118	-.034	-.055	-	-
NW size	-.115	-.235*	-.307**	-.232*	-.112	.246*	-.038	-
NW attract.	-.262**	-.104	-.318**	-.283**	-.057	-.052	-.097	.226*

Note***: *=p<.05, **=p<.01.*** *BSQ=Body Shape Questionnaire; EDE-Q=Eating Disorder Examination Questionnaire; NW attract.=attractiveness ratings for normal weight body images from the P-IAT; NW size=size ratings for normal weight body images from the P-IAT; P-IAT=Picture-based Implicit Association Test; Q-IAT=Questionnaire-based Implicit Association Test; SATAQ-3=Sociocultural Attitudes Towards Appearance Questionnaire; UW attract.=attractiveness ratings for underweight body images from the P-IAT; UW size=size ratings for underweight body images from the P-IAT.*

5.2.3 Pilot Discussion

Overall, our findings from the pilot study fit with the predicted patterns of a normative sample of students and can be used in clinical samples. First, the size ratings of the body image stimuli suggest that the stimuli size can be accurately estimated, and that participants are able to distinguish the underweight and normal weight stimuli. This implies that the P-IAT stimuli have face validity. Second, the valence ratings (i.e., attractiveness) are consistent with those reported by the developers of the stimuli (Moussally, Grynberg, et al., 2017), increasing the reliability of the stimuli across samples.

Overall, the undergraduate sample showed mild levels of explicit body shape concern (Cooper & Taylor, 1988), and comparable SATAQ-3 and EDE-Q scores to other female undergraduate populations (e.g. Calogero et al., 2004; Carey et al., 2019). This implies that this sample is representative of a student-aged norm. Furthermore, the outcomes of the implicit measures suggest that the current sample of undergraduate students, on average, do not endorse ITI or high levels of body dissatisfaction, aligning with their explicit attitudes. Importantly, this pilot study illustrates the feasibility of the use of the IATs to implicitly measure ITI and body dissatisfaction in a clinical sample.

5.3 Main study

The pilot study allowed for the testing of two novel, implicit measures within a non-clinical sample. It was concluded that both measures were acceptable and feasible for use in future research. Following on from the outcome of the pilot study, the aim of the main study was to examine the implicit attitudes of three participant groups: autistic women with a RED, non-autistic women with a RED and autistic women without a RED.

5.3.1 Methods

5.3.1.1 Participants

The participants in this study are a subset of the participants outlined in Chapter 4. All participants (online and in-person) were given the option to complete the P-IAT. However, because of the technological requirements of the P-IAT (i.e., requires an electronic device with a physical keyboard to complete), the P-IAT was not a mandatory element of the online study. Moreover, due to technical and time restraints, the Q-IAT was only completed by participants seen in-person. Demographics for the subset of participants who completed the P-IAT and Q-IAT can be found in Table 5.6.

Table 5.6. Participant demographics and statistical differences for those who completed the P-IAT and Q-IAT.

P-IAT Demographics

		Autism+REDs (n=40)	**REDs only (n=67)**	**Autism only (n=32)**	**Statistical test**
Recruitment location	***In-person***	45% (n=18)	1.5% (n=1)	81.3% (n=26)	
	Online	55% (n=22)	98.5% (n=66)	18.7% (n=6)	
Gender identity	***Female***	90% (n=36)	100% (n=67)	93.8% (n=30)	
	Non-binary	7.5% (n=3)	N/A	3.1% (n=1)	
	Prefer not to say	2.5% (n=1)	N/A	3.1% (n=1)	
Age (years)	***Mean***	31.95	28.33	39.13	*Welch's* *F*(2,65.13)= 11.97, *p*<.01, η^2 =.155
	SD	11.68	8.31	11.14	
	Range	18-61	18-60	20-61	
Age at autism diagnosis	***Mean***	28.58	N/A	35.48	*t*(67)=-2.31, *p*<.05, 95% CI [-12.87, -.94], Hedges' g_s=.55
	SD	12.15	N/A	12.59	
	Range	11-58	N/A	9-60	
Age at eating disorder diagnosis	***Mean***	19.03	21.45	N/A	*t*(102)=-1.498, *p*>.05, 95% CI [-5.64, .79], Hedges' g_s=.3
	SD	8.47	7.65	N/A	
	Range	9-54	11-54	N/A	
Current BMI	***Mean***	18.29	17.36	28.24	

	SD	3.53	2.62	6.49	*Welch's F*(2,56.86)= 41.02, *p*<.01, η^2 =.56
	Range	13.11-30.04	11.76-24.14	18.5-40.89	
BMI missing		10% (n=4)	7.5% (n=5)	N/A	

Q-IAT Demographics

		Autism+REDs (n=17)	**Autism only (n=27)**	**Statistical test**
Recruitment phase	***In-person***	100% (n=17)	100% (n=27)	
	Online	N/A	N/A	
Gender identity	***Female***	88.2% (n=15)	100% (n=27)	
	Non-binary	11.8% (n=2)	N/A	
	Prefer not to say	N/A	N/A	
Age (years)	***Mean***	37.29	37.93	*t*(42)=-.171, *p*>.05, 95% CI [-8.09, 6.83], Hedges' g_s=.05
	SD	13.29	11.02	
	Range	20-61	20-59	
Age at autism diagnosis	***Mean***	33.94	34.12	*t*(41)=-.044, *p*>.05, 95% CI [-8.23, 7.88], Hedges' g_s=.01
	SD	13.48	12.34	
	Range	14-58	9-56	
Age at eating disorder diagnosis	***Mean***	21.67	N/A	N/A
	SD	11.58	N/A	
	Range	9-54	N/A	

Current BMI	***Mean***	19.39	28.25	*t*(41.9)=-5.571, *p*<.01, 95% CI [-12.06, -5.65], Hedges' g_s=1.54
	SD	4.16	6.38	
	Range	14.84-30.04	18.5-40.89	
BMI missing		N/A	N/A	

Note: *BMI=Body Mass Index; P-IAT=Picture-based Implicit Association Test; Q-IAT=Questionnaire-based Implicit Association Test; RED=restrictive eating disorder; SD=standard deviation.*

Statistical tests revealed that of the participants that completed the P-IAT, the Autism only group was significantly older and had a significantly higher BMI than the Autism+REDs and REDs only group. The Autism only group was also significantly older than the Autism+REDs group when they received their autism diagnosis. There was no significant difference between the Autism+REDs group and REDs only group in the age at which they received an ED diagnosis. For participants who completed the Q-IAT, there was no significant difference in age or autism diagnosis age for the Autism+REDs and Autism only group. The Autism only group had a significantly higher BMI than the Autism+REDs group.

5.3.1.2 Materials

Implicit measures

The P-IAT and Q-IAT described in the pilot study were used in this study to measure implicit attitudes towards ITI and body dissatisfaction respectively.

Explicit measures

The body image stimuli ratings of attractiveness and size outlined in the pilot study were also used in the current study. Similarly, the same self-report measures were used: the EDE-Q, the BSQ and the SATAQ-3. See Chapter 4 for full details on these measures.

5.3.1.3 Procedure

The IATs were completed as part of the battery of questionnaires and tasks outlined in Chapter 4. For in-person participants, the order in which the IATs were presented was counterbalanced with the other experimental tasks. Both IATs were presented to participants on a laptop (Dell Latitude 5490 XCTO with a 14” screen). Participants were instructed by the researcher to complete the task, which would take approximately 5-7 minutes, and to follow the instructions on the screen. They were able to ask the researcher questions at any point.

For online participants, only the P-IAT was completed, which was sent in a separate weblink leading to the online platform for running PsychoPy experiments, Pavlovia (Peirce et al., 2019). The task was identical to the P-IAT completed by in-person participants. Participants had the option to email any questions about the IAT to the researchers or arrange a phone/video call if preferred. The majority of participants were able to complete the IAT without reporting any issues, questions, or concerns. Some participants reported technical issues, of which were rectified by one of the researchers. One participant requested a phone call due to a preference for verbal instruction, which was accommodated by one of the researchers. Once the IATs were completed, all participants were presented with the body image stimuli along with two 9-point Likert scales to rate the attractiveness and size of each of the body shapes shown in the P-IAT.

5.3.1.4 Analysis

Data Cleaning

Similarly to the pilot study, in order to reduce the risk of Type I and Type II errors and improve the distribution of non-normal data, outliers were identified using the outlier labelling method (Hoaglin & Iglewicz, 1987) and any outliers identified were corrected using the Winsorizing procedure (e.g. Field, 2013; Wainer, 1976). This procedure was chosen over other outlier correcting procedures, such as trimming means, as there is evidence to suggest that this is a more robust technique (Dixon, 1980; Tukey, 1962). When analysing the data, statistical tests were run with and without outlier corrections. We found no differences in the outcome of the analysis when using either the data with or without outliers, and so the original data with outliers has been reported.

Statistical Analysis

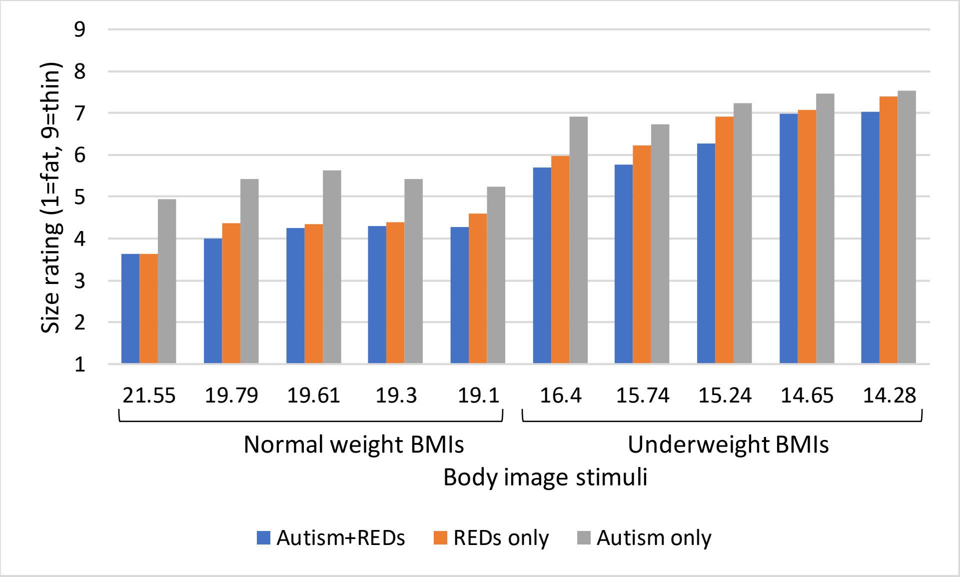
To test the primary hypotheses, one-way ANOVAs and appropriate post-hoc tests were carried out using IBM SPSS Statistics for Windows, Version 26.0. Uneven group sizes and violations of the assumption of homogeneity of variance were dealt with using the same process outlined in Chapter 4. Due to study disruptions related to COVID-19 leading to a lack of REDs only group participants completing the Q-IAT (n=1), this group was not included in the analysis for this task. Therefore, an independent samples t-test was carried out in place of the one-way ANOVA. For further exploration of Picture IAT stimuli ratings, mixed-model ANOVAs were also carried out. The same process of corrections was applied as outlined in Chapter 4. Moreover, as in Chapter 4, a Hedges' g effect sizes were calculated, and confidence intervals (CI) are reported.

5.3.2 Results

5.3.2.1 P-IAT body image stimuli size ratings

Overall, the body sizes were estimated accurately, in that smaller BMIs were generally rated as thinner (see Figure 5.14)

Figure 5.14. Mean P-IAT body size ratings for each participant group.



Note: *BMI=body mass index; P-IAT= Picture-based Implicit Association Test; RED=restrictive eating disorder.*

To compare average body image stimuli size ratings for the P-IAT categories (underweight BMIs and normal weight BMIs), a 3 (Group) x 2 (BMI Weight categories) mixed-model ANOVA was conducted. Table 5.7 shows means and standard deviations for the average body size ratings for BMI weight categories per group.

Table 5.7. Means and standard deviations for size ratings of body image stimuli BMI categories for the P-IAT for the three participant groups.

	Underweight stimuli		Normal weight stimuli	
	Mean	**Standard deviation**	**Mean**	**Standard deviation**
Autism+REDs	6.35	1.78	4.1	1.31
REDs only	6.72	1.72	4.27	1.39
Autism only	7.18	2.33	5.32	1.23

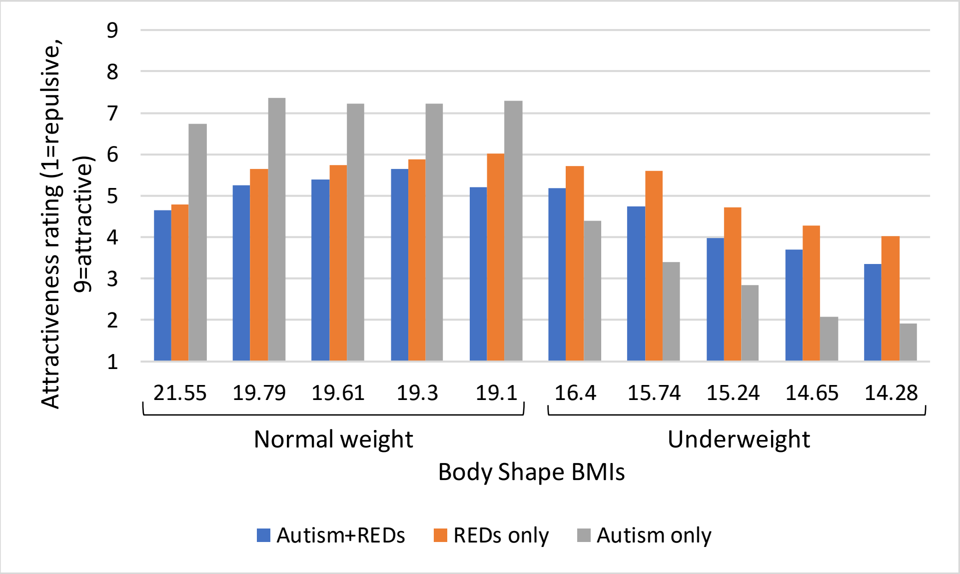
Note: *BMI=body mass index; P-IAT=Picture-based Implicit Association Test; RED=restrictive eating disorder.*

The mixed-model ANOVA revealed a significant main effect of mean body size rating, F(1, 134)=144.1, p<.01, η^2=.518. On average, underweight stimuli were rated as thinner than normal weight stimuli. A significant main effect of group was also revealed, F(2,134)=6.1, p<.01, η^2=.083. Overall, the Autism only group rated the body image stimuli as thinner than the Autism+REDs and REDs only groups. There was not a significant interaction effect of group x body size rating, F(2, 134)=.909, p>.05.

Body image stimuli attractiveness ratings

For the Autism only group, attractiveness decreased as BMIs decreased with a definitive incline for the underweight stimuli, but this pattern is less clear for the Autism+REDs and REDs only group (see Figure 5.15).

Figure 5.15. Mean attractiveness ratings of body shapes for the P-IAT for each participant group.



Note: *BMI=body mass index; P-IAT=Picture-based Implicit Association Test; RED=restrictive eating disorder.*

To compare average attractiveness ratings for the P-IAT categories (underweight BMIs and normal weight BMIs), a 3 (Group) x 2 (BMI Weight categories) mixed-model ANOVA was conducted. Table 5.8 shows means and standard deviations for the three participant groups' attractiveness ratings for the two P-IAT weight categories.

Table 5.8. Means and standard deviations for attractiveness ratings of body image stimuli BMI categories for the for the three participant groups.

	Underweight stimuli		Normal weight stimuli	
	Mean	**Standard deviation**	**Mean**	**Standard deviation**
Autism+REDs	4.19	1.64	5.23	1.75
REDs only	4.87	1.93	5.62	1.99
Autism only	2.93	1.48	7.13	1.59

Note: *BMI=body mass index; RED=restrictive eating disorder.*

The mixed-model ANOVA revealed a significant main effect of mean attractiveness rating, *F*(1, 134)=63.35, *p*<.01, η2=.321. Overall, normal weight stimuli were rated as more attractive than underweight stimuli. There was also a significant interaction effect of group x attractiveness rating, *F*(2, 134)=17.794, *p*<.01, η2=.21. Pairwise comparisons are detailed in Table 5.9 for the three participant groups. All three participant groups had significantly higher attractiveness ratings for the normal weight stimuli than the underweight stimuli, but this effect was much stronger for the Autism only group. There was not a significant main effect of group, *F*(2,134)=2.846, *p*>.05, η2=.041.

Table 5.9. Pairwise comparisons for mean attractiveness ratings across groups for each weight category interaction.

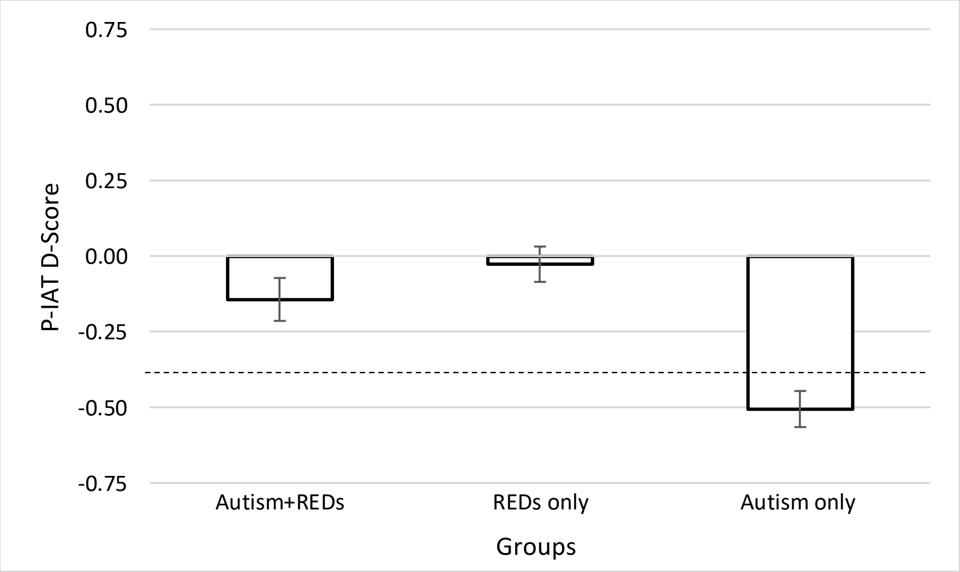
Groups	Stimuli weight category interaction	P-value	95% Confidence intervals	Effect size (Hedge's g_{av})
Autism+REDs	Normal weight x Underweight	**.023***	[.14, 1.93]	.6
REDs only	Normal weight x Underweight	**.034***	[.06, 1.44]	.38
Autism only	Normal weight x Underweight	**.000****	[3.24, 5.18]	2.67

Note: ***=p<.05; **=p<.01.*** *BMI=body mass index; RED=restrictive eating disorder.*

Picture Implicit Association Test (P-IAT)

Means and standard errors for P-IAT D-Scores for the three groups can be seen in Figure 5.16. A Welch's F-Test revealed a significant effect of P-IAT score for the three groups, *Welch's F*(2, 80.646)=17.32, *p*<.01, η2 =.159. Post-hoc comparisons using the Games-Howell test indicated that the mean score for the Autism only group was significantly lower than both the Autism+REDs group (*p*<.01, 95% CI [.14, .58], Hedges' g_s=.89) and the REDs only group (*p*>.01, 95% CI [.28, .68], Hedges' g_s=1.08). The mean P-IAT score did not significantly differ for the Autism+REDs and REDs only groups (*p*>.05, 95% CI [-.34, .1], Hedges' g_s=.25).

Figure 5.16. Mean scores on the P-IAT for the three participant groups. Error bars show +/-1 standard error. Reference line shows P-IAT mean score for the pilot sample of undergraduate students.



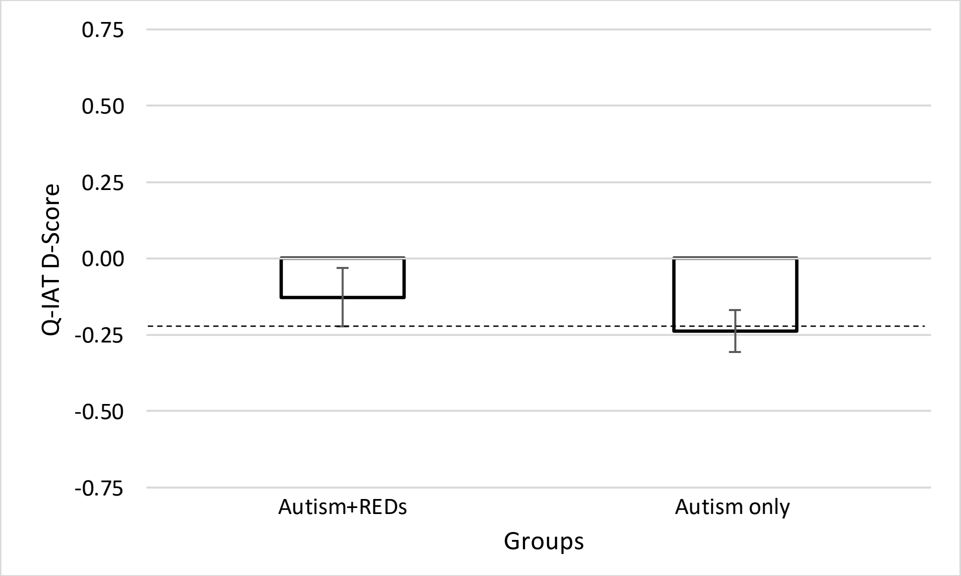
Note: *P-IAT=picture-based Implicit Association Test; RED=restrictive eating disorder.*

A one-sample t-test was carried out to assess whether the groups' scores were significantly different from 0. The t-test revealed that the Autism+REDs group (*t*(39)=-2.022, *p*=.05, CI [-.29, 0]) and Autism only group (*t*(31)=-8.472, *p*<.01, CI [-.63, -.38]) were significantly different from 0, but the REDs only group (*t*(66)=-.463, *p*>.05, CI [-.14, .09]) was not. The lack of significance from 0 for the REDs only group can be interpreted as a lack of implicit association, whereas for the Autism+REDs and Autism only groups, there is an implicit association between underweight stimuli and negative words and/or normal weight stimuli and positive words.

Questionnaire Implicit Association Test (Q-IAT)

Means and standard errors for Q-IAT D-Scores for the two groups can be seen in Figure 5.17. A t-test was conducted to compare Q-IAT scores for the Autism+REDs and Autism only groups. There was no significant difference between the Autism+REDs group (*M*=-.13, *SD*=.39) and the Autism only group (*t*(42)=.965, *p*>.05, 95% CI [-.12, .34], Hedges' g_s=.29).

Figure 5.17. Mean scores on the Q-IAT for two participant groups. Error bars show +/-1 standard error. Reference line shows Q-IAT mean score for the pilot sample of undergraduate students.



Note*:* *Q-IAT=questionnaire-based Implicit Association Test; RED=restrictive eating disorder.*

A one-sample t-test was carried out to assess whether the groups' scores were significantly different from 0. The test revealed that the Autism only group (*t*(26)=-3.457, *p*<.01, CI [-.38, -.1]) was significantly different from 0, but the Autism+REDs group (*t*(16)=-

1.323, *p*>.05, CI [-.33, .08]) was not. The lack of significance from 0 for the Autism+REDs group can be interpreted as a lack of implicit association, whereas for the Autism only group, there is an implicit association between body satisfaction and true statements and/or body dissatisfaction and false statements.

Explicit and Implicit Measures

Pearson's correlations for each group were carried out to understand relationships between the implicit and explicit measures and body image stimuli ratings (see Table 5.10). The implicit measures (Q-IAT and P-IAT) were significantly correlated for the Autism+REDs group but not for the Autism only group. The explicit questionnaires (EDE-Q, BSQ and SATAQ-3) were significantly correlated with each other across all groups. The implicit measures were not significantly correlated with any explicit measure across all groups (with the exception of one significant, negative correlation between the P-IAT and normal weight stimuli attractiveness ratings for the Autism+REDs group). The EDE-Q and the BSQ were significantly correlated with explicit attractiveness evaluations of underweight stimuli for the REDs group, i.e., the more attractive the underweight stimuli is rated, the higher the EDE-Q and BSQ scores. The same pattern is seen for the Autism only and Autism+REDs group, but only for the BSQ. The opposite pattern is seen for explicit attractiveness and size evaluations of normal weight stimuli for all groups in some capacity, i.e., the more attractive or thinner the normal weight stimuli is rated, the lower the EDE-Q and BSQ scores.

Table 5.10. Pearson’s r correlation matrices for implicit and explicit measures for the three participant groups

Autism+REDs

	P-IAT	**Q-IAT**	**EDE-Q**	**BSQ**	**SATAQ-3**	**UW size**	**UW attract.**	**NW size**
P-IAT	-	-	-	-	-	-	-	-
Q-IAT	.631**	-	-	-	-	-	-	-
EDE-Q	.105	.013	-	-	-	-	-	-
BSQ	.114	.144	.704**	-	-	-	-	-
SATAQ-3	-.036	-.277	.327*	.59**	-	-	-	-
UW size	.019	-.229	-.138	.13	.036	-	-	-
UW attract.	.244	-.148	.176	.371*	.311	.306	-	-
NW size	-.18	-.061	-.37*	-.32*	-.259	.082	.066	-
NW attract.	-.354*	.01	-.198	-.051	-.061	.111	-.113	.395*

REDs only

	P-IAT	**Q-IAT**	**EDE-Q**	**BSQ**	**SATAQ-3**	**UW size**	**UW attract.**	**NW size**
P-IAT	-	-	-	-	-	-	-	-
Q-IAT	N/A	-	-	-	-	-	-	-
EDE-Q	.004	N/A	-	-	-	-	-	-
BSQ	.227	N/A	.683**	-	-	-	-	-

SATAQ-3	.186	N/A	.223*	.447**	-	-	-	-
UW size	-.041	N/A	-.124	-.113	.246*	-	-	-
UW attract.	.086	N/A	.444**	.483**	.07	.089	-	-
NW size	.13	N/A	-.244*	-.214	.166	.328**	-.118	-
NW attract.	.18	N/A	-.285*	-.068	.438**	.443**	-.278*	.711**
Autism only								
	P-IAT	**Q-IAT**	**EDE-Q**	**BSQ**	**SATAQ-3**	**UW size**	**UW attract.**	**NW size**
P-IAT	-	-	-	-	-	-	-	-
Q-IAT	-.191	-	-	-	-	-	-	-
EDE-Q	.089	-.216	-	-	-	-	-	-
BSQ	.15	-.217	.844**	-	-	-	-	-
SATAQ-3	.172	-.127	.287*	.463**	-	-	-	-
UW size	-.247	-.081	-.181	-.249	-.024	-	-	-
UW attract.	-.025	.196	.301	.351*	353*	-.24	-	-
NW size	.134	-.063	-.442**	-.332	-.122	.238	-.201	-
NW attract.	-.051	-.1	-.114	-.041	0	.116	-.278	.513**

Note: **=p<.05, **=p<.01. BSQ=Body Shape Questionnaire; EDE-Q=Eating Disorder Examination Questionnaire; NW=normal weight; P-IAT=Picture-based Implicit Association Test; Q-IAT=Questionnaire-based Implicit Association Test; SATAQ-3=Sociocultural Attitudes Towards Appearance Questionnaire; UW=underweight.*

5.3.3 Main Study Discussion

The main study aimed to assess the implicit attitudes of autistic women with a RED, autistic women without an ED and non-autistic women with a RED towards body dissatisfaction and ITI. This was done via two adapted versions of the IAT – the P-IAT and the Q-IAT. Comparisons were made between the three groups for the P-IAT and the two autism groups (autistic women with and without a RED) for the Q-IAT.

5.3.3.1 Picture-based IAT (P-IAT)

My hypothesis for the P-IAT - that the REDs only group would show stronger endorsement of ITI than the Autism+REDs group, and the Autism only group would show the lowest levels of ITI endorsement – was partly supported by our findings. Firstly, for the REDs only group, their P-IAT score was not significantly different from zero, suggestive of no clear association for this group. Conversely, the P-IAT scores for the Autism only group and Autism+REDs group were significantly different from zero. This is suggestive of a significant association between underweight body image stimuli and negative words, and/or normal weight body image stimuli and positive words, which is indicative of a lack of endorsement of the ITI, and therefore supports our hypothesis. Nonetheless, when we compare the scores between the three groups, the P-IAT score for the Autism only group was significantly lower than the P-IAT scores for the Autism+REDs and REDs only groups. There was not a significant difference between the Autism+REDs and REDs only group P-IAT scores and therefore this part of the findings does not support our hypothesis. Our findings, to some extent, match the pattern of findings we saw for the explicit measures of ITI for the three groups, with the REDs only group scoring the highest for this measure, the Autism only group scoring the lowest, and the Autism+REDs group's score falling in between these two groups. Moreover, our P-IAT findings of a lack of association (i.e., not significantly different from zero) in the REDs only group are comparable to other P-IAT studies that measure ITI (Borgers et al., 2021; Izquierdo et al., 2019), strengthening the reliability of our findings.

5.3.3.2 Questionnaire-based IAT (Q-IAT)

Our hypothesis for the Q-IAT - that the Autism+REDs group would show similar levels of body dissatisfaction to the Autism only group – is, similarly to the P-IAT, somewhat supported by our findings. Both the Autism+REDs and Autism only groups had a negative mean score, indicative of a lack of body dissatisfaction. However, the Autism+REDs group's score was not significantly different from zero, suggestive of a lack of association for this group, which does not support our hypothesis. Despite this, when comparing the two groups, the Q-IAT scores for the Autism only and Autism+REDs group did not significantly differ from each other, suggesting similar levels of body dissatisfaction, and therefore supporting our hypothesis. An advantage of using the Q-IAT is the inclusion of self-relevant statements, which may be more reflective of own beliefs and attitudes rather than learnt associations, as highlighted as a potential limitation of the P-IAT.

The Q-IAT study measuring attitudes towards dieting (Izquierdo et al., 2019) found that those with Avoidant-Restrictive Food Intake Disorder (ARFID) and a healthy control group showed implicit associations between non-dieting and true statements, reflecting a lack of fear of weight gain and body image disturbance, whereas those with fat phobic AN and non-fat phobic AN showed implicit associations between pro-dieting and true statements, reflecting a fear of weight gain and body image disturbance. There are some conceptual overlaps between the dieting attitudes measured in the previous Q-IAT study and the attitudes towards body dissatisfaction measured in the current study, allowing for relative comparison of findings. Our findings from autistic women with and without a RED reflect the findings of those with ARFID and the healthy control group in the previous Q-IAT study. Our findings are limited due to the lack of REDs only group for the Q-IAT but due to the conceptual overlap, it could be hypothesised that data from the REDs only group would be similar to those found in the previous Q-IAT for the two AN groups (fat phobic and non-fat phobic AN), indicative of body dissatisfaction, which would therefore represent and reinforce the discrepancy between the autistic and non-autistic women with a RED.

5.3.3.3 Explicit ratings of body image stimuli

Although not included as a hypothesis, it is interesting to note that the Autism+REDs and REDs only groups' mean ratings of attractiveness and size were similar to each other. The Autism only group rated the body image stimuli overall as thinner than the Autism+REDs and REDs only groups did. Moreover, while all three groups rated the normal weight body image stimuli as more attractive than the underweight body image stimuli, the Autism+REDs and REDs only groups did not differentiate between the attractiveness of the normal weight and underweight stimuli as much as the Autism group did. Given findings in the previous chapter that the Autism+REDs group report lower levels of body dissatisfaction and endorsement of the ITI than the REDs only group, we might have expected their ratings to be less similar. Therefore, this is an unexpected finding, and suggests that the differences found in levels of body dissatisfaction and endorsement of ITI between autistic and non-autistic women with a RED are perhaps multi-faceted and these findings may be reflecting different features or elements of these overall constructs.

5.3.3.4 Limitations

Despite being a widely used measure of implicit attitudes, the IAT has been criticised for a number of reasons. For example, the IAT's reliance on response latency means that there is an increased likelihood of measurement error, which in turn may reduce its reliability as a measure (Cunningham, Preacher, & Banaji, 2001; Goodall, 2011). The IAT measure is claimed to overcome biases that occur when using self-report methods such as social desirability bias (M. F. King & Bruner, 2000). However, research has suggested that users are still able to exert cognitive control to suppress their automatic, implicit responses and falsify their responses (De Houwer, Beckers, & Moors, 2007).

Concerns have also been raised regarding the overly simplistic nature of the IAT (e.g., Farrell, Cochrane, & McHugh, 2015; Goodall, 2011) due to its dependence on presenting two opposing stimuli categories (i.e., underweight and normal weight) and two opposing evaluative categories (i.e., positive and negative). In reality, it is likely that true attitudes and beliefs are actually much more complex than this simple representation of attitudes, and therefore the findings may be reflecting something other than personal attitudes, such as learnt, societal rules or norms (De Houwer, 2002). Indeed, Ahern and Hetherington (2006) hypothesised that the self-relevance of attitudes rather than schema-congruent associations are the most important when measuring ITI implicitly. The lack of significance from zero in our findings for the Autism+REDs and REDs only group for the P-IAT may reflect a complex relationship that women with a RED have with body image and thinness, particularly when faced with others' body shapes (i.e., the computer-generated body image stimuli) as opposed to being faced with their own body shape.

An alternative implicit measure to the IAT that addresses some of these limitations is the Implicit Relational Assessment Procedure (IRAP; D. Barnes-Holmes et al., 2006). This measure involves an element of perspective-taking, a skill that is thought to be defective in autistic individuals, ultimately leading to the observed differences in social communication and interaction in autistic people (Baron-Cohen, 2001). Moreover, to my knowledge, this measure has not yet been used and validated in autistic populations.

Therefore, it was decided that the IAT, despite its limitations, would be the best option for the current study.

Another potential limitation identified within the current study is the consistency of body image stimuli used in the P-IAT. All body image stimuli had the same skin tone, and while this could be viewed as an advantage as it can control for confounding variables, it may also serve as a limitation for those who do not identify with this skin tone. The principles of social learning theory suggest that individuals tend to identify more with those that they perceive as similar to themselves (Bandura & Walters, 1977), and this has consistently been found in research of same- versus cross-race modelling (e.g., M. M. King & Multon, 1996; Zirkel, 2002). Future research could aim to overcome this limitation, perhaps by creating multiple versions of the IAT with different skin tones, which can be tailored more closely to the individual.

5.3.3.5 Clinical implications

The findings of this current chapter strengthen the findings of the previous chapter, implying a discrepancy between the levels of body dissatisfaction and ITI in autistic and non-autistic women with a RED. This reinforces the idea that many of the current ED interventions available are not appropriately tailored to fit the needs of autistic women, who make up a significant proportion of individuals in treatment for an ED. It is important to note the mixed findings within this chapter, which reinforce the idea that there is not a clear-cut distinction between autistic and non-autistic women's ED profiles. This supports the need for individualised treatment and service provision for those within ED services, as identified through Chapter 2 and 3. The IATs used in the current study could be useful for identifying levels of body dissatisfaction and ITI within ED services, especially if social desirability bias within routinely-used self-report measures is suspected (M. F. King & Bruner, 2000). However, these novel IATs would benefit from further use in clinical populations to confirm their validity.

5.3.3.6 Conclusion

The aim of this chapter was to: (i) pilot two novel implicit measures of attitudes towards ITI and body dissatisfaction and; (ii) compare the implicit levels of ITI and body dissatisfaction in autistic women with a RED (Autism+REDs), non-autistic women with a RED (REDs only), and autistic women without an ED (Autism only). Our pattern of findings was similar to those found in the explicit self-report measures in the previous chapter – with the Autism only group presenting with the lowest levels of endorsement of ITI and body dissatisfaction, and the REDs only group presenting with the highest levels. Statistically, there were some mixed findings depending on how scores were compared. Some limitations have been identified, namely relating to drawbacks with the IAT measure and the validity of body image stimuli used in the P-IAT. The findings reinforce the clinical implications outlined in the previous chapter through the utilisation of alternative, implicit methods of measurement of body image constructs.

Chapter 6: Examining the differences between the eating disorder service experiences of autistic and non-autistic women

6.1 Introduction

The previous two chapters investigated the ED profile of autistic and non-autistic women with a RED, with autistic women reporting lower levels of body image concern and internalisation of the thin ideal than non-autistic women, both explicitly (Chapter 4) and implicitly (Chapter 5). Moreover, autistic women seemed to have fewer traditional ED-related traits that predict their current ED behaviours and cognitions than non-autistic women. These differences in ED profile may have implications for the treatment of their ED.

Previous quantitative research has explored the relationship between levels of autistic traits and ED treatment outcomes. For example, those with AN presenting with higher levels of autistic traits have been associated with poorer clinical outcomes (Nielsen et al., 2015), fewer improvements following ED intervention and a need for more treatment augmentation (Stewart et al., 2017; Tchanturia et al., 2016), and longer, more frequent inpatient stays (Nazar et al., 2018). Moreover, the presence of autistic traits has been related to a longer duration of AN (Saure et al., 2020). Autistic traits in these studies are determined using a variety of measures, including self- and parent reports, e.g., the Autism-Spectrum Quotient (AQ; Baron-Cohen et al., 2001) and the Social Aptitude Scale (SAS; Liddle, Batty, & Goodman, 2009), in-depth, observational and interview measures, such as the Autism Diagnostic Observation Schedule-2 (ADOS-2; Catherine Lord et al., 2012) and the Development and Well-Being Assessment (DAWBA; Goodman, Ford, Richards, Gatward, & Meltzer, 2000), and measures of neuropsychological characteristics related to autism, e.g. the Rey-Osterrieth Complex Figure Test (Osterrieth, 1944). Taken together, these findings suggest that higher levels of autistic traits are associated with overall worse ED outcomes and subsequent treatment outcomes.

Evidence from stage of illness-based models indicate that the longer the duration of the ED, the more entrenched, habitual and chronic the ED presentation becomes (Treasure et al., 2015). The model stresses that the first three years of onset is a particularly crucial stage for the potential of full recovery (Treasure et al., 2015). This model is supported by developmental epidemiological studies of AN (Herzog, Hopkins, & Burns, 1993) and neurobiological studies, demonstrating that a longer duration of AN is associated with more severe, irreversible shrinkage of grey matter in the brain (Fonville, Giampietro, Williams, Simmons, & Tchanturia, 2014). Given evidence that elevated autistic traits are associated with poorer ED treatment outcomes and longer duration of AN, it could be implied that autistic individuals are at greater risk of presenting with a chronic and enduring ED.

The qualitative research described in Chapter 3 demonstrates the barriers and difficulties currently faced by autistic women when accessing ED services. The autistic women described that their autistic traits were often misconstrued by healthcare professionals, leading to being labelled as resistant and disengaging from treatment. A lack of knowledge about autism in ED services made it difficult for these women to feel understood, with some healthcare professionals labelling autistic service users as too complex. Moreover, the standardised treatments offered were often deemed inappropriate or ineffective by the autistic women. There was a particular emphasis on the inaccessibility of standard Cognitive Behavioural Therapy (CBT) due to its one-size-fits-all approach and the underlying assumptions of skills needed to benefit from the intervention. Alternative approaches such as Dialectical Behaviour Therapy (DBT) and Occupational Therapy (OT) were thought to be more effective due to their more practical emphasis. Finally, autistic women highlighted the importance of services being flexible to meet their communication and environmental needs, and these were particularly salient in inpatient environments. Due to the misunderstanding of autism reported by autistic women and healthcare professionals in Chapter 3 and the need for treatment augmentation, e.g., via more intensive service provision, reported in other studies (Stewart et al., 2017), it could be theorised that autistic women would experience a broader range of treatment options due to the lack of autism-informed treatments or treatments modified for autistic individuals.

It is clear from this research that ED services need to do more to support the significant proportion of their service users that are autistic. However, we need to understand whether the findings from my qualitative analysis are specific to autistic individuals, or whether they reflect more universal barriers, affecting both autistic and non-autistic women. Previous research gives us important insights into the presence of autistic traits and their relationship with ED treatment outcomes. However, what is not known is whether poorer treatment outcomes are seen for women with an autism diagnosis, in comparison to those without an autism diagnosis. whether this remains the case for those with and without a diagnosis of autism. Autistic traits are often described as being dimensional - or on a spectrum - extending into non-clinical populations (e.g. Happé & Frith, 2006). However, these findings may be convoluted by the superficial elevation of autistic-like traits seen in individuals with AN when in a state of semi-starvation (Calugi, Chignola, et al., 2018; Keys et al., 1950). Moreover, we know from the first theme in the results of Chapter 3 that having a diagnostic label of autism may affect a person's experience of ED services. In contrast to previous research, the current chapter includes women with a clinical diagnosis of autism.

6.1.1 Aims and Hypotheses

The aims of the current study were to compare the ED characteristics and ED service experiences of women with and without an autism diagnosis. I hypothesise that, overall, autistic women would report poorer ED service experiences. Based on previous literature, I hypothesise that autistic women with a restrictive eating disorder are likely to have:

1. A longer duration of ED treatment
2. Received a broader range of treatments for their ED
3. Lower ratings of how beneficial they found CBT, which aims to target more traditional ED cognitions

Secondary to this, and in line with our findings in Chapter 4 and 5, I hypothesise that these three factors relating to poorer ED service experience will correlate with a lack of traditional ED cognitions and behaviours, namely relating to pride in eating, body shape concerns and internalisation of the thin ideal.

6.2 Method

6.2.1 Participants

As part of the larger study described in Chapter 4, participants who were autistic with a RED (Autism+REDs) and non-autistic participants with a RED (REDs only) answered questions about their ED and ED service experiences. We collected this data for 46 participants in the Autism+REDs group and 110 participants in the REDs only group. Demographics relating to age and BMI for these groups can be found in Table 6.1. T-tests revealed that there were no significant differences in age, current BMI and lowest ever BMI between the two groups.

Table 6.1. Participant demographics.

		Autism+REDs (n=46)	REDs only (n=110)	T-test
Age (years)	***Mean***	30.41	29.99	*t*(154)=.245, *p*>.05, 95% CI [-2.98, 3.83]
	SD	11.02	9.28	
	Range	18-61	18-63	
Current BMI	***Mean***	17.89	17.35	*t*(142)=1.141, *p*>.05, 95% CI [-.4, 1.49]
	SD	2.27	2.72	
	Range	13.11-22.34	11.76-26.2	
Lowest ever BMI (<18 years)	***Mean***	13.25	14.09	*t*(29)=-1.164, *p*>.05, 95% CI [-2.34, .64]
	SD	1.9	2.1	
	Range	10.1-16.61	10.94-18.66	
Lowest ever BMI (18+ years)	***Mean***	14.03	14.34	*t*(110)=-.586, *p*>.05, 95% CI [-1.33, .72]
	SD	2	2.39	
	Range	10.3-19.76	10.16-23.05	

Note*:* *BMI=Body Mass Index; ED=eating disorder; SD=standard deviation; RED=restrictive eating disorder.*

Frequency of ED diagnoses reported for the Autism+REDs and REDs only groups and their mean current BMIs can be found in Table 6.2.

Table 6.2. BMIs for Autism+REDs and REDs only participant group per reported eating disorder diagnosis.

Eating disorder diagnosis		**Autism+REDs (n=46)**	**REDs only (n=110)**
Anorexia Nervosa	***Frequency***	78.26% (n=36)	80.91% (n=89)
	BMI mean	17.79	16.84
	BMI SD	2.37	2.4
	BMI range	13.11-22.34	11.76-26.2
Atypical Anorexia	***Frequency***	8.7% (n=4)	9.1% (n=10)
	BMI mean	19	21.06
	BMI SD	1.59	1.97
	BMI range	17.85-21.22	17.72-24.14
Avoidant-Restrictive Food Intake Disorder (ARFID)	***Frequency***	4.35% (n=2)	N/A
	BMI mean	17.38	
	BMI SD	.24	
	BMI range	17.21-17.56	
Other Specified Feeding or Eating Disorder (OSFED)	***Frequency***	N/A	2.73% (n=3)
	BMI mean		20.06
	BMI SD		3.66
	BMI range		15.84-22.32
BMI and/or eating disorder diagnosis missing		8.7% (n=4)	7.27% (n=8)

Note: *BMI=Body Mass Index; SD=standard deviation; RED=restrictive eating disorder.*

6.2.2 Materials

Questions about the participants' ED and their service experiences were presented as part of the demographic questionnaire outlined in Chapter 4. Questions about their ED included the age at which their ED symptoms started and age at ED diagnosis. ED service experience questions were as follows:

1) Have you been in treatment for your eating disorder? If so, for how long (roughly) have you had treatment for your eating disorder (in years and months)?

2) How many times (if any) have you been discharged and re-referred for treatment?

3) Which type of healthcare service have you used for your eating disorder? Select all that apply. (Multiple choice options: Specialist eating disorder service, general mental health service, CAMHS, GP, Other).

4) In treatment for your eating disorder, were you under any of the following? Select all that apply. (Multiple choice options: Inpatient care, Outpatient care, Day patient care, Community-based care, Other, Not sure).

5) Did you have any of the following treatments? Select all that apply. (Multiple choice options: Medication, Dietitian input, Occupational therapy, Psychological therapy, Other, Not sure).

6) If you had psychological therapy, which approach(es) did you receive? Select all that apply. (Multiple choice options: Cognitive Behavioural Therapy (CBT), Family Therapy, Maudsley Anorexia Nervosa Treatment for Adults (MANTRA), Specialist Supportive Clinical Management (SSCM), Dialectical Behaviour Therapy (DBT), Other, Not sure).

For questions 4-6, for each selected answer, participants were asked to rate their experience on a scale from 1-7 (1=not beneficial at all, 7=extremely beneficial).

Other measures relevant to this chapter include: the Pride in Eating Pathology Scale (PEP-S), the Body Shape Questionnaire (BSQ), the Sociocultural Attitudes Towards Appearance Questionnaire (SATAQ-3), the Ritvo Autism & Asperger's Diagnostic Scale (RAADS-14) and the Picture-based Implicit Association Test (P-IAT). These questionnaires are outlined in more detail in Chapter 4, and the P-IAT is outlined in Chapter 5.

6.2.3 Procedure

Participants completed questions about their ED and service experience as part of the demographic questionnaire outlined in Chapter 4. This demographic questionnaire was presented to all participants first, before any other questionnaires were completed. The

PEP-S, BSQ, SATAQ-3 and RAADS-14 were completed as part of a larger battery of questionnaires outlined in Chapter 4, and these were presented to participants in a randomised order. The presentation of the P-IAT is outlined in more detail in Chapter 5.

6.2.4 Data Analysis

Relating to the hypotheses outlined in the introduction, the outcome variables of interest were:

1. Age at start of ED symptoms and diagnosis, and ED and treatment duration
2. Frequency of services and treatments accessed, and mean number of different services and treatments accessed across groups
3. Mean ratings of perceived benefit of services and treatments accessed across groups
4. Eating disorder service experiences in relation to traditional ED characteristics across groups

6.2.4.1 Data cleaning

Distribution of data was tested using the Kolmogorov-Smirnov test and by calculating z-scores to detect skewness and kurtosis. For non-normally distributed variables, logarithmic transformations and square root transformations were performed separately on the raw data to attempt to improve distribution. Logarithmic transformations improved normality for some variables, and therefore these were used in the analysis. To improve distribution and reduce the risk of Type I and Type II errors for the variables that were not improved by transformations, the same approach to identifying and correcting outliers was used as described in Chapter 4. When analysing the data, statistical tests were run with and without outlier corrections. We found no differences in the outcome of the analysis when using either the data with or without outliers, and so the original data with outliers has been reported. Moreover, where parametric tests were run with non-normal data, a non-parametric alternative was also conducted. There were few differences between the parametric and non-parametric outputs, so parametric tests are reported to preserve statistical power.

6.2.4.2 Statistical analysis

Statistical analyses were carried out using IBM SPSS Statistics for Windows, Version 26.0. T-tests and chi-squared tests were performed to compare variables and frequencies between the two groups. We also examined the relationship between variables using Pearson's r correlations. As in Chapter 4 and 5, a Hedges' g effect size was calculated, and confidence intervals (CI) are reported.

6.3 Results

6.3.1 Hypothesis 1: Eating disorder characteristics

Independent samples t-tests were carried out to examine differences between the two groups for: (1) the age at which ED symptoms started; (2) the age of ED diagnosis; (3) the duration of ED (in years); and (4) ED treatment duration (in months). T-test results can be seen in Table 6.3. There was no significant difference in duration of ED treatment between the two groups. The Autism+REDs group had a significantly lower age at which ED symptoms started and at which they received their ED diagnosis. The Autism+REDs group also had a significantly longer total duration of ED.

Table 6.3. Means, SD, range, and t-test results for the ED characteristics variables. Significant t tests are highlighted in bold.

		Autism+REDs (n=46)	REDs only (n=110)	T-test
Age that ED symptoms started	Mean	14.87	16.97	***t*(152)=-2.079, *p*<.05, 95% CI [-.11, -.002], Hedges' g_s=.32**
	SD	5.74	6.84	
	Range	5-34	6-46	
Age at ED diagnosis	Mean	18.13	22.06	***t*(153)=-2.845, *p*<.01, 95% CI [-.13, -.03], Hedges' g_s=.47**
	SD	5.85	9.22	
	Range	9-35	11-59	
ED duration (years)	Mean	12.28	8	***t*(153)=2.117, *p*<.05, 95% CI [.01, .29], Hedges' g_s=.45**
	SD	12.36	7.83	
	Range	1-52	0-33	
Total ED treatment duration (months)	Mean	74.63	61.66	*t*(148)=.936, *p*>.05, 95% CI [-.1, .28], Hedges' g_s=.17
	SD	80.88	72.13	
	Range	1-312	1-336	

Note: *ED=eating disorder; RED=restrictive eating disorder; SD=standard deviation.*

6.3.2 Hypothesis 2: Frequency and mean total eating disorder services and treatments accessed

Table 6.4 depicts the percentage and number of ED services and treatments the participants received across groups.

Table 6.4. Types of services and treatments accessed for an eating disorder reported by Autism+REDs and REDs only participant groups. Significant chi-squared tests are highlighted in bold.

Question	Answer	Autism+REDs (n=46)	REDs only (n=110)	Chi-squared
Have you been in treatment for your eating disorder?	Yes	93.5% (n=43)	97.3% (n=107)	$X^2(1)=1.26$, $p>.05$
	No	6.5% (n=3)	2.7% (n=3)	
Type of care setting accessed	Specialist eating disorder service	90% (n=40)	90% (n=99)	$X^2(1)=.31$, $p>.05$
	General mental health service	52.2% (n=24)	40% (n=44)	$X^2(1)=1.96$, $p>.05$
	CAMHS	54.3% (n=25)	28.2% (n=31)	**$X^2(1)=9.65$, $p<.01$**
	GP	60.9% (n=28)	66.4% (n=73)	$X^2(1)=.43$, $p>.05$
Type of eating disorder service setting accessed	Inpatient	60.9% (n=28)	56.4% (n=62)	$X^2(1)=.27$, $p>.05$
	Outpatient	76.1% (n=35)	68.2% (n=75)	$X^2(1)=.97$, $p>.05$
	Day patient	32.6% (n=15)	35.5% (n=39)	$X^2(1)=.12$, $p>.05$
	Community-based	37% (n=17)	38.2% (n=42)	$X^2(1)=.02$, $p>.05$
Type of treatment received for an eating disorder	Medication	78.3% (n=36)	69.1% (n=76)	$X^2(1)=1.35$, $p>.05$
	Dietitian	91.3% (n=42)	81.8% (n=90)	$X^2(1)=2.24$, $p>.05$
	Occupational therapy	37% (n=17)	50% (n=55)	$X^2(1)=2.2$, $p>.05$
	Psychological therapy	90% (n=40)	78.2% (n=86)	$X^2(1)=1.6$, $p>.05$

Types of psychological treatment received for an eating disorder	CBT	65.2% (n=36)	67.3% (n=74)	$X^2(1)=1.88, p>.05$
	Family Therapy	32.6% (n=15)	31.8% (n=35)	$X^2(1)=.01, p>.05$
	MANTRA	17.4% (n=8)	23.6% (n=26)	$X^2(1)=.74, p>.05$
	SSCM	8.7% (n=4)	8.2% (n=9)	$X^2(1)=.01, p>.05$
	DBT	32.6% (n=15)	21.8% (n=24)	$X^2(1)=2.01, p>.05$

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

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

Within each of the different categories of care settings and treatment types were several different options that the participants could endorse (see Table 6.5). To explore this further, we totalled the number of experiences in each of the four categories (care setting, ED service setting, ED treatment and psychological therapies) that each participant reported accessing (see Table 6.5).

Table 6.5. Means, SD's, and t-tests for totalled experiences across the four service and treatment categories. Significant t-tests are highlighted in bold.

Eating disorder service/treatment categories	**Mean (SD)**		**T-test**
	Autism+REDs	**Autism only**	
Care settings	2.98 (1.17)	2.44 (1.07)	***t*(148)=2.704, *p*<.01, 95% CI [.15, .93], Hedges' g_s=.49**
Eating disorder service settings	2.35 (1.0)	2.13 (1.04)	*t*(148)=2.499, *p*>.05, 95% CI [.11, .93], Hedges' g_s=.21
Eating disorder treatments	3.44 (1.08)	2.93 (1.17)	***t*(148)=1.176, *p*<.05, 95% CI [-.15, .58], Hedges' g_s=.44**
Psychological therapies	2.26 (1.68)	1.82 (1.43)	*t*(148)=1.598, *p*>.05, 95% CI [-.1, .97], Hedges' g_s=.29

Note: *RED=restrictive eating disorder; SD=standard deviation.*

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

6.3.3 Hypothesis 3: Eating disorder service and treatment ratings

Participants rated the ED service experiences they reported accessing (with the exception of care settings, as these were deemed too broad to rate) on a scale from 1-7, where 1=not beneficial at all, and 7=extremely beneficial. Ratings for each service/treatment type were averaged across their categories (ED service setting, ED treatment and psychological therapies). Table 6.6 shows the mean ratings, standard deviations, and t-test results for each category.

Table 6.6. Means, SD's, and t-tests for overall ratings of perceived benefit for eating disorder services, treatments and psychological therapies received for the Autism+REDs and REDs only groups. Significant t-tests are highlighted in bold.

	Rating Mean (SD)		T-Test
	Autism+REDs	**REDs only**	
Eating disorder service settings accessed	3.76 (1.22)	4.3 (1.47)	***t*(136)=-2.062, *p*<.05, 95% CI [-1.05, -.02], Hedges' g_s=.38**
Eating disorder treatments received	3.78 (1.33)	4.41 (1.38)	***t*(146)=-2.53, *p*<.05, 95% CI [-1.12, -.14], Hedges' g_s=.46**
Psychological therapies received	3.41 (1.42)	4.12 (1.62)	***t*(116)=-2.261, *p*<.05, 95% CI [-1.33, -.09], Hedges' g_s=.45**

Note: *RED=restrictive eating disorder; SD=standard deviation.*

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

To understand each category further, individual t-tests were conducted for mean ratings for each type of service/treatment. Bonferroni corrections were applied for each category to decrease the risk of Type I errors when carrying out multiple t-tests. Table 6.7 shows the mean ratings from 1-7, standard deviations and t-test results for the ED service settings, treatments and psychological therapies received for their ED. Specialist Supportive Clinical Management (SSCM) was not included in the t-test comparisons due to the small number of participants that reported receiving this intervention.

Table 6.7. Means, SD’s, and t-tests for ratings of perceived benefit for each service experience reported by the Autism+REDs and REDs only groups. Significant t-tests are highlighted in bold.

		Rating Mean (SD)		**T-Test (Bonferroni-adjusted alpha=.0125)**
		Autism+REDs	**REDs only**	
Type of eating disorder service setting accessed	Inpatient	3.29 (1.74)	4.44 (1.64)	***t*(88)=-3.027, *p*<.0125, 95% CI [-1.91, -.4], Hedges’ g_s=.68**
	Outpatient	3.63 (1.65)	3.87 (1.72)	*t*(108)=-.686, *p*>.0125, 95% CI [-.93, .45], Hedges’ g_s=.14
	Day patient	4.8 (2.04)	4.31 (1.72)	*t*(52)=.894, *p*>.0125, 95% CI [-.61, 1.6], Hedges’ g_s=.27
	Community-based	4.18 (1.81)	4 (1.99)	*t*(57)=.316, *p*>.0125, 95% CI [-.94, 1.29], Hedges’ g_s=.09
Type of treatment received for an eating disorder	Medication	4.08 (1.76)	4.07 (1.65)	*t*(64.94)=.05, *p*>.0125, 95% CI [-.68, .72], Hedges’ g_s=.001
	Dietitian	3.52 (1.8)	4.52 (1.84)	***t*(82.02)=-2.948, *p*<.0125, 95% CI [-1.67, -.33], Hedges’ g_s=.54**
	Occupational therapy	3.71 (1.8)	4.09 (1.8)	*t*(26.71)=-.773, *p*>.0125, 95% CI [-1.41, .64], Hedges’ g_s=.21
	Psychological therapy	4.25 (1.77)	4.95 (1.61)	*t*(124)=-2.216, *p*>.0125, 95% CI [-1.33, -.08], Hedges’ g_s=.42
Types of psychological treatment	CBT	3.07 (1.51)	4.31 (1.68)	***t*(102)=-3.522, *p*<.0125, 95% CI [-1.95, -.54], Hedges’ g_s=.75**

received for an eating disorder	Family Therapy	3.4 (1.68)	3.37 (2.07)	*t*(48)=-.047, *p*>.0125, 95% CI [-1.19, 1.25], Hedges' g_s=.02
	MANTRA	3.5 (1.6)	3.92 (1.47)	*t*(32)=-.698, *p*>.0125, 95% CI [-1.66, .81], Hedges' g_s=.27
	DBT	3.93 (1.1)	4.38 (1.64)	*t*(36.74)=-1.007, *p*>.0125, 95% CI [-1.41, .53], Hedges' g_s=.3

Note: *CAMHS=Child and Adolescent Mental Health Services; CBT=Cognitive Behavioural Therapy; DBT=Dialectical Behaviour Therapy; GP=General Practitioner; MANTRA=Maudsley Anorexia Nervosa Treatment for Adults; RED=restrictive eating disorder; SD=standard deviation.*

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

6.3.4 Hypothesis 4: Eating disorder characteristics and service experience in relation to eating disorder profile

It was proposed that a longer duration of ED treatment, receiving a broader range of treatments for their ED and lower ratings of CBT would be associated with a lack of traditional ED cognitions and behaviours. Pearson's r correlations were performed to test this. Results of the correlations can be seen in Table 6.8.

Table 6.8. Pearson's r correlations for traditional ED measures and the variables relating to the hypotheses.

		PEP-S	BSQ	SATAQ-3	P-IAT
ED treatment duration	Autism+REDs	-.174	-.082	.053	-.237
	REDs only	.01	-.051	-.139	-.012
Number of ED treatments accessed	Autism+REDs	***-.429****	***-.375****	-.121	***-.353****
	REDs only	.092	.092	-.084	-.056
Number of ED psychological therapies accessed	Autism+REDs	-.207	-.099	.22	-.176
	REDs only	.073	-.016	.001	-.026
CBT ratings	Autism+REDs	-.285	-.188	.189	.204
	REDs only	-.178	-.032	.134	-.129

Note: *BSQ=Body Shape Questionnaire; CBT=Cognitive Behavioural Therapy; ED=eating disorder; P-IAT=picture-based Implicit Association Test; PEP-S=Pride in Eating Pathology Scale; RED=restrictive eating disorder; SATAQ-3=Sociocultural Attitudes Towards Appearance Questionnaire-3.*

For the Autism+REDs group – but not the REDs only group – lower scores on the PEP-S, BSQ and P-IAT were associated with accessing more types of ED treatment, such as dietitian input, OT, medication, and psychological therapy. Number of different psychological therapies accessed (e.g., CBT, DBT, MANTRA, Family Therapy) were not related to the questionnaire and IAT measures for either groups. Similarly, ED treatment duration and ratings of CBT were not related to the questionnaire and IAT measures for either groups.

6.4 Discussion

The current study aimed to explore the ED characteristics and ED service experiences of autistic and non-autistic women with a RED. The findings of this study are explored further below, in line with each of the original hypotheses.

6.4.1 Eating disorder characteristics

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

The findings also add to the current literature base with the implication that ED symptoms develop at a younger age in autistic individuals and those with high autistic traits. Previous research consistently reports atypical eating behaviours and food selectivity in autistic children (Baraskewich, von Ranson, McCrimmon, & McMorris, 2021; Cermak, Curtin, & Bandini, 2010; Kral, Eriksen, Souders, & Pinto-Martin, 2013). The current findings support qualitative interviews with autistic women with a RED who reported eating difficulties in childhood which contributed to the development of an ED (Brede et al., 2020). Interventions to address atypical eating behaviours may help to reduce some of these initial eating difficulties that lead to more disordered eating in adolescence and adulthood, but interventions that are currently available have high variability in their success rates and overall a relatively low rate of success across interventions (Ledford, Whiteside, & Severini, 2018).

6.4.2 Frequency and total services and treatments accessed

With the exception of CAMHS – which may reflect the younger age at which autistic women received their ED diagnosis – a similar number of autistic and non-autistic women reported accessing different types of treatment settings, services, and treatments for their ED. We also totalled the number of different healthcare settings, ED services, ED treatments and psychological therapies that each participant reported accessing. Autistic women reported accessing significantly more healthcare settings and ED treatments than non-autistic women in the treatment of their ED. This could be viewed positively – that a multi-disciplinary approach is being adopted, particularly when treating autistic individuals with an ED, offering a more holistic approach towards treatment. Indeed, this approach is positively received and encouraged in the qualitative research outlined in Chapter 3.

However, it could be reflecting the narrative also seen in Chapter 3 that autistic individuals are “too complex”, and that these individuals are passed around different healthcare settings and ED treatment types more often than are non-autistic individuals due to the perceived complexity. Indeed, in previous research, females with high autistic traits in treatment for AN required greater treatment augmentation than those with lower levels of autistic traits (Stewart et al., 2017), suggesting there may be a need for further or more intensive treatment approaches for autistic individuals. Whichever narrative this might be reflecting, it is important to acknowledge the challenges faced by many autistic individuals, one of which is pertinent to this point and expressed by an interviewee in Chapter 3 when describing her experience of ED services: “I don’t think they took into account how… difficult I found it seeing lots of different people”. Previous research supports this notion that clinicians view autistic service users as complex and requiring additional service input beyond their usual role (Morris, Greenblatt, & Saini, 2019) and this could be reflected in these findings of autistic women accessing a broader range of healthcare settings for their ED.

6.4.3 Eating disorder service and treatment ratings

Participant ratings of individual ED settings and treatments that they had accessed were, on the whole, similar across both groups. However, when we averaged ratings across the three categories in which the individual ED settings and treatments fell (ED service settings, ED treatments and psychological therapies), autistic women’s ratings reflected that they felt these to be significantly less beneficial in regard to their recovery than non-autistic women, suggesting overall poorer experiences and feelings about the services and treatments they received. Where individual ratings did differ, autistic women rated inpatient care, dietetic input, and CBT as significantly less beneficial than non-autistic women.

Although not a theme in itself, many of the challenging environments described by autistic women throughout the qualitative interviews in Chapter 3 were experienced within an inpatient environment, e.g., “It felt like they didn’t care... I used to like to sit in the same seat, just because I knew where it was, and every day a different staff member would go and sit there. And they wouldn’t understand why I was getting upset”. In their autism strategy, the UK government acknowledged the unaccommodating nature of inpatient environments for autistic people, pledging to put in better supports for these individuals

(Department of Health, 2016). This highlights the importance of tailoring inpatient settings to be suitable to autistic service users who may need to use them.

We also found that autistic women rated dietetic input as less beneficial than non-autistic women. Whilst dietetic input was not a theme in itself within autistic women's narratives in Chapter 3, it could be related to the broader communication difficulties reported by autistic women when in treatment for an ED. In Chapter 3, autistic women praised healthcare professionals that were able to adapt their communication styles to meet their own needs, e.g., writing a summary for them after appointments to aid information-processing. It could also be speculated that this relates to a lack of understanding about autism amongst healthcare professionals working in ED services, as reported in the interviews in Chapter 3. For example, for dietitians specifically, this may include having a knowledge of sensory sensitivities to different food items for autistic people and incorporating this into their dietary advice. Our finding that autistic women rated CBT as significantly less beneficial than non-autistic women supports the findings from our qualitative interviews in Chapter 3. Autistic women reported that in its traditional form, CBT was challenging and often ineffective as they felt that they did not possess the foundational skills needed to fully engage with the therapy, e.g., generalising information from CBT into everyday situations. CBT has been adapted to treat EDs (i.e., CBT-ED; Fairburn, 2008) but this adaptation does not take into account neurodiversity and that many people in ED treatment may be autistic. Studies have found that some characteristics related to autism such as rigid thinking and emotion recognition may reduce the efficacy of using a cognitive-behavioural approach when treating psychiatric conditions, e.g., anxiety and depression, in young autistic people (Lickel, MacLean, Blakeley-Smith, & Hepburn, 2012; Puleo & Kendall, 2011). Consequently, modifications to CBT have been recommended for autistic individuals when treating common mental health conditions, and these are outlined in the National Institute for Health and Care Excellence (NICE) guidelines (National Institute for Health and Care Excellence, 2012). Suggested adaptations include: (i) a more structured and concrete approach using visual and written information; (ii) placing a greater emphasis on behaviour change as opposed to cognitions; (iii) encouraging familial involvement; (iv) maintaining attention by offering regular breaks and incorporating special interests and; (v) avoiding or limiting the use of metaphors and hypothetical situations (National Institute for Health and Care Excellence, 2012). Much research for modified CBT for autism currently focuses on treating mental health conditions such as anxiety, OCD and depression (Walters, Loades,

& Russell, 2016), but the same does not yet exist for EDs. The findings in this study emphasise the need to make specific adaptations to therapeutic approaches such as CBT-ED (Fairburn, 2008) for autistic people.

6.4.4 Eating disorder characteristics and service experience in relation to eating disorder profile

Contrary to our hypotheses, there were no associations between levels of traditional ED characteristics and (i) ED duration, (ii) number of psychological treatments accessed and (iii) CBT ratings in the Autism+REDs group. However, we did find significant, negative associations between levels of traditional ED characteristics and number of ED treatments accessed in the Autism+REDs group. This significant correlation suggests that reporting fewer traditional ED characteristics such as pride in eating and body dissatisfaction was associated with accessing a broader range of ED treatments. This could be representing the need for a more multi-disciplinary approach to treatment within ED services for autistic service users who present with fewer traditional ED characteristics. Alternatively, this could signify that treatments received were not effective for these individuals and could represent the movement needed across different treatment modalities.

It could be speculated that the reason we found non-significant associations was because of the different stages of recovery that the participants are at. Our inclusion criteria included those at any stage of their ED – some had recently developed an ED, whereas others were in recovery. Because of this, those who had had a successful CBT approach, for example, and therefore rated it highly, may have lower levels of traditional ED characteristics as a result of this therapeutic approach. This highlights the importance of recognising these findings as correlations rather than inferring causation, as there might be multiple reasons for these associations found. Future research that takes a more nuanced approach and takes into consideration the stage of ED would help us to understand these relationships further.

6.4.5 Limitations

The research presented in this chapter relied upon on self-report for the ED and service experience data. Whilst this has its advantages, e.g., ease of access to a broad range of personal information (Paulhus & Vazire, 2007), there are also some clear disadvantages. For example, the way in which the questions are posed may be interpreted differently across participants, subsequently reducing internal validity. There was high variability across the length of time in treatment for an ED, and while this could be indicative of the wide range of participants' experiences, it could also reflect differences in the interpretation or reporting of ED treatment duration, e.g., some may give an overall estimate from when they were first diagnosed, whereas others may have more meticulously calculated month by month their time in treatment. A more accurate way to measure these variables would have been via access to individual health records. However, this method would be much more time-consuming and may have limited the number of participants recruited in the study.

6.4.6 Clinical Implications

These findings support previous studies (e.g., Nazar et al., 2018; Nielsen et al., 2015; Saure et al., 2020) suggesting that across some aspects of ED services, autistic people experience poor service provision in comparison to their non-autistic counterparts. It highlights the need for adaptations to be made for autistic people using ED services and to raise awareness and knowledge of autism within these services to understand which adaptations can be made. In our sample, duration of ED was significantly longer for autistic women than non-autistic women, and it could be speculated that this may be partly due to the poorer service experiences they reported.

Autistic women reported that CBT was significantly less beneficial for them than did non-autistic women, suggesting that adaptations and modifications to this evidence-based therapeutic approach is needed within services. Furthermore, it is speculated that there is a need for clearer and more direct communication with autistic people to facilitate engagement, e.g., with dietitians, as this is hypothesised to be a contributing factor to some of the service experiences reported by the autistic women in this study. These implications for clinical environments can be implemented with the inclusion of adequate autism training. Such training is being developed and rolled out in some ED services in the United Kingdom where the need has been identified, and an autism-specific pathway has been developed as part of this (Tchanturia et al., 2020). This model could be used as a foundation for other services to base their own provisions on to support their autistic clients.

6.4.7 Conclusion

This study broadens our understanding of autistic and non-autistic women's experiences of ED services. We hypothesised that autistic women with a restrictive ED would report poorer experiences of ED services than non-autistic women. Despite some similarities across experiences of services, we found that for some aspects of service provision, autistic women did report poorer experiences. These findings highlight the need for adjustments to be made within ED services to accommodate autistic individuals and recommendations for models of autism training and pathways are given.

Chapter 7: General Discussion

7.1 Aims of thesis

Autistic women are overrepresented in ED populations (Postorino et al., 2017; Westwood, Mandy, et al., 2017) and studies suggest that ED treatment options do not currently meet the needs of autistic individuals (Kinnaird, Norton, Stewart, et al., 2019). There is growing evidence to suggest that those with high autistic traits have poorer ED service experiences and treatment outcomes than those with low autistic traits (e.g. Saure et al., 2020; Stewart et al., 2017) However, there is little research comparing the ED service experiences of women with and without an autism diagnosis.

To address this research gap, the overarching aim of this thesis was to gain a better understanding of autistic women's experiences of ED services to inform and improve service provision for these individuals. The starting point for this work was to gain a better understanding of ED services from the viewpoint of service users themselves, which was explored in Chapter 2. Following on from this, Chapter 3 explored autistic women's ED service experiences specifically, through qualitative interviews with autistic women with experience of an ED, parents of autistic women and healthcare professionals working in ED services. This research subsequently informed quantitative comparisons of traits that are traditionally related to EDs and inform ED treatment in: (i) autistic women with a RED; (ii) non-autistic women with a RED and (iii) autistic women without a RED, measured using explicit (Chapter 4) and implicit (Chapter 5) methods. In Chapter 6, a comparison of the ED service experiences of autistic and non-autistic women with a RED was conducted.

7.2 Summary of findings

Prior to addressing the overarching aim, Chapter 2 aimed to broaden our current understanding of service user perspectives and experiences of ED services as a whole. I found that there were some consistent themes across service users' narratives. The included: (i) the overfocus on treating physical symptoms at the cost of the psychological underpinnings of the ED; (ii) the importance of managing control in the treatment of the ED; (iii) the importance of the credentials and understanding of staff working with individuals through their treatment; and (iv) the positive and negative role that peers with an ED played in their recovery. A running thread throughout the themes was the need to adopt an individualised approach to treating someone with an ED.

Chapter 3 introduced a qualitative investigation of autistic women's ED service experiences. Autistic women, their parents, and healthcare professionals working in ED services recognised the barriers faced by autistic women when accessing services. Traits that were inherently linked to their autism were described to be misunderstood by staff, often being misinterpreted as ED-related traits instead. Participants also reported that current standardised treatment approaches without adaptations tend to be either inaccessible due to the women's autistic traits or inappropriate due to a lack of typical ED traits, such as body image concern. Furthermore, these three participant groups highlighted the need for adaptations to be made to accommodate autistic traits, e.g., being flexible to make adaptations to the service environment and meeting the communication needs of the individual. To my knowledge, this is the only qualitative study to combine the views of three stakeholders in understanding the ED service experiences of autistic women within one study.

Chapter 4 and 5 aimed to further our understanding via a comparison of autistic women with a RED, autistic women without a RED and non-autistic women with a RED. In Chapter 4, through explicit questionnaire measures, I found that autistic women with a RED presented with significantly lower levels of body dissatisfaction and significantly less endorsement of the ITI than non-autistic women with a RED. Levels of pride in eating did not differ across the two RED groups. As predicted, autistic women without a RED showed the lowest levels across all three measures. I also found that non-autistic women's ED psychopathology was predicted by more traditional ED traits than autistic women, suggesting there are differences in the antecedents that lead to the development and maintenance of an ED.

To overcome the limitations associated with explicit, self-report questionnaires, Chapter 5 explored implicit levels of ITI across the three participant groups and implicit levels of body dissatisfaction across autistic women with and without a RED. First, I developed two novel IAT tasks and piloted these with a sample of female undergraduate students, which confirmed the acceptability of the tasks. I found that for the implicit measurement of endorsement of the ITI, non-autistic women with a RED showed a lack of association with ITI endorsement, as overall their score was not significantly different from 0. Autistic women with and without a RED did score significantly differently from 0, with their negative mean scores indicating the opposite of the ITI and a preference for normal weight stimuli over underweight stimuli. This lack of ITI endorsement was significantly stronger for autistic women without a RED. For the implicit measurement of body dissatisfaction, autistic women with a RED showed a lack of association with levels of body (dis)satisfaction, as overall their score was not significantly different from 0. Autistic women without a RED did score significantly different from 0, with their mean score being negative, suggestive of a tendency towards body satisfaction.

Chapter 6 aimed to compare the ED service experiences of autistic and non-autistic women with a RED. First, autistic women were significantly younger when they received their ED diagnosis, reported significantly more experience of CAMHS and a longer duration of ED than non-autistic women. Second, autistic women reported accessing a significantly broader range of healthcare settings and ED treatments than non-autistic women in the treatment of their ED. Third, autistic women rated ED services and treatments as significantly less beneficial than did non-autistic women. When broken down into individual treatments and services, inpatient care, dietetic input, and CBT were rated as significantly less beneficial by autistic women than non-autistic women. Finally, we found that when taking into consideration traditional ED-related characteristics such as ITI, pride in eating and body dissatisfaction, having fewer traditional ED characteristics was associated with accessing more ED treatments for autistic women with an ED. This pattern was not seen for the non-autistic women with an ED. Taken together, these findings suggest that overall autistic women report poorer service experiences than non-autistic women and this may partly relate to a non-traditional ED presentation.

Overall, through varied research methodologies, this thesis has explored the ED service experiences and the ED profile of autistic women, which have direct implications for their service provision. Autistic women, parents and healthcare professionals reported barriers directly related to their autism when accessing ED services. Moreover, autistic women with a RED have a less traditional ED profile when compared to non-autistic women with a RED. Autistic women also reported overall poorer ED service experiences than non-autistic women.

7.3 Clinical implications and recommendations for clinicians

The overarching clinical implications of this thesis emphasise the need for service and treatment adaptations for autistic women with a RED to accommodate their needs and non-traditional ED profile. This will ultimately lead to more appropriate ED service provision for these individuals and, potentially, a better prognosis. Chapter 3 highlights some of the barriers faced by autistic women when accessing ED services, and this is supported by Chapters 4-6, in which autistic women report poorer ED service experiences than their non-autistic counterparts and present with an ED profile that does not align with many of the current ED treatments available. Below I outline some recommendations for clinicians alongside some more broader recommendations to improve service provisions for autistic individuals.

7.3.1 Adaptations to ED psychological treatment approaches

CBT-E is one of the most widely-used therapeutic approaches for adults with an ED and is often recommended as a first-line therapy in the UK and internationally (Hilbert, Hoek, & Schmidt, 2017; National Institute for Health and Care Excellence, 2017). However, the findings in this thesis consistently suggest that CBT is not always appropriate or accessible for many autistic women, and the inaccessibility has been attributed directly to their autistic traits. This implies that it may not be effective for autistic individuals in treatment for an ED. Moreover, the NICE guidelines recommend that CBT for EDs should cover body image concern, which the findings in Chapter 4 and 5 suggest may be less relevant for many autistic women, when compared to non-autistic women.

CBT has been adapted to be appropriate for autistic individuals, specifically for mental health difficulties such as for anxiety and depression (Kerns, Roux, Connell, & Shattuck, 2016) and obsessive-compulsive disorders (Flygare et al., 2020). To my knowledge, there are currently no specific guidelines for adapting CBT-E for autistic individuals to aid the treatment of EDs. However, there are broader guidelines outlined by NICE for the adaptation of CBT for autistic individuals (National Institute for Health and Care Excellence, 2012), which could be interpreted for use in ED treatment. These include: using a structured and concrete approach with more written and visual materials; placing greater emphasis behavioural change than cognition; using explicit and contextualised rules; avoiding metaphors and hypothetical situations; incorporating special interests; and familial involvement if appropriate (National Institute for Health and Care Excellence, 2012). Some examples of how these modifications have been implemented include using ratings scales and visual 'thermometers' to concretely measure feelings (Sofronoff, Attwood, & Hinton, 2005) and step-by-step instructions for cognitive restructuring (Cardaciotto & Herbert, 2004). Other research has found that while these guidelines provide a useful template for clinicians, additional modifications may be needed to treat co-morbid mental health difficulties, e.g., using social stories to facilitate a literal thinking style and difficulties with Theory of Mind (Walters et al., 2016). These modifications could be incorporated into CBT approaches for the treatment of EDs to improve access for autistic individuals. Recently, autism-informed adaptations based on anecdotal clinical experience have been recommended for children and adolescents undergoing family-based interventions for AN (Loomes & Bryant-Waugh, 2021). It is likely that many of these recommendations, which overlap with those outlined above, would be relevant for autistic adults too.

MANTRA is another NICE-recommended evidence-based treatment specifically developed for AN (National Institute for Health and Care Excellence, 2017; Treasure & Schmidt, 2013). In Chapter 6, approximately 20% of participants reported receiving MANTRA and ratings of its benefits were similar for both autistic and non-autistic women. Unlike CBT-E, MANTRA has less focus directly on body image concerns, with scope to tailor the intervention modules to the specific needs of the individual (Schmidt, Startup, & Treasure, 2018). In line with the findings in Chapters 4 and 5, this approach fits more appropriately with the ED profile of autistic women. MANTRA is informed by the cognitive-interpersonal maintenance model of AN (Schmidt & Treasure, 2006), and aims to tackle the maintaining factors associated with AN, such as a rigid thinking style (e.g., perfectionism) and social and emotional difficulties (Wade, Treasure, & Schmidt, 2011). As explored in Chapter 1, many of these maintaining factors that are challenged in MANTRA overlap with autistic traits. On face value, this could be hypothesised to be an appropriate treatment for autistic people. However, given the inherent nature of these traits to autism and their moderate stability across the lifespan (M. J. Taylor, Gillberg, Lichtenstein, & Lundström, 2017), these traits are likely to be less malleable for autistic people than for non-autistic people.

Cognitive Remediation Therapy (CRT) – which features in one of the MANTRA modules (Schmidt et al., 2018) - aims to increase cognitive flexibility. It has been trialled in individuals with AN, including those who are autistic and/or present with high autistic traits. Findings in these studies are mixed, with one recent case study of an autistic person with AN reporting improvements in flexibility after individual CRT (Yasemin Dandil, Baillie, & Tchanturia, 2020), and another study reporting no improvements in flexibility and motivation after a group CRT intervention for those with high autistic traits (Tchanturia et al., 2016).

Rather than attempting to modify these traits, it could be that these inherent traits can be used to the individual's advantage to support their recovery. Chapter 3 highlights the importance of routine and structure for autistic women to be better able to engage with services. It has been suggested that for autistic individuals with a RED, traits that may have initially had a negative impact on health, e.g. rigidity and restriction, can be utilised in recovery and treatment (Bullivant & Woods, 2020). Indeed, research has evidenced the many skills that autistic individuals can contribute in the workplace that are directly related to their autistic traits, including cognitive skills, e.g., attentional superiority and logical thinking style, and personal skills, such as unique creativity and empathy with those who might be considered different (Buckley, Pellicano, & Remington, 2021; Cope & Remington, 2021). These traits could similarly be utilised and employed as strengths to support the ED recovery of an autistic individual.

7.3.2 Adaptations to service environments

Importantly, it has been recognised that in order to maximise and utilise the strengths outlined above in recovery, the person-environment fit (i.e., the match between a person's needs and their surrounding environment) must be optimised (Anderson, Sosnowy, Kuo, & Shattuck, 2018; N. Warren et al., 2021). Chapter 3 highlighted the lack of person-environment fit experienced in ED services for autistic women. Furthermore, in Chapter 6, autistic women rated their inpatient experiences as significantly less beneficial than non-autistic women, which based on the findings from Chapter 3, could be hypothesised to be related to the inpatient environment. Changes to routine, unpredictability and novel situations are commonly reported to be distressing and anxiety-provoking for autistic individuals, and these features are naturally characteristic of an inpatient environment (Howlin, 2004). In Chapter 3, I highlight the reported adjustments made – or those that could have been made – to improve autistic women's inpatient experiences. These included flexibility to allow more home comforts such as bringing in bedding from home or adapting the sensory environment, e.g., minimising noise. One concern may be that making adaptations and special arrangements for certain individuals on an inpatient ward could be judged as unfair to other inpatients. This relates to the findings in Chapter 2 in which ED inpatient environments were found to be prone to comparison and competition amongst peers. However, it could be suggested that many of these modifications to the inpatient environment would benefit all individuals, not just those who are autistic, and therefore could be applied to everyone. Indeed, the integrative, holistic concept of Universal

Design (UD) suggests that accessible, usable and conveniently designed environments lead to universal benefit (Story, 2001). Autism-specific examples of UD have demonstrated benefits to all users (Milton, Martin, & Melham, 2016), implying that this approach may be warranted in an ED inpatient setting.

Research suggests that, currently, adjustments for autistic individuals within healthcare services are rare and often unavailable (Brice et al., 2021). A recent update to the NICE guidance for autistic adults gives broad recommendations for adapting service environments when working with autistic individuals (National Institute for Health and Care Excellence, 2012). These recommendations generally echo what participants in Chapter 3 outlined, including adjusting for personal space preferences, considering auditory and visual sensitivities (e.g., by adjusting lighting and noise levels), and using visual supports to aid communication. An additional adjustment to consider that may be more specific to ED services would be olfactory sensitivities, particularly to food smells. Importantly, given the heterogeneous nature of autism (Happé, Ronald, & Plomin, 2006), adjustments should be made in collaboration with autistic service users to meet their individual needs. Furthermore, as identified in Chapter 2 and highlighted above, these adjustments could benefit all service users and a tailored, individualised and collaborative approach should be adopted across the board in regards to the service environment.

7.3.3 Mandatory autism training within ED services for all professions

With research indicating that approximately a quarter of those with AN are also autistic (Huke et al., 2013), it is important that those treating individuals with an ED have a comprehensive understanding of autism. Chapter 3 illustrated the lack of understanding about autism amongst healthcare professionals working in ED services, with the misinterpretation of autistic traits being a salient theme across autistic women's narratives. Adapting communication to meet the needs of autistic individuals was also a key recommendation resulting from Chapter 3. These findings are supported by other studies that find low levels of clinician confidence in treating autistic individuals with an ED (Kinnaird et al., 2017). Incorporating mandatory autism training for professions working in ED services would aid the implementation of the service adjustments recommended above as it would increase awareness of the challenges faced by autistic people and draw attention to any incongruence in person-environment fit. Furthermore, a better understanding of the characteristics associated with autism would assist in the ability to adapt one's own communication style to improve engagement with autistic individuals.

Multidisciplinary training in autism is conducted as part of the Pathway for Eating disorders and Autism developed from Clinical Experience (PEACE) at the South London and Maudsley NHS ED service (Tchanturia et al., 2020). Following a training programme developed by experts and clinicians in the autism field, they found an increase in professionals' confidence in supporting autistic individuals with an ED and in making treatment adaptations (Tchanturia et al., 2020). Furthermore, preliminary research into the effectiveness of the PEACE pathway suggests that it can reduce admission length for autistic individuals with an ED, making it a cost-effective initiative (Tchanturia et al., 2021). Further research is needed to continue to validate this pathway, but there is hope that it can be established across more ED services to better accommodate autistic individuals with an ED on a larger scale (Tchanturia, 2021). As identified in Chapter 3, many women did not have an autism diagnosis prior to accessing ED services. Adopting a more autism-informed culture in ED services may have potential benefits such as better signposting to autism services for diagnostic assessment and recognition of and support with autistic traits, regardless of diagnostic status.

7.3.4 Recognition and treatment of ARFID

A broader recommendation that results from this thesis relates to the more novel ED, ARFID. Research demonstrates an overlap in autism and ARFID presentations (Zimmerman & Fisher, 2017), with similarities being drawn with the food selectivity, anxiety and sensory sensitivities often observed in autistic children (Dovey, Kumari, & Blissett, 2019). Given the lower levels of body image concern reported by autistic women in Chapters 4 and 5, it is likely that some of these women may fit the criteria for ARFID. Indeed, in a qualitative investigation of autistic women diagnosed with AN, some retrospectively suspected that a diagnosis of ARFID would have been more appropriate (Brede et al., 2020). However, at present many NHS ED services are not commissioned to treat clients with an ARFID presentation (Coglan & Otasowie, 2019) and there are currently no NICE evidence-based recommendations for the identification and management of ARFID (National Institute for Health and Care Excellence, 2017). There is recognition of the need for better understanding and training amongst healthcare professionals to aid identification and management of ARFID in children and adolescents, with clear pathways and service provision for this client group (Bryant-Waugh et al., 2021; Ailish Harrison, 2021). The findings in this thesis highlight and extend this need for clear ARFID pathways within adult services to ensure these clients do not fall through the identified gaps in service provision.

7.4 Strengths and limitations

7.4.1 Strengths

One of the key strengths of this thesis is the mixed methods approach, which expands the depth, breadth and richness of the research (McKim, 2017). In an area of investigation in which research is still relatively limited and in its early stages, the initial qualitative interview study allowed me to explore unanswered questions and ultimately give direction to the subsequent quantitative studies. In this thesis, using an exploratory sequential mixed methods design allowed for a more comprehensive, nuanced view of autistic women's experiences of a RED and using ED services.

Through the studies outlined in Chapters 3-6, this thesis boasts large datasets of participants with autism and RED co-morbidity. To my knowledge, these studies represent the largest dataset of autistic women with a RED within this research area. The high number of participants also has statistical advantages, in that it increases statistical power and decreases the probability of a Type II error (Field, 2013). The ability to collect such a large dataset is partly due to the project collaboration between two universities (Cardiff University and University College London). This collaboration not only allowed for more time and resources to collect and analyse data, but also brought unique expertise and ideas to enhance the quality of the studies within (and outside the scope of) this thesis.

A final strength is the inclusion of experts by experience throughout the studies and projects related to this thesis. In the past, autism research has been criticised by the autistic community for the medicalisation and deficit-focused nature of research (Milton & Bracher, 2013). However, the movement towards a meaningful participatory role for autistic individuals throughout the research process (from research design to dissemination) has enabled researchers to shape their research to ensure it yields relevant and important benefits for autistic people themselves (Fletcher-Watson et al., 2019; Keating, 2021; Long, Panese, Ferguson, Hamill, & Miller, 2017). Throughout this project, we strived to include autistic individuals in the research process, e.g., from the co-design of the interview schedules used in Chapter 3, through to dissemination of the research to the autism community and other stakeholders, such as clinicians. I believe that this process of participatory research has enhanced the quality of my research and the impact it can have within clinical settings and for those supporting an autistic person with a RED.

7.4.2 Limitations

Despite the strengths and clinical implications of the findings within this thesis, it should be acknowledged that there remain some limitations associated with my research. Specific limitations have been outlined at the end of each chapter, but there are also some overarching limitations across chapters.

Chapter 4-6 split participants with a RED into two groups: those with and without a formal autism diagnosis. One of the reasons for only including those with a formal autism diagnosis was due to the artificial inflation of autistic traits observed in individuals with AN which likely do not represent true autism (Westwood, Eisler, et al., 2016). Previous research tends to adopt a dimensional approach, in which autistic traits are measured on a continuum and a correlational analysis is conducted (e.g., Saure et al., 2020; Stewart et al., 2017; Tchanturia et al., 2019). This approach does not account for the autism phenocopy that may arise from the effects of semi-starvation (Treasure, 2013). However, there are some drawbacks associated with the method adopted within this thesis, which represents a categorical approach.

First, despite overcoming the challenge of artificially inflated autistic traits not representing true autism, it is possible that some participants in the group without an autism diagnosis are indeed autistic, but without a formal diagnosis. There is growing evidence to suggest that autistic females are identified and diagnosed later than their male counterparts and face more barriers to receiving a diagnosis (Estrin, Milner, Spain, Happé, & Colvert, 2020; Giarelli et al., 2010). This may have limited these women's opportunities to seek a diagnosis earlier. Indeed, in the study in Chapter 3, almost all of the autistic women and autistic daughters of the parents interviewed received their ED diagnosis before receiving their autism diagnosis. Moreover, the study advertisement may have attracted those with a prior interest or identification with the topic of autism and EDs, potentially further inflating the number of undiagnosed autistic women within the non-autistic group.

Second – and related to the previous point – the exclusion criteria throughout the studies in this thesis included those who self-identified as autistic but did not have a formal autism diagnosis. This exclusion was incorporated for methodological rigour, to ensure that all participants had been formally identified and diagnosed as autistic by a healthcare professional. However, research suggests that self-diagnosis is relatively common, with one study reporting that autistic adults self-diagnosed themselves for an average of 3.25 years before they received their formal diagnosis (Lewis, 2016). Barriers faced particularly by marginalised groups mean that, often, the diagnosis process is long, costly and arduous, and sometimes even unobtainable (Garfield & Yudell, 2019). It has been suggested that self-diagnosis should be seen as valid due to these barriers and to promote inclusivity in research (Garfield & Yudell, 2019). Whilst more research is required to determine the validity of self-diagnosis, future studies should consider the experiences of those who identify as autistic without a formal diagnosis given the current barriers to diagnosis, which may limit representation across participant samples.

A strength of the thesis is the utilisation of both self-report and experimental measures to explore concepts through Chapters 4 and 5, rather than relying solely on self-report. However, the experimental measure used – the IAT – poses its own limitations. The IAT measures the relative strength of an association between two concepts, and IAT studies often conclude that the two concepts most closely associated are indicative of the individual’s personal views, beliefs or attitudes (e.g., J. Harrison & Lakin, 2018; Steffens, 2005). However, one of the main criticisms of the IAT is that it cannot determine the relational nature of this association, and as a result, the associations captured by the IAT could be reflecting something other than personal attitudes, such as learnt, societal attitudes or the salience of the concepts presented (De Houwer, 2002). As such, we cannot reliably conclude that the implicit attitudes reported in Chapter 5 are reflective of personal attitude.

To overcome this limitation of the IAT, a non-relative implicit measures was developed, known as the Implicit Relational Assessment Procedure (IRAP; D. Barnes-Holmes et al., 2006). This measure was developed using Relational Frame Theory (RFT) which assumes that the relations (rather than associations, as is the underlying assumption for the IAT) between stimuli determine our attitudes and beliefs (Y. Barnes-Holmes, Hayes, Barnes-Holmes, & Roche, 2001). In the first IRAP study (D. Barnes-Holmes, Hayden, Barnes-Holmes, & Stewart, 2008) participants were presented with: (i) one of two attribute stimuli (either “Pleasant” or “Unpleasant”); (ii) a positive or a negative target stimulus (e.g., “Love” or “Sickness”); and (iii) two relational terms (“Similar” and “Opposite”) as their response options. Participants were asked to respond either consistently with the stimuli (e.g., choosing the “Similar” response option when presented with “Pleasant” and “Love”), or respond inconsistently (e.g., choosing the “Opposite” response option when presented with “Pleasant” and “Love”). Response latencies were faster for consistent blocks than inconsistent blocks (D. Barnes-Holmes et al., 2008). The IRAP has been used to measure pro-thin/anti-fat attitudes towards self and others in individuals with AN (Parling, Cernvall, Stewart, Barnes-Holmes, & Ghaderi, 2012) and to measure actual vs. ideal body image (Hernández-López, Quiñones-Jiménez, Blanco-Romero, & Rodríguez-Valverde, 2021).

Unlike the IAT, the IRAP measure requires the user to respond in a certain way in each trial (i.e., either consistently or inconsistently with a pre-determined belief). In the actual vs. ideal body image IRAP, participants are asked to respond to trials “as if they are fat” or “as if they were thin” (Hernández-López et al., 2021). This requires an element of perspective-taking, i.e., responding in a way that might not be consistent with the self. Rooted in ToM research, autistic individuals tend to show poorer ability in taking others’ perspectives compared to non-autistic individuals (e.g., Baron-Cohen, 2001). To my knowledge, the IRAP has not been trialled in autistic individuals, and given the need for perspective-taking for this approach, it seemed inappropriate to use the IRAP as an implicit measure for this thesis, despite its advantages over the IAT. Future research should strive to pilot an IRAP measure with autistic adults to understand whether its use would be viable in this population.

A final limitation of the thesis was the unforeseeable limits posed on the study conducted through Chapters 4-6 due to COVID-19. Between September 2019 and March 2020, the quantitative study was being conducted in-person, with participants being seen either at the University or in their own homes. This allowed for the use of sophisticated, in-depth assessments, such as the ADOS-2 (Catherine Lord et al., 2012), and experimental measures, such as the two IATs. However, the first COVID-19 lockdown in March 2020 and the uncertainty that followed led us to make the decision to move the study to an online format.

Using an online format came with some advantages: for example, it gave scope to reach a larger number of potential participants, as well as those who had expressed interest prior to COVID-19 but were unable to be seen in-person, e.g., due to location. The online format increased accessibility, meaning that those who may not have been comfortable being seen in-person also had the opportunity to participate. The online study format was also quicker to complete than completing it in-person, further widening the study's accessibility.

There were also, however, some limitations associated with moving the study online. First, there may have been a decrease in internal validity due to the lack of control of extraneous variables. For example, for all participants seen in-person, the IAT was completed on a laptop with one screen size and one processing speed. This could not be controlled for when the study was moved online. Furthermore, in-person, the participants were able to ask any questions during the study with the researcher present. While participants had been given the option to ask any questions during the study via email or telephone when completing it online, this lack of proximity may still act as a barrier to raising concerns.

Another limitation of conducting the study online was being unable to use the autism observational assessment tool that had been used for the in-person study. Module 4 of the ADOS-2 (Catherine Lord et al., 2012) has been recognised as a 'gold-standard' instrument for assessing autistic traits in adults (Maddox et al., 2017) which involves carrying out a number of activities and conversations between a trained clinician or researcher and the individual being assessed. Due to the nature of the instrument, it cannot be conducted remotely, and therefore an alternative measure of autistic traits was chosen for the online study – the AQ (Baron-Cohen et al., 2001). Whilst it is widely used, the AQ has a number of limitations (see Chapter 4 for an overview). Nevertheless, given the dearth of available, validated autism assessment questionnaires for adults (Wigham et al., 2019), the AQ was chosen to measure autistic traits alongside the RAADS-14 (Eriksson et al., 2013), which measures current and childhood autistic traits.

Due to time and resource limitations, I did not have the scope to move both IAT measures to an online format. This meant that we were unable to include the REDs only group in the Q-IAT analysis, limiting the interpretation of the results. Inferences could be made, based on hypotheses and previous research (see Chapter 5 discussion), but without the data, we cannot know how similar or dissimilar the REDs only and Autism+REDs groups would score on implicit levels of body dissatisfaction.

7.5 Future directions

The current thesis adopts a categorical approach throughout, relying on diagnostic labels to guide the focus of the research. However, an alternative stance, which was outside of the scope of the current thesis but could be considered for future research, would be to use a more fluid, transdiagnostic approach. This involves moving away from diagnostic labelling and instead, focusing on symptoms, behaviours and/or underpinnings of the problem. Historically, diagnostic labels in mental health have led to stigmatisation, stereotyping, and influencing of our judgements or interpretation of a person (Critchley, 1979; Herson, 1974). Research indicates that clinical judgements about assessment, appropriate therapeutic approaches and clinical outcomes for a person are influenced by the presence of a diagnostic label, even when behavioural presentations are identical (Lam, Salkovskis, & Hogg, 2016). We know from the transdiagnostic theory of EDs that AN, BN and BED often overlap in their core psychopathology of an overvaluation of shape and weight and their control (Fairburn et al., 2003), and hence CBT-E is a transdiagnostic treatment that can be applied across different ED diagnoses (Fairburn, 2008). Future studies may find that the current research can also be applied to different, but overlapping, ED presentations.

The focus of the current thesis was on the experiences of autistic women only. This was due to a number of reasons, including the gender differences observed in autism presentations and the low numbers of males who are treated for a RED (see Chapter 1). However, future research could replicate the studies in this thesis with autistic men with a RED to understand whether their experiences are similar or different to autistic women. In Chapter 2, we learnt that men face unique challenges when accessing ED services and will often require an individualised approach. Therefore, it could be hypothesised that autistic men would face unique challenges relating to their gender but may additionally experience autism-specific difficulties when accessing ED services. Moreover, previous research has found that males consistently score significantly lower than females on the EDE-Q measure, in comparisons of both clinical and non-clinical samples (J. Mond et al., 2014; K. E. Smith et al., 2017). This gendered pattern has also been found in measures of body dissatisfaction, such as levels of body checking/avoidance behaviours (Striegel-Moore et al., 2009) and body image-related cognitions (Núñez-Navarro et al., 2012). Future research could examine whether the same gendered pattern is found in autistic females and males with a RED, given the findings in this thesis suggesting that autistic women present with significantly lower levels of ED psychopathology and body dissatisfaction than non-autistic women.

Recent research has found that autistic individuals are significantly more likely to express gender variance, i.e., express a wish to be a different gender, or identify as non-binary, than non-autistic individuals (Dewinter, De Graaf, & Begeer, 2017; Strang et al., 2014; van der Miesen, Hurley, Bal, & de Vries, 2018). Transgender and gender diverse adults also have an elevated risk of developing an ED (Hartman-Munick et al., 2021). Therefore, future research could expand beyond a binary conception of gender to include those who identify as gender diverse or transgender. Intersectionality theory would indicate that individual characteristics – in this case, neurodiversity and gender identity – interact in a complex manner that affects individual experiences (Crenshaw, 1989). In minority characteristics, like those described above, these often lead to increases in marginalisation. It may be that, similar to men, autistic gender diverse or transgender individuals with an ED will face unique barriers due to intersectionality.

7.6 Conclusion

This thesis presents novel findings relating to autism and REDs and the unique challenges faced by autistic women when accessing treatment for a RED. Whilst a link between autism and REDs such as AN have been proposed for nearly 40 years (C. Gillberg, 1983), research has mostly been limited to a dimensional perspective of autistic traits in non-clinical populations, or to making inferences from trait overlaps across both autistic individuals and those with an ED. This thesis explored autistic women's experiences of ED services through qualitative (Chapter 3) and quantitative (Chapter 6) investigation, finding that autistic women overall tended to report poor experiences of being treated for an ED compared to non-autistic women, raising important clinical implications for best practice for accommodating autistic people within these services. Related to the management and treatment of an ED, Chapter 4 and 5 compared the ED profile of autistic women with and without a RED and non-autistic women with a RED. The psychopathology that is traditionally associated with an ED (e.g., body dissatisfaction and thin-ideal internalisation) was found to be significantly lower for autistic women with a RED than for non-autistic women with a RED. This suggests that there may be differences in these women's ED profile, which has subsequent consequences for their ED treatment. This thesis highlights that a one-size service cannot fit all, and an individualised, tailored treatment approach is particularly imperative for the accommodation of autistic women in ED services. This thesis also raises the need for more autism understanding and expertise within these services to aid the breaking down of barriers reported by these women when accessing treatment for an ED.

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Appendix

Appendix A: Full list of measures used in study (Chapter 4).

Measure	Type	What is it measuring?	Who completed the measure?
Demographic questionnaire	Self-report questionnaire	Questionnaire used to collect data relating to age, education level, occupation, eating disorder diagnosis and background, autism diagnosis and background, family eating disorder and autism history, height, and weight. The online participants also answered questions relating to COVID-19 and how it has impacted them.	All participants (additional COVID-19 questions for online participants)
Ritvo Autism Asperger Diagnostic Scale –14 (RAADS-14; Eriksson et al. (2013)	Self-report questionnaire	A fourteen-item screening measure of autistic traits for adults.	All participants
Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Hus & Lord, 2014)	Observational schedule	Gold-standard, semi-structured autism assessment tool used to support autism diagnosis (or lack thereof) in a research capacity.	In-person participants
Dimensional, Developmental and Diagnostic Interview-Adult Version (3Di-Adult, Mandy et al., 2018)	Informant report	A seventy-item informant report of early developmental history and current presentation of autistic traits.	All participants (optional)

Eating Disorder Evaluation - Questionnaire (EDE-Q, Fairburn & Beglin, 1994)	Self-report questionnaire	A thirty-two-item questionnaire to measure eating disordered behaviours and cognitions.	All participants
SWedish Eating Assessment for Autism spectrum disorders (SWEAA; Karlsson, Råstam, & Wentz, 2013)	Self-report questionnaire	A sixty-item questionnaire to measure eating disturbances in autism.	All participants
Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)	Self-report questionnaire	A fourteen-item questionnaire to measure symptoms relating to depression and anxiety	All participants
Test of Premorbid Functioning (ToPF; Wechsler, 2011)	Reading test	A brief measure of IQ comprised of the pronunciation of 70 individual words.	In-person participants
Glasgow Sensory Questionnaire (GSQ; Robertson & Simmons, 2012)	Self-report questionnaire	A forty-two-item questionnaire to measure abnormal sensory behaviours relating to visual, auditory, gustatory, olfactory, tactile, vestibular, and proprioception modalities.	All participants
'Taste strips' taste sensitivity task (Burghart, Messtechnik, Germany, Landis et al. 2009)	Psychophysical experimental measure	The task measures accuracy and subjective perception of taste identification for sour, bitter, sweet and salty tastes.	In-person participants
Intolerance of Uncertainty Scale (IUS-12, Carleton, Norton & Asmundson, 2007)	Self-report questionnaire	A twelve-item questionnaire to screen for anxious and avoidant components of	All participants

		intolerance of uncertainty.	
Interoception Sensory Questionnaire (ISQ; Fine et al, 2018)	Self-report questionnaire	A twenty-item questionnaire to measure ability to sense interoceptive bodily states.	All participants
Social Comparison Scale (SCS; Allan & Gillbert, 1995)	Self-report questionnaire	An eleven-item questionnaire to measure perceived social standing in relation to others.	All participants
Submissive Behaviour Scale (SBS; Allan & Gillbert, 1997)	Self-report questionnaire	A sixteen-item questionnaire to measure own perceived submissive behaviour.	All participants
Social Phobia Inventory (SPIN; Connor et al, 2000)	Self-report questionnaire	A seventeen-item questionnaire to screen for and measure social anxiety disorder severity.	All participants
Brief Fear of Negative Evaluation Scale (BFNE; Leary, 1983)	Self-report questionnaire	A twelve-item questionnaire to measure symptoms of social anxiety.	All participants
Pride in Eating Pathology Scale (PEP-S; Faija et al., 2017)	Self-report questionnaire	A sixty-item questionnaire to measure pride in relation to disordered eating behaviours and cognitions.	All participants
Body Shape Questionnaire (BSQ; Cooper et al., 1987)	Self-report questionnaire	A thirty-four-item questionnaire to measure the cognitive and attitudinal aspects of body shape dissatisfaction.	All participants

Picture Implicit Association Task (IAT; Greenwald et al., 2003)	Computer-based implicit experimental task	An implicit measure of the internalisation of the thin ideal.	All participants
Questionnaire-based Implicit Association Task (Q-IAT; Yovel & Friedman, 2013)	Computer-based implicit experimental task	An implicit measure of body (dis)satisfaction.	In-person participants
Sociocultural Attitudes Towards Appearance Scale (SATAQ-3; Thompson, van den Berg, Roehrig, Guarda & Heinberg, 2004)	Self-report questionnaire	A thirty-item questionnaire to measure endorsement of societal appearance ideals.	All participants
Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2018)	Self-report questionnaire	A twenty-five-item questionnaire to measure behaviours relating to camouflaging of autistic traits	All participants
Adult Repetitive Behaviours Questionnaire-2 (RBQ-2A; Barrett et al., 2015)	Self-report questionnaire	A twenty-item questionnaire to measure restricted and repetitive behaviours related to autism.	All participants
Autism-Quotient (AQ; Baron-Cohen et al., 2001)	Self-report questionnaire	A fifty-item questionnaire to measure autistic traits.	Online participants

Appendix B: Pearson’s *r* correlations to explore relationships between measures of autistic traits, disordered eating and mental health across three participant groups (Chapter 4).

Autism+REDs

Variable	***M***	***SD***	***N***	**RAADS-14**	**AQ**	**ADOS-2**	**EDE-Q**	**SWEAA**	**HADS-D**	**HADS-A**	**CAT-Q**	**PEP-S**	**BSQ**
RAADS-14	*35.06*	*5.83*	*51*										
AQ	*38.45*	*4.15*	*33*	.635**									
ADOS-2	*14.6*	*4.11*	*20*	.044	N/A								
EDE-Q	*3.46*	*1.43*	*51*	.198	-.068	-.123							
SWEAA	*50.47*	*11.48*	*51*	.478**	.293	-.208	.233						
HADS-D	*10.18*	*5.54*	*51*	.491**	.23	.082	.477**	.42**					
HADS-A	*14.88*	*4.26*	*51*	.396**	.144	.275	.099	.385**	.457**				
CAT-Q	*130.84*	*19.64*	*51*	.44**	.203	-.14	.192	.203	.37**	.33*			
PEP-S	*75.73*	*28.41*	*51*	.179	.045	-.568**	.551**	.214	.147	-.11	.199		
BSQ	*125.94*	*36.89*	*51*	.215	-.173	-.056	.704**	.189	.331*	.034	.181	.645**	
SATAQ	*88.67*	*29.52*	*51*	.115	.181	-.241	.327*	-.036	.191	.019	.175	.352*	.59**

REDs only

Variable	*M*	*SD*	*N*	RAADS-14	AQ	EDE-Q	SWEAA	HADS-D	HADS-A	CAT-Q	PEP-S	BSQ
RAADS-14	*17.2*	*10.88*	*110*									
AQ	*24.85*	*8.45*	*109*	.786**								
EDE-Q	*4.27*	*1.15*	*110*	.221*	.264**							
SWEAA	*41.08*	*13.5*	*110*	.537**	.587**	.44**						
HADS-D	*10.73*	*4.03*	*110*	.33**	.367**	.466**	.42**					
HADS-A	*14.45*	*3.54*	*110*	.301**	.314**	.458**	.312**	.384**				
CAT-Q	*105.25*	*25.74*	*110*	.559**	.524**	.338**	.41**	.267*	.148			
PEP-S	*84.22*	*25.4*	*110*	.072	.111	.563**	.243*	.092	.243*	.176		
BSQ	*146.91*	*34.15*	*110*	.299**	.192*	.683**	.403**	.311**	.299**	.376**	.513**	
SATAQ	*102.29*	*27.25*	*110*	-.052	-.093	.223*	-.033	-.13	.013	.3**	.366**	.447**

Autism only

Variable	*M*	*SD*	*N*	RAADS-14	AQ	ADOS-2	EDE-Q	SWEAA	HADS-D	HADS-A	CAT-Q	PEP-S	BSQ
RAADS-14	*32.83*	*7.6*	*48*										
AQ	*35*	*7.48*	*20*	.63**									

ADOS-2	*11.33*	*4.26*	*33*	.254	N/A								
EDE-Q	*1.75*	*1.3*	*48*	.316*	.077	-.135							
SWEAA	*31.8*	*12.22*	*48*	.319*	.024	.044	.402**						
HADS-D	*6.4*	*4.34*	*48*	.071	-.187	.082	.141	.265					
HADS-A	*11.06*	*4.53*	*48*	.338*	-.087	-.116	.45**	.353*	.356*				
CAT-Q	*120.46*	*24.99*	*48*	.004	.084	-.228	.25	.042	-.172	.258			
PEP-S	*57.47*	*23.03*	*48*	.197	-.102	.172	.613**	.29*	.103	.403**	.286*		
BSQ	*88.81*	*33.3*	*48*	.253	-.076	-.236	.844**	.445**	.171	.542**	.358*	.61**	
SATAQ	*74.9*	*26.65*	*48*	-.123	-.546*	-.123	.287*	.22	.318	.33*	.389**	.46**	.463**

Appendix C: Body image stimuli used in Picture-based Implicit Association Test (Chapter 5).

Normal weight body stimuli:


BMI 21.55


BMI 19.79


BMI 19.61


BMI 19.30


BMI 19.10

Underweight body stimuli:


BMI 16.40


BMI 15.74


BMI 15.24


BMI 14.65


BMI 14.28