

Understanding Eating Behaviours in Autistic Women with Eating Disorders

INSIGHTS AND PERSPECTIVES
FROM RESEARCH AND CLINICAL PRACTICE



Sabrina Schröder

**Understanding Eating Behaviours in
Autistic Women with Eating Disorders:**

Insights and Perspectives from Research and Clinical Practice

Sabrina Stefanie Schröder

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Understanding Eating Behaviours in Autistic Women with Eating Disorders:
Insights and Perspectives from Research and Clinical Practice

Eetgedrag bij Vrouwen met Autisme en een Eetstoornis:
Inzichten en Perspectieven vanuit Onderzoek en Klinische Praktijk

(met een samenvatting in het Nederlands)

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door

Sabrina Stefanie Schröder

geboren op 21 juli 1992

te Wiesbaden, Duitsland

Promotor:

Prof. dr. A.A. van Elburg

Copromotoren:

Dr. U.N. Danner

Dr. A. Spek

Beoordelingscommissie:

Prof. dr. J.M.P. Baas

Prof. dr. P.A. Boelen

Prof. dr. H.W. Hoek

Dr. A. Mol

Prof. dr. E. Salemink

The world needs all kinds of minds.

— Dr. Temple Grandin

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Chapter 1:

General Introduction



A COMPLEX CASE: WHERE QUESTIONS BEGIN



“Sometimes I wonder if I’m doing life wrong — like there’s a manual everyone else got and I missed it.”

When Eva, 30, first arrived at our highly specialized clinic for eating disorders, Rintveld, her frame appeared fragile, her posture slightly rigid. She spoke in a formal tone, her eye contact shifting between brief moments of staring and looking away. In a clear and detailed manner, she explained how she came to Rintveld: after more than a decade in care, she remained severely underweight, isolated, and locked in rigid routines of eating and exercise — for which she was seeking help again. Eva had previously been diagnosed with a personality disorder, following years of difficulties with mood, suicidality, and emotion regulation. She had received multiple rounds of standard evidence-based treatment for eating disorders, but none had led to sustained improvement. She described group therapy as overstimulating and confusing and often felt misunderstood by professionals. Her strict food rituals and need for detailed explanations were seen as resistance or avoidance — rather than as signs of something deeper. It wasn’t until she was 28 that a diagnostic reassessment was conducted. This led to a revised diagnosis: autism spectrum disorder. The new perspective reframed many aspects of her clinical picture. Her longstanding sensitivity to food textures, discomfort in social settings, and difficulties with interoception (e.g., recognizing hunger and fullness) suddenly made more sense. Her structured routines — including rigid eating and extensive daily exercise — appeared less as attempts at weight loss, and more as strategies to create predictability in an overwhelming world. Eva’s eating disorder had started during her first year at university. Feeling isolated and anxious, she began to believe that being thinner might make her more socially acceptable. Compliments on her changing appearance reinforced this idea. Within six months, she had lost 30 kilograms and was hospitalized for medical instability. Since then, her eating behavior had remained inflexible, with compulsive movement and a persistent fear of letting go of control. By the time she was referred to our clinic, Eva was seeking more than just symptom relief. She wanted to better understand how her autism shaped her eating behaviors — and how to live with more flexibility and self-acceptance. Despite many years in care, her core needs around structure, sensory sensitivity, and identity had rarely been addressed.

Eva’s case illustrates how the combination of autism spectrum disorder (ASD; henceforth *autism*) and an eating disorder (ED) can create a complex and seemingly ED treatment-resistant presentation. In recent years, researchers and clinicians alike have increasingly begun to question whether traditional ED frameworks sufficiently capture the presentation of

an ED in autistic¹ individuals, particularly women (e.g., Brede et al., 2020; Longhurst et al., 2024; Tchanturia et al., 2019). These questions, which first emerged in clinical settings, have gained broader societal resonance. In both Dutch and international media, stories have surfaced of women who “fall through the cracks” in care systems due to a dual presentation of autism and an ED. Many report years of treatment without sustainable progress, conflicting diagnoses, or exclusion from services for being considered “too complex.” At the same time, ED treatments are rarely adapted to the neurocognitive profiles of autistic clients. To explore why current treatment approaches may not suffice in such cases, it is first necessary to clarify how EDs are currently defined.

WHAT ARE EATING DISORDERS?

EDs are serious psychiatric conditions marked by persistent disturbances in eating behavior, often accompanied by psychological distress and impaired physical health (American Psychiatric Association, 2013). While typically associated with concerns around weight or shape, EDs present with a diverse range of symptoms and motivations and vary widely in their clinical course. The DSM-5 includes several conditions under the category of feeding and eating disorders, including anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), avoidant/restrictive food intake disorder (ARFID), and other specified feeding or eating disorder (OSFED). Among these, AN, BN, BED, and OSFED are typically considered the most commonly diagnosed EDs in clinical practice. A summary of the DSM-5 diagnostic criteria for these conditions is presented in **Table 1.1**²

-
- 1 While we acknowledge that individual preferences vary across autistic communities, this paper adopts “identity-first” language (i.e., “autistic person”) rather than “person-first” language (i.e., “person with autism”) in line with the preferred terminology of the English-speaking autism community (Bury et al., 2023; Kenny et al., 2016). Notably, in the Netherlands — the country of origin of most of the authors and participants — “person-first” language is preferred over “identity-first” language (Buijsman et al., 2023).
 - 2 Throughout this dissertation, the term *eating disorders* refers specifically to disorders that are characterized by restrictive eating, compensatory behaviors, and/or body image concerns — namely AN, BN, and OSFED. While BED and ARFID are formally classified within the DSM-5, they were not included in the empirical studies presented here. ARFID is, however, discussed in relation to autism-related eating behaviors due to its conceptual relevance.

Table 1.1**DSM-5 Diagnostic Criteria of Eating Disorders.**

Diagnosis	Key DSM-5 Criteria
Anorexia Nervosa (AN)	<ul style="list-style-type: none"> - Restriction of energy intake leading to significantly low body weight - Intense fear of gaining weight or becoming fat - Disturbance in body image or denial of seriousness of low weight
Bulimia Nervosa (BN)	<ul style="list-style-type: none"> - Recurrent episodes of binge eating - Recurrent compensatory behaviors (e.g., vomiting, laxatives, excessive exercise) - Self-evaluation unduly influenced by body shape and weight
Binge-Eating Disorder (BED)	<ul style="list-style-type: none"> - Recurrent episodes of binge eating (marked distress, loss of control) - No regular use of compensatory behaviors - Occurs at least once a week for 3 months
Avoidant/Restrictive Food Intake Disorder (ARFID)	<ul style="list-style-type: none"> - Avoidance or restriction of food intake due to lack of interest in food, sensory sensitivity and/or a fear of aversive consequences (e.g., choking, vomiting) - Results in significant weight loss, nutritional deficiency, dependence on supplements and/or psychosocial impairment - Not driven by body image concerns
Other Specified Feeding or Eating Disorder (OSFED)	<ul style="list-style-type: none"> - Symptoms cause significant distress/impairment - Do not meet full criteria for another ED diagnosis - Examples include atypical AN, subthreshold BN or BED, purging disorder

Note: Although *Avoidant/Restrictive Food Intake Disorder (ARFID)* is technically classified as a feeding disorder, it is included here due to its clinical relevance to this dissertation. Other feeding and eating disorders recognized in the DSM-5 - namely *Pica*, *Rumination Disorder*, and *Unspecified Feeding or Eating Disorder (UFED)* - are not included in this overview, as they fall outside the scope of this dissertation.

EDs are linked to substantial physical and psychiatric risk. AN has the highest mortality rate of any psychiatric disorder, with approximately 5% of patients dying per decade due to both medical complications and suicide (Auger et al., 2021; Smink et al., 2012). Mortality rates are also elevated — though to a lesser extent — in BN and BED (Keski-Rahkonen, 2021; Van Eeden et al., 2021). In addition, up to 70% of individuals with an ED meet criteria for at least one other psychiatric diagnosis, most commonly mood and anxiety disorders (Momen et al., 2022; Ulfvebrand et al., 2015). These comorbidities can complicate not only treatment engagement, but also the course of illness, responsiveness to interventions and long-term outcomes. Despite the severity, chronicity, and risk associated with EDs, treatment outcomes for many adults with EDs remain suboptimal — particularly for those whose clinical features fall outside the scope of conventional diagnostic models and are less amenable to existing treatment frameworks.

TREATMENT LIMITATIONS IN EATING DISORDERS

Even among individuals with typical clinical presentations, treatment outcomes remain mixed — particularly for adults (Monteleone et al., 2022). Interventions recommended by the National Institute for Health and Care Excellence (NICE, 2017) include Cognitive Behavioral Therapy for Eating Disorders (CBT-E) for AN, BN and BED, and either MANTRA (Maudsley Anorexia Nervosa Treatment for Adults) or SSCM (Specialist Supportive Clinical Management) as additional options for AN. While these treatments are evidence-based and recommended as first-line interventions, outcomes remain mixed (Monteleone et al., 2022; National Institute for Health and Care Excellence, 2017; Treasure et al., 2020). Remission rates for AN, BN and BED range between 40 and 60% percent (Monteleone et al., 2022). A recent meta-analysis found that 26% of individuals with EDs experience relapse after recovery and approximately 25% develop a longstanding course of illness — characterized by prolonged illness duration, repeated hospitalizations, and persistent psychosocial impairment (Solmi et al., 2024). In addition, dropout rates of 20 to 40% are common in outpatient care, especially among those with AN (DeJong et al., 2012). Even in those who attain weight restoration, difficulties with body image, emotion regulation, and interpersonal functioning often persist (Tomba et al., 2019). These findings point to a pressing need to refine treatment models to better meet the needs of adults who do not respond to standard interventions. This urgency becomes even more apparent when considering individuals whose EDs co-occur with autism — presentations that are often described in the literature as more serious and complex (Nimbley et al., 2025; Zhang et al., 2022).

AUTISTIC INDIVIDUALS WITH EATING DISORDERS

Autistic individuals appear to benefit even less from current interventions. To understand why, it is important to first clarify what autism entails. Autism is described as a lifelong neurodevelopmental condition, but also as neurodivergence, that influences how individuals perceive the world, process sensory information, and interact socially (American Psychiatric Association, 2013). It is increasingly recognized as a spectrum, encompassing individuals with a broad range of cognitive abilities and support needs (Lord et al., 2020). While manifestations differ widely, many autistic people share certain core characteristics that affect how they engage with others and adapt to change. These core characteristics are reflected in the current diagnostic criteria, which are organized into two domains: (1) persistent differences in social communication and interaction, and (2) restricted, repetitive patterns of behavior, interests, or sensory experiences. **Table 1.2** provides a summary of these diagnostic domains and associated features as outlined in the DSM-5 (American Psychiatric Association, 2013).

Table 1.2**DSM-5 Diagnostic Criteria of Autism Spectrum Disorder.**

Domain	Examples
A. Persistent deficits in social communication and interaction	<ul style="list-style-type: none"> - Challenges with social-emotional reciprocity (difficulties with back-and-forth conversation; reduced sharing of interests, emotion, or affect) - Challenges with nonverbal communication used for social interaction (e.g., challenges in understanding and use of eye contact, facial expressions, or gestures) - Difficulties in developing, maintaining, or understanding social relationships (e.g., difficulties adjusting behavior to various social contexts)
B. Restricted, repetitive patterns of behavior, interests, or activities	<ul style="list-style-type: none"> - Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects) - Insistence on sameness, inflexible routines, or ritualized patterns (e.g., great distress with changes, rigid thinking patterns) - Highly restricted, fixated interests of abnormal intensity or focus (e.g., excessive preoccupation with hobbies or interests) - Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., strong aversions to textures, difficulties with feeling and interpreting bodily signals)
Additional criteria	<ul style="list-style-type: none"> - Symptoms must be present in early developmental period - Symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning - Disturbances are not better explained by intellectual disability or global developmental delay

Although autism is often diagnosed in early childhood, many individuals — particularly girls, women, and those with higher cognitive abilities — receive a diagnosis only in adolescence or adulthood (Fountain et al., 2011; A. S. Russell et al., 2025). This delay is partly due to sex-based diagnostic biases, as well as to camouflaging behaviors — adaptive strategies some individuals use to mask or compensate for social and sensory challenges (Cruz et al., 2025; Wood-Downie et al., 2021). These factors contribute to the persistent under-recognition of autism in girls and women, particularly those without co-occurring intellectual disability or overt externalizing behaviors (Rynkiewicz et al., 2019; Schröder et al., 2022).

As awareness of these biases has grown, so too has interest in understanding how autism may interact with other psychiatric conditions — particularly EDs. In recent years, both research and clinical attention have increasingly focused on the co-occurrence of autism, autism-related eating problems, and disordered eating, raising new questions about diagnostic clarity, illness trajectory, and the need for adapted treatment approaches (e.g., Baraskewich et al., 2021; Huke et al., 2013; Spek et al., 2020; Westwood & Tchanturia, 2017).

WHAT DO WE KNOW ABOUT AUTISM AND EATING DISORDERS?

A growing body of literature has begun to explore how autism and EDs intersect — both in clinical presentation and in treatment implications (Brede et al., 2020; Kinnaird, Norton, Stewart, et al., 2019; Nimbley et al., 2023, 2025). Even in the absence of a formal ED diagnosis, many autistic individuals report longstanding and distinct eating patterns — referred to here as autism-related eating behaviors³ — such as a strong preference for sameness in meals, heightened sensitivity to textures or temperature, and reliance on predictable routines (Mayes & Zickgraf, 2019; Schröder et al., 2022; Spek et al., 2020). These behaviors are not inherently maladaptive and may serve important sensory, emotional, or social functions (Longhurst et al., 2024; Nimbley et al., 2023). However, when these patterns result in adverse consequences, they may become maladaptive or meet diagnostic criteria for an ED such as ARFID (Schröder et al., 2022).

Recent studies suggest that autistic individuals — particularly women — may also engage in traditionally disordered eating behaviors, including restricting, bingeing, purging, or compulsive exercise, possibly in response to body image concerns or the desire to fit into neurotypical norms (Brede et al., 2020; Demartini et al., 2021; Healy et al., 2021; Spek et al., 2020). These behaviors — commonly seen in non-autistic ED populations as well — are typically shaped by sociocultural ideals, perfectionism, emotional dysregulation, or internalized standards around control and appearance (Frayn & Knäuper, 2018; Jankauskiene & Baceviciene, 2022; Marks et al., 2020). They may not meet the full threshold for a clinical ED but nonetheless pose significant psychological and physical risks (Marks et al., 2020).

Despite limited systematic investigation into the perceived burden of illness and quality of life in this group, emerging literature suggests that when EDs occur in autistic individuals, they are often more complex and enduring than in non-autistic populations. Clinical observations and empirical findings describe longer illness durations, increased risk of chronicity, and a greater likelihood of requiring intensive interventions such as repeated inpatient admissions or nutritional rehabilitation via tube feeding (Nielsen et al., 2022; Nimbley et al., 2025; Saure et al., 2020; Tchanturia et al., 2019; Zhang et al., 2022). These trajectories are further marked by lower recovery rates, heightened relapse risk, and poorer long-term psychosocial outcomes (Nielsen et al., 2022; Schröder et al., 2025; Tchanturia et al., 2019; Zhang et al., 2022).

3 While we recognize that eating behaviors such as food neophobia or selectivity are not exclusive to autistic individuals, we use the term ‘autism-related eating behaviors’ to enhance readability and emphasize their markedly higher prevalence in autistic individuals compared to those with other developmental conditions such as ADHD or intellectual disabilities (Malhi et al., 2017; Mayes & Zickgraf, 2019).

Importantly, these more severe illness trajectories are not only shaped by individual-level factors but also unfold within systems that are poorly equipped to meet autistic individuals' needs. Beyond the clinical complexity, autistic individuals also face considerable systemic barriers — further complicating access to effective, sustained, and autism-sensitive treatment. Many report that existing ED services are poorly adapted to their sensory and cognitive needs: clinical environments are often overstimulating, communication styles can feel ambiguous or invalidating, and therapeutic demands may conflict with a need for routine, predictability, and control (Adamson et al., 2020; Tint et al., 2017). These mismatches can lead to distress, disengagement, or withdrawal from care — even when motivation for recovery is high (Adamson et al., 2020; Huke et al., 2014; Kinnaird et al., 2017; Kinnaird, Norton, Stewart, et al., 2019).

In both clinical reports and first-person accounts, autistic individuals with EDs are frequently described as “difficult to place” (Babb et al., 2021, 2022; Kinnaird et al., 2017, 2021; Loomes et al., 2025). Autism services may refer them elsewhere due to concerns about physical health risks or a lack of ED expertise, while ED clinics may hesitate to proceed with treatment when autistic traits interfere with standard care pathways (Adamson et al., 2020; Bruder et al., 2012). Clinicians sometimes report feeling unprepared to adapt existing interventions or uncertain about how to interpret autism-related behaviors — leading to reluctance to admit clients whose needs exceed the scope of standard protocols (Adamson et al., 2020; Kinnaird et al., 2017). This disconnect between services contributes to a significant care gap, leaving many autistic individuals with EDs without appropriate or sustained support.

These systemic barriers are compounded by diagnostic ones. Autism — particularly in women — often goes unrecognized or is misattributed to other psychiatric conditions such as borderline personality disorder, anxiety or trauma-related presentations (Dell’Osso & Carpita, 2023; Kentrou et al., 2024). As a result, many may enter ED treatment without an accurate diagnosis, leading to interventions that do not align with their neurodevelopmental needs. Even when autism is identified, adaptations are rarely implemented in a structured way (Kinnaird et al., 2021). One key challenge is that ED clinicians often lack a clear pathway to refer patients for autism assessment and existing diagnostic tools may be ill-suited to detect autism in women (Adamson et al., 2020; Kinnaird et al., 2017; Sedgewick et al., 2019). These obstacles hinder adequate care planning and prevent many autistic individuals from receiving tailored support. Despite growing evidence that tailored approaches may be essential for treatment engagement and recovery, autism-specific modifications remain the exception rather than the norm (Adamson et al., 2020; Kinnaird et al., 2017; Kinnaird, Norton, Stewart, et al., 2019; Tint et al., 2017). Together, these findings suggest that the co-occurrence of autism and EDs is marked by a complex clinical presentation and a significant mismatch between individual needs and existing care systems. This misalignment in care is compounded by ongoing uncertainty about how best to conceptualize and respond to the unique eating behaviors observed in autistic individuals with EDs.

INVESTIGATING EATING BEHAVIORS OF AUTISTIC WOMEN WITH AN EATING DISORDER

Despite increasing recognition of the co-occurrence of autism and EDs, the question of why EDs in autistic individuals often present more severely and respond less readily to treatment remains unresolved — hindering efforts to develop appropriate interventions and improve clinical outcomes. A core challenge lies in the dual nature of eating behaviors observed in this group. Many autistic women engage in both traditionally disordered eating behaviors — such as restriction, bingeing, or purging — and autism-related eating behaviors that serve regulatory, sensory, or emotional functions (Brede et al., 2020; Schröder et al., 2022; Spek et al., 2020). However, these patterns have rarely been studied in parallel or disentangled in diagnostic contexts. This overlap between autism-related and traditionally disordered eating behaviors creates both diagnostic and clinical ambiguity — particularly when behaviors like food selectivity, rigid mealtime routines, or sensory-based avoidance may reflect longstanding autism-related patterns rather than pathology. When such behaviors co-occur with disordered eating, it becomes difficult to determine which warrant clinical intervention and what treatment approach is most appropriate. Moreover, the motivations behind these behaviors may diverge from those typically seen in EDs (Brede et al., 2020; Kinnaird, Norton, Stewart, et al., 2019). While restrictive eating in non-autistic individuals is often linked to weight or shape concerns, in autistic individuals it may instead function as a coping strategy — offering predictability, reducing sensory overwhelm, or regulating emotional states (Bradley et al., 2024; Carpita et al., 2022). Standard interventions that focus on body image or cognitive distortions may therefore fail to address the core drivers of behavior in this group (Schröder et al., 2025).

To clarify the processes driving these behaviors, there is growing interest in the underlying mechanisms that may contribute to the persistence and complexity of EDs in autistic individuals. One such mechanism may be cognitive flexibility — the ability to shift between mental sets or behavioral strategies in response to changing circumstances (Dajani & Uddin, 2015; Happé & Frith, 2006; Miles et al., 2020).

Although impaired cognitive flexibility is well-documented in both autism and EDs, its role may differ across these conditions. In autistic individuals with EDs, it may contribute to uniquely persistent or functionally distinct eating behaviors — such as rigid routines around food, difficulties adapting to change, or heightened distress when confronted with new treatment strategies (Lang et al., 2014; Sternheim et al., 2022). Understanding how impaired cognitive flexibility manifests in this population is essential, as it may help explain why standard ED interventions are often less effective and support the development of more tailored therapeutic approaches. However, few studies have directly examined cogni-

tive flexibility in autistic individuals with EDs, and the role of this trait in shaping their eating behaviors remains unclear.



STUDY RATIONALE AND AIMS

Together, these gaps underscore the need for more robust research conducted in clinically diagnosed samples of autistic women with EDs. Much of the existing literature relies on individuals with ‘autistic traits’, suspected autism, or subthreshold presentations — limiting clinical applicability and making it difficult to draw firm conclusions about this subgroup (Schröder et al., 2023, 2025). Formally diagnosed samples are essential to determine whether observed eating behaviors are truly autism-specific or reflective of broader psychopathology. Without such diagnostic clarity, it remains unclear to what extent the eating behaviors seen in autistic women with EDs differ from those in non-autistic ED populations (Schröder et al., 2025; Sharp, 2025).

This dissertation aims to address these limitations by studying a well-characterized group of autistic women with EDs, and by examining how their eating behaviors compare to those of non-autistic women with EDs, autistic women without EDs, and non-autistic control participants. In addition to behavioral patterns, the dissertation examines one potential underlying mechanism — cognitive flexibility — a neurocognitive trait known to differ in both autistic and ED populations and hypothesized to contribute to the persistence of rigid eating behaviors. While not exhaustive, our focus offers a starting point for understanding how specific cognitive traits may influence clinical presentation and treatment response in this group. In addition, the dissertation includes an exploratory assessment of psychological distress and mental health-related quality of life in this group — providing further context for the lived experience and clinical complexity described in the literature. The goal is to move beyond diagnostic categories and generate a more complete picture of the eating patterns observed in autistic women with EDs — one that can inform more effective, adequate, and sustainable forms of care.

STRUCTURE OF THIS DISSERTATION

In addition to the general introduction (**Chapter 1**) and general discussion (**Chapter 6**), this dissertation consists of four interrelated chapters (**Chapters 2-5**), which together provide a stepwise exploration of eating behaviors in autistic women with EDs — moving from broad literature synthesis to more detailed empirical investigation.

Chapter 2 presents a scoping review of the literature on eating behaviors in autistic women. It maps how eating-related traits and behaviors have been described across studies, examines the terminology and theoretical frameworks used, and identifies gaps in the quality and focus of current research.

Chapter 3 offers a conceptual paper exploring the intersection of autism and EDs. Drawing on clinical experience, existing research, and theoretical reasoning, it outlines why traditional ED models may not fully capture the experiences of autistic women and discusses implications for assessment, diagnosis, and treatment adaptation.

Chapter 4 presents a cross-sectional empirical study comparing eating behaviors across four well-defined groups: autistic women with EDs, non-autistic women with EDs, autistic women without EDs, and non-autistic controls. The study examines both traditional ED symptoms and autism-related eating behaviors, and assesses levels of psychological distress, comorbid symptoms and mental health–related quality of life to better understand the clinical burden experienced by each group.

Chapter 5 investigates cognitive flexibility as a potential underlying mechanism. It assesses self-reported cognitive flexibility across the four groups presented in **Chapter 4** and explores how this trait relates to patterns of eating behavior — offering initial insight into possible mechanisms underlying these behaviors.

Together, these chapters aim to advance our understanding of autistic women with EDs by characterizing key behavioral and cognitive patterns, exposing critical gaps in current clinical models, and laying the groundwork for more personalized, autism-informed approaches to care. The dissertation concludes with a general discussion (**Chapter 6**) in which the results are synthesized, and their clinical and scientific implications are explored.



Chapter 2:

Problematic Eating Behaviors of Autistic Women with an Eating Disorder — A Scoping Review

Schröder, S. S., Danner, U. N., Spek, A. A., & van Elburg, A. A. (2022). Problematic eating behaviors of autistic women - A scoping review. *European Eating Disorders Review*, 30(5), 510-537. <https://doi.org/10.1002/erv.2932>



ABSTRACT

Background: Eating and feeding behaviors of autistic individuals and related consequences have been mainly investigated in autistic children or in autistic adults with intellectual disabilities. Behaviors such as food selectivity or food neophobia have been shown to persist into adolescence and adulthood and are associated with aversive consequences. However, much less is known about the eating behaviors of autistic adults without intellectual disabilities, especially those of women. By means of a scoping review, we aim to assess the extent of the scientific literature on what is known about the eating behaviors of these women and the possible consequences of such eating behavior.

Method: Medline, Cochrane, PubMed and PsycInfo databases were searched according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Results: Five studies met the eligibility criteria and were included in this review. Autistic women not only reported high levels of eating behavior frequently seen in autism spectrum disorders (ASD), but also high levels of disordered eating behavior, similar to that of women with eating disorders (ED).

Conclusions: Autistic women seem to exhibit high levels of eating behavior frequently seen in ASD as well as disordered eating behavior. Future research needs to shed light on what underlies these problematic eating behaviors, in order to help to adapt current treatment modalities to meet the unique needs of these women.

AUTHOR CONTRIBUTIONS

Sabrina Schröder: Conceptualization, Formal Analysis, Methodology, Writing – Original Draft Preparation, Writing – Review & Editing

Unna Danner: Conceptualization, Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annelies Spek: Conceptualization, Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annemarie Van Elburg: Conceptualization, Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that is defined by challenges in social communication and social interactions as well as by the occurrence of restricted and repetitive patterns of behavior, interests or activities that persist over the whole course of a person's life (American Psychiatric Association, 2013). A suggested 1.4-1.7% of the general population are autistic (Baron-Cohen et al., 2009; Brugha et al., 2011; D. L. Christensen et al., 2018; Fombonne, 2010; G. Russell et al., 2014). For quite some time, reported male to female ratios are between 12:1 (Fombonne, 2003) and 4:1 (American Psychiatric Association, 2013) but have recently been found to be closer to 3:1 (Loomes et al., 2017), although exact data are still lacking (Lord et al., 2020). But even with women and girls now more often recognized as being on the autism spectrum, they are still thought to be underrepresented and often remain undetected.

Theories on the etiology of ASD such as the Extreme Male Brain Theory (Baron-Cohen, 2002) and the Female Protective Model of Neurodevelopmental Disorders (Jacquemont et al., 2014) have attributed genetic factors to be partly responsible for the overrepresentation of autistic males. However, there has been increasing evidence for a particular female phenotype of ASD (Dworzynski et al., 2012; Hull, Petrides, et al., 2020; G. Russell et al., 2011), suggesting that the female expression of ASD differs from the behavioral expression described in current diagnostic criteria. These criteria form the basis of current standard diagnostic instruments for ASD, which have been developed and validated on the basis of predominantly male populations thought to be autistic (Bastiaansen et al., 2011; Gotham et al., 2007; Lord et al., 1994, 2000). Possibly due to a longstanding male bias towards an understanding of what ASD is and how it manifests (Brown & Stokes, 2020; Lai et al., 2015), autistic girls and women frequently require a more severe presentation of their autistic traits to be recognized (i.e., a more "male" presentation) (Geelhand et al., 2019; G. Russell et al., 2011; Rynkiewicz & Łucka, 2018), and are also often overlooked because of the different expression of their autistic traits; Autistic girls and women are thought to use more strategies to compensate for and mask autistic characteristics during social interaction called camouflaging (Hull, Lai, et al., 2020), present with less restrictive and repetitive behaviors (Hull, Petrides, et al., 2020; Lai et al., 2015; Supekar & Menon, 2015) and different special interests (Halladay et al., 2015). In addition to these traits, autistic females are more likely to appear to have co-occurring internalizing psychiatric problems than their male counterparts such as depression, anxiety, and problems with emotion regulation (Attwood, 2006; Mandy et al., 2012; Oswald et al., 2016), which can cloud the expression of their autistic traits even more.

ASD is associated with significant impairments of an individuals' daily functioning such as having difficulties managing everyday tasks or communicating one's needs, difficulties

with social interaction and interpreting other people's behavior, or processing sensory or cognitive information (Malhi et al., 2017). ASD often co-occurs with a range of physical and psychiatric difficulties, such as gastrointestinal problems (Leader et al., 2021; McElhanon et al., 2014), sleep disturbances (Hare et al., 2006; B. Morgan et al., 2020), depressive and anxiety disorders (Hollocks et al., 2019; Margari et al., 2019) and problems around eating behavior (Marí-Bauset et al., 2014; Sharp, Berry, et al., 2013; Spek et al., 2020).

In recent years, there has been a growing interest in the prevalence and origins of eating or feeding problems frequently seen in autistic individuals, with the great majority of studies focusing on autistic children (Leader et al., 2020; Mayes & Zickgraf, 2019). Between 43.6 and 96% of autistic children are reported to have eating or feeding problems (Margari et al., 2020), more than typically developing children (Malhi et al., 2017) or children with other developmental disorders such as Attention Deficit Hyperactivity Disorder (Mayes & Zickgraf, 2019) or intellectual disability (Crasta et al., 2014; Rastam, 2008). These eating or feeding problems range from being very selective with regards to what they eat or refusing food intake altogether (Bandini et al., 2010), refusing to try out new foods (i.e. food neophobia) (Sun et al., 2013), eating either too much or too little (Geier et al., 2012), exhibiting both emotional over- and undereating (Wallace et al., 2021) or showing behavioral problems around mealtime (Curtin et al., 2015). In autistic individuals with intellectual disabilities, abnormal eating behaviors such as pica, rumination or regurgitation seem to be more prevalent than in autistic individuals without such disabilities (Brown & Stokes, 2020; Gravestock, 2000).

Eating behaviors frequently seen in autistic individuals have been theorized to be the result of a combination of certain cognitive and behavioral patterns characteristic of ASD: cognitive and behavioral rigidity, restricted interests as well as sensory sensitivities (in this case with regards to the properties of food) are considered to underlie these problems (S. S. Christensen et al., 2019; Cooke et al., 2006; Margari et al., 2020; Marí-Bauset et al., 2014). The consequences of these eating behaviors are manifold and have been linked to gastrointestinal problems (Leader et al., 2020), being over- or under-weight (Matheson & Douglas, 2017; Ptomey et al., 2020; Sobanski et al., 1999) and nutrient deficiencies (Zimmer et al., 2012). These eating behaviors have been shown to persist into adolescence and adulthood (Fodstad & Matson, 2008; Lundin Remnélius et al., 2022; Nieminen-von Wendt et al., 2005; Spek et al., 2020), but very little is still known about the eating behaviors and corresponding problems of autistic adults, especially those of women.

Unsurprisingly, autistic men as well as autistic women have been shown to report more eating behaviors frequently seen in ASD compared to controls (Demartini et al., 2021; Spek et al., 2020) and have been described to struggle with being overweight or obese (Ptomey et al., 2020), with some studies reporting a higher prevalence of obesity than in control populations (Croen et al., 2015). Especially autistic women however also seem to struggle with

increased eating disturbances associated with “traditional” eating disorders (henceforth *disordered eating behaviors*), such as a pathological avoidance of certain (fattening) foods (e.g., foods with a high carbohydrate or with a high sugar content) and a desire to be thin, as well as increased bulimic behaviors such as bingeing and purging (Demartini et al., 2021; Karjalainen et al., 2016; Spek et al., 2020), disturbances for which women in general seem to be particularly vulnerable (Micali et al., 2015; Striegel-Moore et al., 2009). Moreover, autistic women have reported more hyperreactivity to sensory information compared to autistic men (Lai et al., 2015; Spek et al., 2020), which might pose an additional vulnerability to developing problematic eating behaviors (i.e., eating behaviors frequently seen in ASD and/or disordered eating behaviors) because of the various sensory properties of food.

However, most studies on problematic eating behaviors of autistic adults either do not provide separate information for men and women (Blomqvist et al., 2015; Demartini et al., 2021; Karjalainen et al., 2016; Karlsson et al., 2013; Nieminen-von Wendt et al., 2005), have included very few female participants (Courty et al., 2013) or have included autistic women with intellectual disability (Lundin Remnélius et al., 2022). To generalize the findings of autistic women with intellectual disabilities to those of autistic women without intellectual disabilities is difficult, since deficits in cognitive functioning might play a bigger role in the development and maintenance of these behaviors in autistic individuals with intellectual disabilities than in autistic individuals without intellectual disabilities (Funayama et al., 2017; Gravestock, 2000; Rastam, 2008). Additionally, in autistic individuals with intellectual disabilities, it is still unclear and difficult to determine which part of the eating or feeding problems is linked to the ASD and which part is linked to the intellectual disability.

The relationship between ASD and problematic eating behaviors in women has mainly been investigated in the literature on EDs where autistic traits have repeatedly been found to be overrepresented in ED populations, especially in women with anorexia nervosa (AN) (Boltri & Sapuppo, 2021; Huke et al., 2013; Westwood & Tchanturia, 2017). Autistic traits have been found to be associated with a more severe clinical presentation of both EDs and other psychopathology on admission of patients with ED (Tchanturia et al., 2019). Additionally, patients with EDs that are on the autistic spectrum report to not profit from “traditional” ED treatments that generally concentrate on a desire to lose weight or a negative body image, while not taking sensory sensitivities into account (Kinnaird, Norton, Stewart, et al., 2019).

Several previous studies have suggested a shared etiopathology between ASD and EDs, as certain behavioral and neurocognitive traits, such as difficulties with emotion recognition and empathic abilities (Kerr-Gaffney, Harrison, et al., 2020; Kerr-Gaffney, Mason, et al., 2020), cognitive inflexibility (Oldershaw et al., 2011; Westwood et al., 2016, 2017b) and repetitive and stereotyped behavior (Pooni et al., 2012), are associated with both ASD and ED. In some ED patients, consequences of the ED, such as being underweight or being in a prolonged

starved state, can lead to reduced cognitive flexibility, increased compulsive behaviors, obsessions and rituals around food, mimicking supposedly autistic traits (Danner, Sanders, et al., 2012; Keys et al., 1950; Tchanturia et al., 2012). It is still not entirely clear whether such similarities persist or get better after nutritional recovery (Miles et al., 2020; Treasure, 2013), making it even more difficult to determine whether these autistic traits are exacerbated by ED psychopathology or in fact warrant a full clinical assessment of ASD (Kinnaird & Tchanturia, 2021). In addition to that, women with AN have been found to show a range of eating behaviors frequently seen in ASD, even after weight gain (Karjalainen et al., 2019).

Still, very little is known about the problematic eating behaviors of autistic women as studies investigating the relationship between autistic traits and problems around eating behavior oftentimes rely on either self-report measures like the Autism Spectrum Quotient (AQ-50; Baron-Cohen et al., 2001) or on various versions of semi-structured assessments like the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2000) to determine the level of autistic traits. While the administration of such measures can be an important first step in the diagnostic process, a full clinical assessment including a thorough investigation of the patient's developmental history is essential to determine whether someone has ASD (NICE, 2012).

The aim of this review is to systematically examine what is currently known about problematic eating behaviors (i.e., eating behaviors frequently seen in ASD and/or disordered eating behaviors) of autistic women as well as their impact on weight. We have opted to concentrate on autistic women without intellectual disabilities, since it is otherwise not possible to determine which part of their eating behaviors is linked to the ASD and which are linked to the intellectual disability. Since both groups would be difficult to compare with regards to problematic eating behaviors, possible results would not be generalizable to both groups.

METHOD

Review Methodology

The primary aim of a scoping review is to identify knowledge gaps and to scope a body of literature (Munn et al., 2018). Given the scarcity of studies about autistic women and the diversity of studies on problematic eating behaviors of autistic women in terms of outcome measures, we opted for a scoping review that is in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Moher et al., 2009; Tricco et al., 2018), with a critical synthesis of the findings instead of a systematic review. A protocol was drafted in accordance with the PRISMA-ScR guidelines (Tricco et al., 2018), which was revised by the research team. The final protocol was not registered beforehand but is available on request from the corresponding author.

Eligibility Criteria

To be included in the review, articles needed to examine or measure any eating-related behavior of women above the age of 18 that have a diagnosis of ASD (e.g. food or eating preferences, eating behaviors frequently seen in ASD, disordered eating behaviors or eating pathology), without intellectual disability. To be as comprehensive as possible with regards to the aim of this scoping review, we also included any studies that examined Body Mass Index (BMI) or weight data in autistic women, in order to investigate whether there is anything known about these eating behaviors and their impact on weight. Another criterion was that the ASD diagnosis had to be obtained or assigned by means of a comprehensive assessment according to DSM-IV or DSM-5 criteria carried out by experienced and trained psychiatrists, psychologists or neurologists (NICE, 2012). Quantitative as well as qualitative studies were eligible for inclusion. Only published and peer-reviewed literature in English, German and Dutch⁴ were considered, without any specific date requirements.

Literature Search Strategy

The literature search was conducted in February 2022. Eligible studies were identified through searches in four electronic databases: Cochrane, Medline, PsychINFO and PubMed. Given the lack of studies on autistic women above the age of 18, we opted for a very broadly defined search strategy so as to not miss any study that has been done on autistic women and anything possibly relating to their eating behaviors. In consultation with a librarian from Utrecht University and after peer-review from the research team, queries were developed and adapted for each electronic database, using a combination of keywords relevant to women, ASD and eating behaviors. Boolean operators (AND, OR, NOT) were used to combine these keywords to result in a more focused search. The full queries for all electronic databases can be found in the appendix.

For Medline: “exp Feeding Behavior/ OR exp “Feeding and Eating Disorders”/ OR exp Food Fussiness/ OR exp Food Preferences/ OR exp Food/ OR exp Eating/ OR exp Meals/ OR exp Diet/ OR exp Pica/ OR exp Rumination Syndrome/ OR exp Avoidant Restrictive Food Intake Disorder/ OR exp Anorexia/ OR exp Bulimia/ OR exp Binge-Eating-Disorder/ OR exp body weight/ OR exp Obesity/ OR exp Body Weight/ OR exp Body Mass Index/ OR eating*.mp OR feed*.mp OR food*.mp OR meal*.mp OR nutrition*.mp OR diet*.mp OR obes*.mp OR anorexia*.mp OR bulimia*.mp OR binge*.mp OR pica*.mp OR orthorexia*.mp OR ARFID*.mp OR ruminati*.mp AND exp Women/ OR exp Adult/ OR exp Female/ OR women*.mp OR woman*.mp OR female*.mp OR adult*.mp AND exp Autism Spectrum Disorder/ OR exp Autistic Disorder/ OR exp Asperger Syndrome/ OR exp Child Development Disorders, Pervasive/ OR autis*.mp OR asperger*.mp”

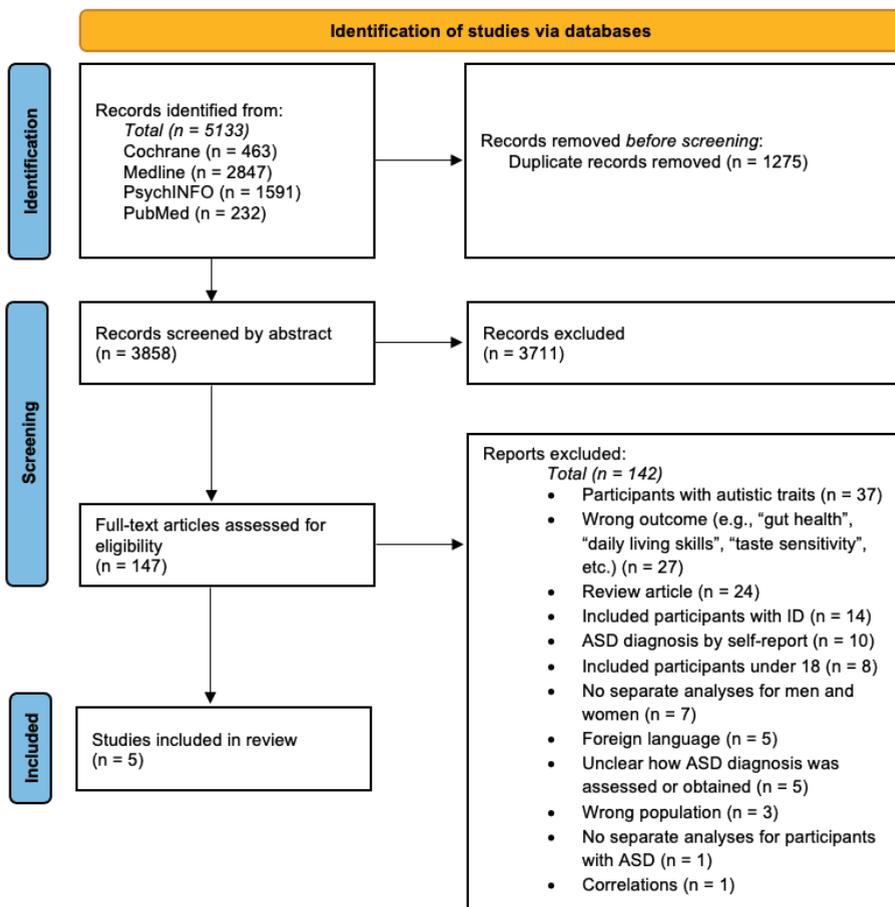
⁴ The first author is of German origin and fluent in all three languages.

Study Selection

The search strategy yielded a total of 5133 articles, which were exported into EndNote Reference Manager. After duplicates were removed, a total of 3858 records remained: 360 records from Cochrane, 2150 from Medline, 1207 from PsychINFO and 141 from PubMed. To ensure that no article was missed, we additionally scanned reference lists of various review articles retrieved through the database searches (e.g., Boltri & Sapuppo, 2021; Carpita et al., 2022; Ledford et al., 2018; Nickel et al., 2019) to identify possible articles that were not included by means of the search queries, but no new articles were retrieved this way. We resolved disagreements on study selection and data extraction by consensus. The PRISMA flow diagram of the selection process is presented in **Figure 2.1**.

Figure 2.1

Selection Process: PRISMA Flow Diagram.



After screening titles and abstracts according to eligibility criteria, a total of 3711 were excluded. The main reasons for exclusion at this point were: studies that included only autistic men or children, articles that did not focus on eating behaviors, studies that did not specify eating behaviors and studies that were in other ways not relevant to review.

A total of 147 full-text articles were then thoroughly examined, of which 142 were excluded for the following reasons: studies of participants with autistic traits instead of having an ASD diagnosis or where it was unclear whether participants qualified for an ASD diagnosis, studies that relied on self-report of the ASD diagnosis instead of a comprehensive assessment including a developmental analysis, studies with insufficient information on how the ASD diagnosis was obtained or assessed⁵, articles without outcome data on eating behavior or BMI/weight data, studies of autistic participants and intellectual disability (without separate analyses), studies of autistic men and women without separate analyses for women and correlational relationships between ASD and eating behavior without separate data of eating behavior in autistic women. For an overview of reasons for exclusion, please see the lowest box on the right in **Figure 2.1**.

Data Charting

After the selection of studies and after the researchers decided conjunctively on how the data was going to be charted, data for the following variables were extracted independently from each study: author(s), year of publication, aim, design, number of participants, gender of participants, percentage of female participants, mean age of participants, BMI, outcome measures of eating related behaviors and key findings. If any information was unclear, the authors of those articles were contacted to clarify.

Synthesis of Results

Studies were grouped by the types of problematic eating behavior measures as well as by eating related outcomes such as weight and BMI. We summarized the type of study design and population, the measures that were used to examine eating related behavior or weight and BMI, as well as the broad findings of the study.

5 When unclear, we contacted the authors of the relevant articles to elaborate on the diagnostic process of determining the ASD diagnosis described in the study or how the ASD diagnosis was assigned or obtained to be included in this review.

RESULTS

Study Characteristics

As can be seen in **Table 2.1**, a total of five studies assessing problematic eating behaviors or BMI and body composition data of autistic women were identified in the current scientific literature and included in this scoping review. All studies were published within the last four years by research groups from the United Kingdom, the Netherlands, Spain, Sweden, and Italy. Four studies, three cross sectional studies and one case study, assessed eating behaviors as measured by self-report questionnaires pertaining to eating behaviors frequently seen in ASD (Karjalainen et al., 2019; Nisticò et al., 2022; Spek et al., 2020) as well as disordered eating behaviors and eating pathology (Dandil, Baillie, et al., 2020; Nisticò et al., 2022). Three of these studies also reported on BMI data (Dandil, Baillie, et al., 2020; Karjalainen et al., 2019; Nisticò et al., 2022). One study, with a cross sectional design, merely assessed BMI data without looking at specific eating behaviors (Garcia-Pastor et al., 2019).

Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
Nisticò et al. (2021)	Comparing ED patients, autistic individuals and CW on measures detecting symptoms of eating disorders and eating disturbances known to be characteristic of ASD	Observational, cross-sectional study	34 women with ED (15 ANR, 7 BN, 12 BED) 34 autistic women 35 CW	ED = 30.82 (13.1) ASD = 37.88 (12.98) CW = 35.66 (12.15)	ASDs were diagnosed by a psychiatrist and psychologist according to DSM-5 criteria and module four of the ADOS-2	BMI EAT-26 SWEAA	BMI (SD) ED = 21.74 (6.85), range: AN (14 - 18.87), BN (18.8 - 26.49), BED (19 - 41.54) ASD = 23.35 (4.98), range: 17.65 - 35.1 CW = 21.68 (3.26), range: 17.67 - 31.55 No sig. difference between ASD and ED No sig. difference between ASD and CW EAT-26 Total Score ED = 21.68 (17.2) ASD = 11.76 (12.383) CW = 3.34 (3.6) ASD < ED ($p = 0.008$) ASD > CW ($p = 0.008$) No sig. effect of BMI EAT-26 subscales <i>Dieting:</i> ED = 11.82 (9.39) ASD = 7.5 (7.88) CW = 2.49 (2.55) ASD > CW ($p = 0.01$) No sig. differences between ASD and ED <i>Bulimia and Food Preoccupation:</i> ED = 4.88 (4.38) ASD = 2.5 (3.51) CW = 0.29 (0.79) ASD < ED ($p = 0.013$) ASD > CW ($p = 0.016$)

Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
							<p><i>Oral Control:</i> ED = 4.97 (5.74) ASD = 1.76 (3.66) CW = 0.57 (1.36) ASD < ED ($p = 0.01$) No sig. differences between ASD and CW</p> <p>Neg. correlation between BMI and subscale oral control</p> <p>SWEAA Total Score ED = 28.65 (14.47) ASD = 31.25 (12.24) CW = 16.6 (6.64) ASD > CW ($p < 0.001$) No sig. differences between ASD and ED No sig. effect of BMI</p> <p>SWEAA subscales <i>Perception:</i> ED = 1.09 (0.82) ASD = 1.63 (0.69) CW = 0.83 (0.55) ASD > ED ($p = 0.004$) ASD > CW ($p < 0.001$)</p> <p><i>Motor Control:</i> ED = 0.58 (0.56) ASD = 0.82 (0.057) CW = 0.42 (0.32) ASD > CW ($p = 0.004$) No sig. differences between ASD and ED</p>

Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
							<p><i>Purchase of Food:</i> ED = 1.95 (0.85) ASD = 2.03 (1.07) CW = 1.49 (0.65) ASD > CW ($p = 0.045$) No sig. differences between ASD and ED</p> <p><i>Eating Behavior:</i> ED = 1.52 (0.79) ASD = 1.41 (0.75) CW = 0.81 (0.43) ASD > CW ($p < 0.0001$) No sig. differences between ASD and ED</p> <p><i>Mealtime Surroundings:</i> ED = 1.52 (0.97) ASD = 1.52 (0.79) CW = 0.53 (0.42) ASD > CW ($p < 0.0001$) No sig. differences between ASD and ED</p> <p><i>Social Situation at Mealtime:</i> ED = 1.21 (0.48) ASD = 1.45 (0.55) CW = 0.96 (0.38) ASD > CW ($p < 0.0001$) No sig. difference between ASD and ED</p> <p><i>Other Behavior Associated with Disturbed Eating Behavior:</i> ED = 0.62 (0.55) ASD = 0.4 (0.34) CW = 0.21 (0.22) No sig. differences between ASD and ED No sig. differences between ASD and CW</p>

Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
							<p><i>Hunger/Satiety:</i> ED = 1.49 (0.9) ASD = 1.03 (0.91) CW = 0.6 (0.53) No sig. differences between ASD and ED No sig. differences between ASD and CW</p> <p><i>Simultaneous Capacity:</i> ED = 0.68 (1.07) ASD = 1 (1.21) CW = 0.17 (0.45) ASD > CW ($p = 0.001$) No sig. differences between ASD and ED</p> <p><i>PICA:</i> ED = 9.24 (0.7) ASD = 0.15 (0.5) CW = 0 (0) No sig. differences between ASD and ED No sig. differences between ASD and CW</p> <p>No sig. effect of BMI on any subscale</p>

Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
Spek et al. (2019)	To assess eating problems in autistic men (with and without housing support) and autistic women and compare their results to control women and men	Observational, cross-sectional study	53 autistic men (30 without housing support, 23 with housing support) 36 autistic women 30 CW 38 CW	Autistic men (with support) = 35.2 (12.7) Autistic men (without support) = 40.7 (12.4) Autistic women = 38.8 (10.9) CM = 38 (13.2) CW = 34.4 (13.5)	ASDs were recruited via an outpatient center and Lister <i>Outpatient Center:</i> ASDs were all diagnosed by trained psychologist or psychiatrist according to DSM-IV or DSM-5 criteria, by means of a semi-structured interview according to DSM-5 ASD criteria and the ADI-R (All autistic women came from the outpatient center)	SWEAA SWEAA Total Score ASD women = 127.8 (33.9) CW = 99.9 (13.5) ASD men = 115.8 (24.8) ASD women > CW ($p < 0.001$) No sig. difference between ASD women and ASD men	SWEAA Total Score ASD women = 127.8 (33.9) CW = 99.9 (13.5) ASD men = 115.8 (24.8) ASD women > CW ($p < 0.001$) SWEAA subscales <i>Perception:</i> ASD women = 26.4 (8.9) CW = 20.6 (4.9) ASD men = 22.5 (6.0) ASD women > CW ($p < 0.001$) ASD women > ASD men ($p = 0.036$) <i>Motor Control:</i> ASD women = 11.4 (3.7) CW = 11.1 (2.6) ASD men = 13.1 (3.8) ASD women < ASD men ($p = 0.049$) No sig. difference between ASD women and CW <i>Purchase of Food:</i> ASD women = 10.1 (2.9) CW = 8.2 (1.9) ASD men = 8.3 (2.9) ASD women > CW ($p = 0.004$) ASD women > ASD men ($p = 0.014$) <i>Eating Behavior:</i> ASD women = 13.2 (4.8) CW = 10.6 (2.7) ASD men = 12.6 (4.7) ASD women > CW ($p = 0.007$) No sig. difference between ASD women and ASD men



Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
							<p><i>Mealtime Surroundings:</i> ASD women = 24 (10.1) CW = 14.6 (3.5) ASD men = 19 (7.6) ASD women > CW ($p < 0.001$) No difference between ASD women and ASD men</p> <p><i>Social Situation at Mealtime:</i> ASD women = 24.2 (4.6) CW = 19.9 (5.3) ASD men = 23.4 (4.8) ASD women > CW ($p < 0.001$) No difference between ASD women and ASD men</p> <p><i>Other Behavior Associated with Disturbed Eating Behavior:</i> ASD women = 10.5 (3.9) CW = 8.8 (1.2) ASD men = 9.2 (2.8) ASD women > CW ($p = 0.012$) No sig. difference between ASD women and ASD men</p> <p><i>Hunger/Satiety:</i> ASD women = 4.6 (1.7) CW = 3.8 (1.5) ASD men = 3.9 (1.8) ASD women > CW ($p = 0.043$) No sig. difference between ASD women and ASD men</p> <p><i>Simultaneous Capacity:</i> ASD women = 2.4 (1.4) CW = 1.2 (0.6) ASD men = 2.6 (1.6) ASD women > CW ($p < 0.001$) No difference between ASD women and ASD men</p>

Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
Karjalainen et al. (2019)	To examine the occurrence of eating behaviors frequently seen in ASD among adolescents and young adults with AN	Observational, cross-sectional study	36 females with AN-C (current) 32 females with AN-1 yr (AN-C after 1 year follow up) 19 autistic females 30 CW	AN-C = 19.6 (2.23), range: 15 – 24 AN-1 yr = 20.7 (2.30), range: 16.2 – 25.1 ASD = 18.5 (3.41), range: 15 – 24 (7 under 18 years old) CW = 18 (2.47), range: 15 – 23	Autistic patients had been thoroughly neuropsychiatrically and neuropsychologically evaluated. ASD diagnoses were assigned on DSM-IV criteria (which were the criteria in place at the time)	BMI SWEAA	<i>P</i> < .05: ASD women = 1.0 (0.2) CW = 1 (0) ASD men = 1.1 (0.4) No difference between ASD women and CW No difference between ASD women and ASD men BMI AN-C = 16.1 (0.89), range: 14 – 17.5 AN-1 yr = 18.2 (1.66), range: 16.2 – 25.1, (n = 31) ASD = 23.2 (5.49), range: 15.75 – 36.89 CW = 21.3 (2.18), range: 17.4 – 26.1 ASD < AN-C (<i>p</i> < 0.001) SWEAA Total Score AN-C = 32 (13.8), range: 8 – 56 AN-1 yr = 25.6 (13.4), range: 5 – 53 ASD = 22.3 (16.0), range: 3 – 55 CW = 11 (3.65), range: 2 – 25 ASD > CW (<i>p</i> < 0.01) ASD < AN-C (<i>p</i> = 0.013) SWEAA BTSD score AN-C = 28 (18.3), range: 6.25 – 72.5 AN-1 yr = 25 (17.2), range: 3.75 – 63.75 ASD = 21.8 (15.8), range: 2.5 – 53.75 CW = 8.83 (4.63), range: 1.25 – 25 ASD > CW (<i>p</i> < 0.001) No sig. difference between ASD and AN-C No correlation between BMI and SWEAA total score or BTSD score
<p>Variables Best Discriminating Between AN-C And ASD (AN-C scoring higher than ASD on all items) Item C3: Multivariable adjusted OR (95% CI) = 2.18 (1.28 – 3.74), area under ROC curve = 0.85, <i>p</i> < 0.01 Items G4: Multivariable adjusted OR (95% CI) = 2.55 (1.12 – 5.80), area under ROC curve = 0.80, <i>p</i> < 0.05</p>							



Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
Dandilet al. (2020)	To provide preliminary evidence to support the efficacy of individual CRT in the treatment of a 21-year-old autistic patient with comorbid AN	Single complex case study	1 autistic female with AN	21 years	Patient was diagnosed with ASD at age 11 in a specialist ASD clinical service. On admission to the inpatient ward, patient completed Module 4 of the ADOS-2, administered by a trained researcher	BMI (calculated before, during and after CRT intervention) EDEQ (calculated before and after CRT intervention)	<p>BMI</p> <ul style="list-style-type: none"> On admission = 14.1 Time 1 (before CRT) = 13.5 Time 2 (after CRT) = 14.5 <p>EDE-Q Global Score</p> <ul style="list-style-type: none"> Time 1 (before CRT) = 5.1 Time 2 (after CRT) = 4.8 <p>Complaints Before CRT</p> <ul style="list-style-type: none"> Eating difficulties following weight gain from chemotherapy and comfort eating (BMI then 30.1) Struggling to manage and maintain weight Overfocus on weight and shape, no target weight but wanting weight to get lower and lower Restriction of food intake “Obsessed” with being healthy Over-exercising, exercising every day Abusing laxatives (“easy way to eat and not keep the food in my body”) <p>Eating Behavior After CRT</p> <ul style="list-style-type: none"> Willingness to eat increased during CRT

Table 2.1 Studies Examining Eating Behavior in Autistic Women.

Study	Aim	Design	N	Mean age (SD)	ASD Assessment	Eating Behavior and Related Outcomes	Main Findings
Garcia-Pastoral (2019)	To compare body composition and physical activity level between autistic children and adults	Observational, cross-sectional study	Autistic women = 11 Autistic men = 23 Young autistic girls = 7 Young autistic boys = 22 Autistic girls = 4 Autistic boys = 11	Autistic women = 28.36 (5.14) Autistic men = 32.39 (7.27) Young autistic girls = 9.43 (1.90) Young autistic boys = 9.41 (1.47) Autistic girls = 13.75 (0.96) Autistic boys = 15.73 (1.74)	All participants had received a clinical diagnosis of ASD from an experienced and recognized psychiatrist or neurologist according to DSM-5 criteria. Individuals met clinical cut-off scores for ASD by either ADOS-2 or ADI-R	BMI Overweight/obesity (%) Body fat (%)	BMI ASD women = 23.65 (4.61) ASD men = 27.18 (4.43) Young ASD girls = 19.09 (2.42) Young ASD boys = 17.96 (4.70) ASD girls = 24.78 (6.48) ASD boys = 23.20 (5.11) ASD women < ASD men ($p < 0.05$) Overweight + Obesity (%) ASD women = 36.4% ASD men = 73.9% Young ASD girls = 14.3% Young ASD boys = 13.6% ASD girls = 75% ASD boys = 9.1% ASD women < ASD men ($p < 0.05$) Obesity (%) ASD women = 9.1% ASD men = 17.4% Young ASD girls = 0% Young ASD boys = 9.1% ASD girls = 25% ASD boys = 9.1% Body Fat (%) ASD women = 29.59 (7.41) ASD men = 22.12 (7.32) Young ASD girls = 26.18 (2.54) Young ASD boys = 19.55 (8.03) ASD girls = 32.93 (11.69) ASD boys = 18.59 (6.57) ASD women > ASD men ($p < 0.05$)

Note: ADI, autism diagnostic interview; ADOS, autism diagnostic observation schedule; AN, anorexia nervosa; ASD, autism spectrum disorder; BED, binge eating disorder; BMI, body mass index; BN, bulimia nervosa; BTSD, best two subscale discriminating score; CRT, cognitive remediation therapy; CW, control women; EAT, eating attitudes test; ED, eating disorders; EDE-Q, eating disorder examination questionnaire; SWEAA, Swedish eating assessment for autism spectrum disorders.

Across all studies, a total of 94 adult women above the age of 18 were included in the studies, with one study including seven participants under the age of 18. All participants were thoroughly assessed and diagnosed according to either DSM-IV or DSM-5 ASD criteria (American Psychiatric Association, 2013) by a psychologist or psychiatrist with regards to their ASD. Four studies also applied a standardized diagnostic instrument such as the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al., 2003), or ADOS-2 (Lord et al., 2012) to aid in the diagnostic process (Dandil, Baillie, et al., 2020; Garcia-Pastor et al., 2019; Nisticò et al., 2022; Spek et al., 2020). One study additionally ensured that the autistic participants had never received a diagnosis of EDs (Nisticò et al., 2022), presumably in order to attribute any findings regarding eating behaviors frequently seen in ASD and disordered eating behaviors to the ASD and not to an underlying ED. The case study included a participant with both ASD and a diagnosis of AN (Dandil, Baillie, et al., 2020). The three other studies did not assess whether the autistic participants had a current or a lifetime ED. Four studies also included other psychiatric or control groups: One study included a group of EDs and a control group (Nisticò et al., 2022), another a group of autistic men as well as female and male control groups (Spek et al., 2020), another included two AN groups (current and after 1 year follow-up) as well as a control group (Karjalainen et al., 2019), and another included a group of autistic men as well as a group of autistic children and adolescents (Garcia-Pastor et al., 2019).

Different Measures of Problematic Eating Behaviors

A total of 3 different measures were used in the included studies to examine problematic eating behaviors in autistic women: the Swedish Eating Assessment for Autism Spectrum Disorders (SWEAA; Karlsson et al., 2013), the Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994) and the Eating Attitudes Test - 26 item (EAT-26; Garner et al., 1982).

Nisticò et al. (2022) compared eating behaviors frequently seen in ASD and disordered eating behaviors between autistic women, women with EDs (including women with AN, bulimia nervosa (BN) and binge eating disorder (BED)) and control women by means of the SWEAA and the EAT-26. In the study done by Spek et al. (2020), eating behaviors frequently seen in ASD were examined in autistic women and compared to autistic men as well as to a group of control women by means of the SWEAA. Karjalainen et al. (2019) compared the occurrence of eating behaviors frequently seen in ASD across three groups, women with AN (current and after 1 year follow-up), autistic women and control women, also by means of the SWEAA⁶. This is the only study included in this review that also included girls under the age of 18 in the ASD group. The case study of a young autistic woman with comorbid AN by

6 Apart from SWEAA total scores, Karjalainen et al. (2019) did not report any separate SWEAA subscale scores. Instead, to find independent variables best discriminating between the ASD group and the AN-C group, they identified the most significant univariable and multivariable variables through logistic regression analyses. On all these items, the AN-C group scored higher than the ASD group.

Dandil, Baillie, et al. (2020) investigated the effects of Cognitive Remediation Therapy (CRT) as a feasible treatment for supporting autistic adults with AN, examining disordered eating behaviors by means of the EDE-Q before and after individual CRT.

SWEAA

The SWEAA is a self-report measure including a total of 65 items across 10 subscales to examine eating problems specifically in adult ASD populations without intellectual difficulties with high reliability and validity (Karlsson et al., 2013). Items are answered on a five-point Likert scale from “never correct” to “always correct”, with higher scores indicating more overall eating behavior frequently seen in ASD. Authors of papers using the SWEAA seem to apply different scoring methods, with the original paper by Karlsson et al. (2013) using a Likert scale of 1 to 5, and calculating the mean for each subscale, then transforming the mean into a scale from 0 to 100 (0 is the lowest and 100 is the highest possible answer on all items) by multiplying the obtained mean by 25. Karjalainen et al. (2019) apply the same strategy recommended by the original authors, whereas Nisticò et al. (2022) make use of the same method of calculation, but instead chose for a Likert scale ranging from 0 to 4. Spek et al. (2020) on the other hand apply a different method, by simply adding up the scores per subscale for subscale scores, then adding those up to a total score. Karjalainen et al. (2019) used a self-calculated cut-off score of 12 to measure overall eating behavior frequently seen in ASD.

EAT-26

The EAT-26 is a standardized self-report measure with 26 items across three subscales to assess symptoms and concerns characteristic of EDs such as AN and BN (Garner et al., 1982). Items are rated on a six-point Likert scale, ranging from “always” to “never”, with higher scores indicating more severe eating pathology. Scores range between 0 and 78, with a score of 20 or above warranting a thorough examination whether the individual meets the diagnostic criteria of an ED. The questionnaire has been deemed reliable and valid (Garner et al., 1982; Mintz & O’Halloran, 2000; Rivas et al., 2010) and has been a successful screening tool in the risk assessment of EDs in various populations (Garner et al., 1998; Lee et al., 2002; Orbitello et al., 2006).

EDE-Q

The EDE-Q is a highly reliable and valid self-report measure of eating pathology, including disordered eating behaviors and attitudes (Berg et al., 2012; Fairburn & Beglin, 1994), consisting of 22 items across four subscales. Items are rated on a seven-point Likert scale ranging from 0 to 6, with higher scores indicating greater eating pathology. Subscores are obtained by adding up the relevant items per subscale and dividing by the total number of items per subscale. The total score is calculated by adding the subscale scores and dividing that by the number of subscales.

Eating Behaviors Frequently Seen in ASD (by Means of the SWEAA)

Overall Eating Behavior Frequently Seen in ASD

When looking at overall eating behavior frequently seen in ASD (as measured by the SWEAA total score), Karjalainen et al. (2019) found that currently ill women with AN scored significantly higher than autistic women, thus reporting more overall eating behavior frequently seen in ASD (here, no comparison was made between autistic women and women with AN after 1 year follow-up). Nisticò et al. (2022) on the other hand did not confirm this finding: both women with EDs and autistic women in this study displayed similar levels of overall eating behavior frequently seen in ASD. Across all studies included in this review that compared autistic women to control women, autistic women reported significantly more overall eating behavior frequently seen in ASD than control women (Karjalainen et al., 2019; Nisticò et al., 2022; Spek et al., 2020). Spek et al. (2020), the only study in this review directly comparing autistic women with autistic men, found no differences between the two groups with regards to overall eating behavior frequently seen in ASD. In Karjalainen et al. (2019), both autistic women as well as both AN groups scored well above the cut-off score of 12 applied in this study showing very high levels of overall eating behavior frequently seen in ASD. These eating behaviors subsided in women with AN at the one-year follow-up.

Sensory Sensitivities

Autistic women reported significantly more sensitivities regarding the sensory properties of food, such as smell, texture, and taste (as measured by the SWEAA subscale *perception*) compared to women with EDs (Nisticò et al., 2022), control women (Nisticò et al., 2022; Spek et al., 2020) and autistic men (Spek et al., 2020).

Motor Control Problems

With regards to problems with motor control that can influence eating behavior (e.g., problems with chewing or drooling, as measured by the SWEAA subscale *motor control*), autistic women reported similar levels of difficulties compared to women with ED (Nisticò et al., 2022). Compared to control women, autistic women reported significantly more difficulties with motor control in Nisticò et al. (2022), but similar levels of difficulties in Spek et al. (2020). In comparison with autistic men on the other hand, autistic women reported less problems with motor control (Spek et al., 2020).

Preferences for Brands of Food

Autistic women also reported similar preferences with regards to brands of food (as measured by the SWEAA subscale *purchase of food*) as women with EDs (Nisticò et al., 2022), and significantly more preferences than control women (Nisticò et al., 2022; Spek et al., 2020) and autistic men (Spek et al., 2020). In Karjalainen et al. (2019), women with AN, rather than autistic women, reported more concerns with regards to control of purchases

(as measured by item C3⁷ on the SWEAA, one of two SWEAA items best discriminating between the two groups in this study).

Food Selectivity

When looking at selectivities with eating such as a preference for certain food items or difficulties trying out new foods (as measured by the SWEAA subscale *eating behavior*), autistic women again reported similar levels compared to women with EDs (Nisticò et al., 2022) and autistic men (Spek et al., 2020) and higher levels than control women (Nisticò et al., 2022; Spek et al., 2020).

Routines Around Mealtime

Autistic women reported similar levels of rituals and routines around mealtimes (e.g., where to eat, where the cutlery is placed) (as measured by the SWEAA subscale *mealtime surroundings*) compared to women with EDs and autistic men, while reporting significantly more rituals and routines than control women (Nisticò et al., 2022; Spek et al., 2020).

Social Situations During Mealtimes

With regards to experiencing difficulties adapting one's eating behavior to other people during the eating situation (e.g., preference for eating alone) (as measured by the SWEAA subscale *social situations at mealtime*), again, autistic women reported similar difficulties as women with EDs and autistic men, but significantly more difficulties than control women (Nisticò et al., 2022; Spek et al., 2020).

Disordered Eating Behaviors

Similar levels of behaviors associated with "traditional" EDs (e.g., vomiting after meals, laxative abuse or restriction of food) (as measured by the SWEAA subscale *other behavior associated with disturbed eating*) were found in autistic women compared to women with EDs as well as compared to autistic men (Nisticò et al., 2022; Spek et al., 2020). Compared to control women, autistic women reported higher levels of disordered eating behaviors (Spek et al., 2020). In Karjalainen et al. (2019), women with AN, rather than autistic women, reported more dieting behavior (as measured by item G4⁸ on the SWEAA, one of two SWEAA items best discriminating between the two groups in this study).

Recognizing Hunger or Satiety

Regarding problems recognizing one's hunger or satiation (as measured by the SWEAA subscale *hunger/satiety*), autistic women report similar levels of difficulties compared to women with EDs and autistic men (Nisticò et al., 2022; Spek et al., 2020) and significantly more problems than control women in Spek et al. (2020), but not in Nisticò et al. (2022).

7 C3: "If I buy food with someone else, I want to check what goods are purchased."

8 G4: "I diet even if other people think I am too thin."

Simultaneous Capacity

When looking at difficulties doing two things at once (e.g., chewing and cutting food) (as measured by the SWEAA subscale *simultaneous capacity*), autistic women report similar levels of difficulties compared to women with EDs and autistic men (Nisticò et al., 2022; Spek et al., 2020) but significantly more difficulties compared to control women (Nisticò et al., 2022; Spek et al., 2020).

Pica

No differences were found regarding the consumption of non-edible items (e.g., soil or mortar) (as measured by the SWEAA subscale *pica*) between autistic women compared to women with EDs (Nisticò et al., 2022), compared to autistic men (Spek et al., 2020) or control women (Nisticò et al., 2022; Spek et al., 2020).

SWEAA – Best Discriminating Score

Apart from investigating overall eating behavior frequently seen in ASD, as measured by means of the SWEAA total score, Karjalainen et al. (2019) calculated another cut-off score, targeting those subscales (social situation at mealtime and simultaneous activity) with items that best discriminate between autistic individuals and a healthy comparison group, (i.e., best two subscale discriminating score (BTSD score), based on the means score from these subscales), where a cut-off value of 10 was determined through Stepwise logistic regression analysis. According to this BTSD score, autistic women reported similar levels of difficulties adapting their eating behavior to other people present during mealtimes as well as having difficulties doing two things at once compared with women currently ill with AN. Here, autistic women scored significantly higher than control women. Autistic women and women with AN (both current and after one year follow-up) scored well above the cut-off score on the BTSD score. In women with AN, there was no decrease in these specific eating behaviors (as measured by the BTSD score) at one year follow-up.

Disordered Eating Behaviors and Eating Pathology (by Means of the EAT-26)

Severity of Eating Pathology

In Nisticò et al. (2022), autistic women reported significantly less overall disordered eating behaviors (as measured by the EAT-26 total score) and thus less severe eating pathology than women with EDs, but significantly more than control women. Overall, autistic women scored well below the suggested cut-off score of 20, compared to women with EDs, who did reach the overall cut-off score with regards to severity of eating pathology.

Dieting

When looking at a pathological avoidance of certain (fattening) foods (e.g., foods with a high carbohydrate or with a high sugar content), a dissatisfaction with one's body size and subsequent desire to be thin (as measured by the EAT-26 subscale *dieting*), autistic women

reported similar levels as women with EDs, and with significantly higher levels than control women (Nisticò et al., 2022).

Bulimic Behaviors and Food Preoccupation

Autistic women displayed significantly fewer bulimic behaviors (e.g., bingeing and purging behavior) and less preoccupation with food (as measured by the EAT-26 subscale *bulimia and food preoccupation*) compared to women with EDs, but significantly more than control women (Nisticò et al., 2022).

Food Restriction

Autistic women reported significantly less food restriction and acknowledgement of a social pressure to gain weight (as measured by the EAT-26 subscale oral control) compared to women with EDs and similar levels as control women (Nisticò et al., 2022).

Disordered Eating Behaviors and Eating Pathology (by Means of the EDE-Q)

Severity of Eating Pathology

In Dandil, Baillie, et al. (2020), the underweight patient (BMI 14.1 kg/m² on admission) was described to have developed difficulties with eating difficulties after gaining weight from chemotherapy and engaging in comfort eating in an effort to regulate difficult emotional feelings, which resulted in a BMI of then 30.1 kg/m². The patient subsequently described becoming obsessed with being “healthy”, having an overfocus on her weight and shape, over exercising, abusing laxatives and restricting her food intake. She told the interviewer that she held her being autistic accountable for her fixation and rigidity with regards to engaging in certain exercises every day and the restriction of food. On the global score of the EDE-Q⁹, the patient scored 5.1. To put this into context, the global score from a community sample of women is 1.5 (Fairburn & Beglin, 1994). After 13 CRT sessions, the patient’s willingness to eat increased, the global score of the EDE-Q dropped down to 4.8 and her BMI increased from 13.5 kg/m² before CRT (but after admission) to 14.5 kg/m² after CRT, so still in the very severe range. The authors of this paper concluded that the results of this case study provide preliminary support for the feasibility of individual CRT in supporting autistic adults with comorbid AN to address rigid thinking styles, before proceeding to more complex therapies targeting disordered eating behaviors.

BMI and Body Composition of Autistic Women

The study of Garcia-Pastor et al. (2019) is the only study that provided separate BMI and body composition data of autistic women without intellectual disability, without including any measures of general or problematic eating behaviors. Here, body composition data was compared between autistic men and women as well as between autistic children and adolescents. Autistic men had a significantly higher BMI than autistic women and were more

⁹ Apart from EDE-Q total score, Dandil et al. (2020) did not report any EDE-Q subscale scores.

often overweight or obese. Autistic women on the other hand had a significantly higher body fat percentage than autistic men. In Nisticò et al. (2022), BMI was compared between autistic women, women with an ED and control women. Here, no significant differences were found between autistic women and women with an ED, and between autistic women and control women. In Karjalainen et al. (2019), BMI was compared between autistic women and women currently ill with AN, with autistic women having a significantly higher BMI than women currently ill with AN.

DISCUSSION

To our knowledge, this is the first scoping review examining the state of knowledge regarding problematic eating behaviors of autistic women without intellectual difficulties. Even though there seems to be a growing interest in the interplay between ASD and problematic eating behaviors, very little is still known about how and why autistic women experience such problems, possibly causing significant impairments in daily life functioning. Across four of the included studies, autistic women demonstrated high levels of problematic eating behaviors typically associated with ASD as well as high levels of disordered eating and eating pathology. This suggests that the eating problems frequently found in autistic girls might persist into adulthood, which gives rise to the assumption that autistic women might be especially vulnerable to develop a range of disordered eating behaviors or already suffer from (undetected) EDs (Margari et al., 2020; Spek et al., 2020).

Problematic Eating Behaviors of Autistic Women

Across the included studies, autistic women reported having eating behaviors frequently seen in ASD such as having problems with sensitivities regarding the sensory properties of food, having rituals and routines around mealtimes, having difficulties adapting one's behavior to other people present during the eating situation and having preferences with regards to brands of food, which is in line with findings of previous research (Demartini et al., 2021; Karjalainen et al., 2016; Margari et al., 2020; Nieminen-von Wendt et al., 2005). Additionally, they reported disordered eating behaviors, such as a pathological avoidance of foods with a high carbohydrate or sugar content, a desire to be thin, a dissatisfaction with their body, as well as bulimic behaviors and a preoccupation with food, all on severity levels similar, though not quite like those of women with EDs.

Specific ASD related characteristics and processes are likely to play a role in the development and maintenance of these behaviors, such as difficulties in sensory processing and engagement in restrictive and repetitive behaviors, though it is not entirely clear which of these characteristics is specifically related to problematic eating behaviors in autistic women. Up to 90% of autistic adults experience difficulties in their sensory processing

(Crane et al., 2009; Leekam et al., 2007; Tavassoli et al., 2014; Taylor et al., 2020), with some reporting sensory avoiding behaviors (hyperreactivity) and some reporting sensory seeking behaviors (hyporeactivity) (Crane et al., 2009). These difficulties in sensory processing could subsequently result in the avoidance of certain food items because of their sensory properties (e.g., texture, smell, taste), food selectivity, food neophobia or in contrast to engaging in over-consumption of certain food items because of their sensory properties. Especially autistic women have been suggested to be impacted by difficulties in sensory processing, more so than autistic men (Lai et al., 2011). This is reflected by the findings of studies included in this review, where autistic women reported high levels of sensory sensitivities specifically related to food, more so than autistic men (Spek et al., 2020), women with EDs (Nisticò et al., 2022) and more than control women (Nisticò et al., 2022; Spek et al., 2020). These differences in levels of sensory sensitivities however, as Spek et al. (2020) discovered, did not lead to large discrepancies in the level of overall eating behavior frequently seen in ASD in autistic women and men they expected, where autistic women were expected to experience more eating behaviors frequently seen in ASD than autistic men. This raises the question whether sensory sensitivities might play less a role than previously assumed. In view of this, Bitsika & Sharpley (2018) found that rather restrictive and repetitive behaviors, not difficulties in sensory processing, were significant predictors of disordered eating in a sample of high functioning autistic girls. They proposed that the girls' behavioral rigidity and restricted range of interests was more relevant in the development and maintenance of their disordered eating habits than difficulties in sensory processing. And even though restrictive and repetitive behaviors are thought to be more common in autistic men (Wilson et al., 2016), it could be that behaviors such as having preferences for a particular food brand (i.e., behavioral rigidity) or engaging in dieting behavior (i.e., being busy with food/not eating as a specific and restricted interest) are yet another example of how ASD manifests itself differently in high functioning autistic girls and women than in autistic males (Rynkiewicz et al., 2016; Wallace et al., 2021). It is important to further investigate the roles of sensory sensitivities and restrictive and repetitive behaviors in the development and maintenance of these eating behaviors in autistic women in future research. This in order to try to unravel whether one process is more impactful than the other, or whether a complex interplay of both is at play.

Furthermore, autistic women reported high levels of disordered eating behaviors, such as bingeing and purging, similar to women with EDs, though not quite reaching the same symptom severity. Such behaviors have been linked to difficulties with emotion regulation in the presence of heightened, oftentimes negative, emotional states. Those states are often followed by increased emotional eating (Danner et al., 2014; Danner, Evers, et al., 2012; Meule et al., 2021), which in turn has been found to trigger bulimic behavior (Engelberg et al., 2007). Autistic girls and women might be particularly vulnerable for such behaviors, as difficulties with emotion regulation have repeatedly been found in autistic

individuals (Cibralic et al., 2019; Mazefsky et al., 2014). Recent studies have corroborated this assumption: Wallace et al. (2021) found emotional eating to be increased in autistic girls along with van 't Hof et al. (2020), who discovered that autistic traits at age six in girls of the general population were predictive of increased emotional eating at a later age, an association which was found to not be the case for boys from the general population. Wallace et al. (2021) theorized emotional overeating to be a strategy of self-stimulation in autistic individuals, a repetitive and stereotyped behavior in order to produce sensory input to cope with negative emotional or cognitive states, such as overstimulation (Zentall & Zentall, 1983) or stress (LeCompte, 1981). Emotional undereating on the other hand, possibly related to the dieting behaviors or food restriction reported by autistic women, could serve as a way to cope with overstimulation, by avoiding additional sensory information of food (Mayes & Zickgraf, 2019). It is not clear however, when such behaviors result in a symptom severity level comparable to that of individuals with EDs on a measurement like the EAT-26. Items might be interpreted differently by an autistic individual compared to someone with an ED, resulting in a lower score, but symptoms may be equally as severe. Future research is needed to unravel whether there are differences in emotional processing and emotion regulation strategies of autistic women compared to women with an ED, and how that relates to problematic eating behaviors in both.

Problematic Eating Behaviors and Their Physical Consequences

When examining the physical consequences of both eating behaviors frequently seen in ASD and disordered eating behaviors displayed by autistic women, results of the included studies indicate that autistic women still had BMIs in the 'normal range', comparable to those of women with a broad range of EDs (Nisticò et al., 2022) but higher than those of currently ill women with AN (Karjalainen et al., 2019). This may suggest that the eating behaviors of autistic women measured with the SWEAA and the EAT-26 do not necessarily result in either over- or underweight. Emotional eating behaviors however can possibly lead to over- or binge eating, which are associated with a higher BMI or obesity in general (Agüera et al., 2021). The only study who investigated BMI and the body composition of autistic women without intellectual disability (Garcia-Pastor et al., 2019) did not report higher weight or obesity percentages of autistic women compared to the general population (Gallus et al., 2015). Compared to autistic men, autistic women had a lower BMI and a higher body fat percentage, which is also seen in the general population (Gallus et al., 2015; Lutoslawska et al., 2014).

Eating Behaviors of Autistic Women Compared to Women with EDs

When comparing the eating behaviors of autistic women to those of women with EDs, it is not only noteworthy that autistic women seem to have similar levels of disordered eating behaviors as women with EDs, but also that women with EDs seem to report similarly high levels (or even higher) of eating behaviors frequently seen in ASD as autistic women. Some

of which persist even after weight gain. Karjalainen et al. (2019) theorize that such eating behaviors in women with AN might overlap with ‘traditional’ AN behaviors and that symptoms of such behaviors, when already premorbidly present, might constitute as a risk factor for developing an ED (Nielsen et al., 2015; Wentz et al., 2009). It is also possible that these eating behaviors frequently seen in ASD are partly exacerbated by the starved state of AN patients or by other traditional ED symptoms (Karjalainen et al., 2019; Nisticò et al., 2022). The presence of eating behaviors frequently seen in ASD in ED populations also has clinical consequences: The fact that patients with various EDs score high on the SWEAA means that such an instrument has no predictive value of whether ASD is present in the patient. In future studies, it is important to examine how the problematic eating behaviors of autistic women compare to those of women with EDs, in order to get a better understanding of what autistic women need in order to recover from these behaviors.

Problematic Eating Behaviors of Autistic Women and Comorbid EDs

Even though very little is evidently known about the eating behaviors of autistic women, there is evidence from the ED field that autistic women with comorbid AN and (suspected) ASD have a more severe presentation at the beginning of treatment and poorer treatment outcomes (Courty et al., 2013; Nielsen et al., 2015; Stewart et al., 2017; Tchanturia et al., 2016, 2019). Autistic women with (suspected) ASD and comorbid AN seem to view both of their conditions as deeply interlinked, which makes it difficult to profit from current treatment modalities as these do not take the autistic traits underlying their ED into account (Kinnaird, Norton, Pimblett, et al., 2019; Kinnaird, Norton, Stewart, et al., 2019).

The case study of Dandil, Baillie, et al. (2020) demonstrates how the combination of eating behaviors frequently seen in ASD and eating pathology can manifest in an autistic woman. The formerly overweight and now severely underweight autistic patient with comorbid AN presents with a history of emotional eating in order to regulate difficult emotions (even before AN was developed), to becoming obsessed with being healthy, over-exercising, hyper focusing on weight and shape and restricting food. This case provides an example of the interplay and interchangeability of specific autistic traits and characteristics and how they relate to problematic eating behaviors: (1) restrictive and repetitive behaviors expressed by emotional overeating to self-stimulate in heightened emotional states, by restricting food to partly deal with sensory overload, and by a hyperfixation on becoming ‘healthy’, and (2) cognitive and behavioral rigidity, expressed by the notion to having to engage in exercises every day. All of which combined, ultimately result in a severe level of eating pathology deeply intertwined with the ASD (Brede et al., 2020).

Recently, a novel clinical pathway for autistic individuals and comorbid AN has been developed, which aims to improve evidence-based treatments offered to these patients (Tchanturia et al., 2020, 2021). Most of the studies on the relationship between eating problems

and ASD however have not applied comprehensive assessments including developmental analysis to determine the diagnosis of ASD. This is of great importance, as instruments like the ADOS-2 (Lord et al., 2012) or the AQ-50 (Baron-Cohen et al., 2001) alone are not sufficient to detect ASD in patients with EDs, and whose eating problems cannot be linked or attributed to ASD this way.

Eating Behaviors Frequently Seen in ASD and Avoidant Restrictive Food Intake Disorder

The eating behaviors of autistic women described in this review also resemble those of individuals with avoidant restrictive food intake disorder (ARFID). Individuals with ARFID experience restrictive eating behaviors that are not driven by body image disturbances or a fear of gaining weight (American Psychiatric Association, 2013). Patients with ARFID can report a range of reasons that may drive the food restriction, such as a sensory based avoidance of food, a lack of interest in food, or the fear of the aversive consequences of eating. Such a severely restricted diet can result in severe weight loss, nutritional deficiencies, and impact psychosocial functioning (American Psychiatric Association, 2013; Bourne et al., 2022). With research into the prevalence and causes of ARFID still lacking, it is theorized that autistic individuals are at an increased risk to develop ARFID (Bourne et al., 2022; Mayes & Zickgraf, 2019; Sharp, Jaquess, et al., 2013). It is however still unclear what role autistic traits play in the onset and maintenance of ARFID, and how eating behaviors frequently seen in ASD relate to ARFID (Bourne et al., 2022). None of the studies have examined the presence of specific ARFID symptoms in autistic women, which highlights a clear need for further research.

CONCLUSION

This review suggests that eating behaviors frequently seen in ASD as well as disordered eating and eating pathology are present in autistic women without intellectual disabilities, however very little research has been done examining either in autistic women. This warrants more research to replicate these findings, to find out more about what these problematic behaviors look like, if they resemble the behaviors of autistic women with intellectual disabilities, how they are different from women who have EDs or feeding disorders such as AN, BN, BED or ARFID, and how to ultimately adapt current treatment modalities that meet the unique needs of these women and help them recover from their eating disturbances.



Chapter 3:

Exploring the Intersection of Autism Spectrum Disorder and Eating Disorders: Understanding the Unique Challenges and Treatment Considerations for Autistic Women with Eating Disorders

Schröder, S. S., Danner, U. N., Spek, A. A., & van Elburg, A. A. (2023). Exploring the intersection of autism spectrum disorder and eating disorders: understanding the unique challenges and treatment considerations for autistic women with eating disorders. *Current opinion in psychiatry*, 36(6), 419-426. <https://doi.org/10.1097/YCO.0000000000000894>

ABSTRACT

Purpose of Review: Autistic women struggle with high levels of both *autistic eating behaviors* and *disordered eating behaviors*, which might make them particularly vulnerable to develop eating disorders. Research investigating the presence and characteristics of EDs in autistic women is however limited, as is research examining the role of autism in the treatment and recovery of an ED in autistic women.

Recent Findings: The link between autism and EDs has mainly been investigated from the field of eating disorder research, with studies finding an overrepresentation of autism or autistic traits in eating disorder populations. Findings also suggest that autism or autistic traits are associated with a more serious presentation of the eating disorder, including a higher chance of a chronic course of the eating disorder. Most studies however lack comprehensive autism assessments, making it difficult to determine the actual prevalence of autism and its role in women with eating disorders.

Summary: Autistic women with an eating disorder seem to suffer from more complex eating disorders and seem to not benefit from current treatment modalities. This could be partly related to specific autism characteristics such as sensory sensitivities, that are not being considered by current treatment protocols. Future research needs to shed light on what underlies the eating behaviors of autistic women with an eating disorder, in order to help to adapt current treatment modalities to meet the unique needs of these women.

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AUTHOR CONTRIBUTIONS

Sabrina Schröder: Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing

Unna Danner: Conceptualization, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annelies Spek: Conceptualization, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annemarie Van Elburg: Conceptualization, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing



INTRODUCTION

Autism Spectrum Disorder (henceforth *autism*) is a complex and heterogeneous neurodevelopmental condition. It is characterized by the early developmental onset of persistent differences and/or challenges in social communication and social interactions as well as by the occurrence of restricted and repetitive patterns of behavior, interests or activities (American Psychiatric Association, 2013). According to recent estimations, the global prevalence of autism is suggested to be around 1% of the general population (Zeidan et al., 2022), with approximate male-to-female ratios of 3:1 (Loomes et al., 2017). Autistic individuals can experience a range of impairments, such as having difficulties with social interactions and interpreting other people's behavior, communicating one's needs and managing everyday tasks (Demetriou et al., 2019; Malhi et al., 2017). Because differences in the way sensory stimuli are being received and processed, autistic¹⁰ individuals also experience hyper- or hyporesponsiveness for sensory stimuli (accounting for a lower and higher sensory threshold for sensory perception), which can significantly impact their daily functioning (Crane et al., 2009).

Up to 80% of autistic individuals additionally struggle with comorbid medical and psychiatric conditions, far more than non-autistic individuals in the general population (Hossain et al., 2020; Lai et al., 2019; Mannion & Leader, 2013). Medical and psychiatric problems such as mood- and anxiety disorders, sleep disturbances, epilepsy or gastrointestinal problems can be prevalent across an autistic person's lifespan (Buckley & Holmes, 2016; Hollocks et al., 2019; Leader et al., 2021; Margari et al., 2019; McElhanon et al., 2014; B. Morgan et al., 2020). When investigating these comorbid problems, it seems that certain eating behaviors such as high levels of food selectivity (i.e., eating a very narrow variety of foods), food refusal, behavioral rigidity during meals (i.e., eating only with specific utensils) as well as abnormalities in dietary intake and nutrition seem to be particularly prevalent in autistic individuals across their whole lifespan, regardless of their cognitive abilities or sex (Baraske-wich et al., 2021; Bourne et al., 2022; Leader et al., 2020; Mari-Bauset et al., 2014; Mayes & Zickgraf, 2019; Rastam, 2008; Sharp, Berry, et al., 2013; Vissoker et al., 2015).

Eating Behaviors of Autistic Individuals

The prevalence of eating behaviors such as food refusal, food selectivity or abnormalities in dietary intake and nutrition in autistic individuals is high, with rates ranging between 44% to 96% (Margari et al., 2020). Such eating behaviors (henceforth *autistic eating behav-*

10 In this paper, we have used "identity-first" language (i.e., "autistic person") rather than "person-first" language (i.e., "person with autism") in accordance with the preferred language of those within the English-speaking autism community. It is of note that in the Netherlands, the preferred language of those within the Dutch autism community is "person-first" language instead of "identify-first" language (Buijsman et al., 2023; Bury et al., 2023; Kenny et al., 2016).

iors¹¹) occur more often in autistic individuals than in individuals with other developmental disorders or individuals of the general population (Mayes & Zickgraf, 2019). Autistic eating behaviors have been theorized to be the result of a combination of certain characteristics of autism, such as cognitive and behavioral rigidity, restricted interests as well as sensory sensitivities (S. S. Christensen et al., 2019; Cooke et al., 2006; Margari et al., 2020; Marí-Bauset et al., 2014). For instance, situations wherein one has to eat as well as the process of eating itself can be quite complex, as the sensory properties of food, changing environments or differences in food items of the same food groups can pose a challenge for individuals who experience sensory sensitivities, have a need for sameness or have difficulties managing novelty (Cermak et al., 2010; D’Cruz et al., 2013; Kushner et al., 2015; Maes et al., 2011; Spratt et al., 2012). The presence of autistic eating behaviors increases the risk of developing feeding- and eating disorders such as avoidant restrictive food intake disorder (ARFID), and can lead to potentially severe physical problems, such as nutrient deficiencies, gastrointestinal problems as well as being overweight, underweight or obese, with all physical consequences that result from this (Bourne et al., 2022; Garcia-Pastor et al., 2019; Leader et al., 2021; Maes et al., 2011; Sammels et al., 2022; Zimmer et al., 2012). For instance, weight problems through poor nutritional health have been linked to an increased risk of other serious health comorbidities in autistic individuals, including type II diabetes and cardiovascular conditions (Croen et al., 2015; Dhaliwal et al., 2019; Matheson & Douglas, 2017; Shedlock et al., 2016).

Problematic Eating Behaviors in Autistic Women

Most research regarding the eating behaviors of autistic individuals has focused on autistic children, autistic individuals with intellectual disabilities, autistic adults without looking at possible sex differences or have included very few women (Blomqvist et al., 2015; Demartini et al., 2021; Karjalainen et al., 2016; Kushner et al., 2015; Leader et al., 2020; Mayes & Zickgraf, 2019). Recent research has found however that autistic women without intellectual disabilities in particular seem to not only present with high levels of autistic eating behaviors, but also report high levels of disordered eating behaviors, that are related to more “traditional” eating disorder behaviors (Karjalainen et al., 2019; Nisticò et al., 2022; Schröder et al., 2022; Spek et al., 2020). Such behaviors include the avoidance of certain (fattening) foods (e.g., foods with a high carbohydrate or with a high sugar content) because of a fear of gaining weight or a desire to be thin, as well as bulimic behaviors such as bingeing and purging.

11 In order to improve the readability of this paper and in order to be able to make a clear distinction with *disordered eating behaviors*, we have chosen to refer to eating behaviors frequently seen in autism (e.g., food selectivity or food neophobia) as *autistic eating behaviors*. We appreciate that those eating behaviors are not exclusive to autistic individuals and can also occur in individuals from the general population or in individuals with other developmental disorders (Malhi et al., 2017; Mayes & Zickgraf, 2019).

Various autism related characteristics and processes are likely to underlie these problematic eating behaviors (i.e., autistic eating behaviors as well as disordered eating behaviors), such as difficulties in sensory processing, difficulties in emotion regulation and the presence of restricted and repetitive interests (Margari et al., 2020; Mari-Bauset et al., 2014; Nisticò et al., 2023). Firstly, sensory processing difficulties are very common in autistic individuals but they seem to be particularly impactful on autistic women (Crane et al., 2009; Lai et al., 2011; Leekam et al., 2007; Spek et al., 2020; Taylor et al., 2020). Such difficulties could, on the one hand, lead to sensory avoiding behaviors (hyperreactivity) in order to reduce overstimulation, which in this case could result in the avoidance of food intake or situations surrounding food because of a sensory overload. On the other hand, they could lead to sensory seeking behaviors (hyporeactivity), in this case increased engagement of food because of its pleasant sensory properties, possibly increasing the chances of binges. Secondly, there is some evidence that autistic individuals have increased difficulties with regulating their emotions in heightened (often negative) emotional states (Cibralic et al., 2019; Mazefsky et al., 2014). As such emotion regulation difficulties are associated with increased emotional eating or disordered eating behaviors such as bingeing and purging during (often negative) emotional states, autistic women might be particularly vulnerable to engage in such behaviors when struggling with emotion regulation during heightened emotional states (Danner et al., 2014; Danner, Evers, et al., 2012). There has been some evidence that these behaviors are already developing at a young age, as increased emotional eating (i.e., eating more or less in heightened emotional states) has been found to be more prevalent in autistic girls than in autistic boys (Van 'T Hof et al., 2020; Wallace et al., 2021). Lastly, considering that restricted and repetitive interests manifest differently in autistic females compared to autistic males and often pertain to more “typical” or “appropriate” areas for females (i.e., interest in animals instead of trains), it could also be that food in general, cooking, eating but also dieting start to become one of those interests (Hattier et al., 2011; Hull, Petrides, et al., 2020; Lai et al., 2015). This interest is then repeatedly engaged in and can therefore pose a risk for increased problematic eating behaviors. Taken together, engaging in problematic eating behaviors might put autistic women at particular risk for developing eating disorders (EDs) (Margari et al., 2020; Schröder et al., 2022; Spek et al., 2020).

Despite this risk, research that investigates the presence and characteristics of EDs in autistic women is limited, as is research examining the role of autism in the treatment and recovery of an ED in autistic women. The link between autism and EDs in general has been explored within the field of ED research, with a range of studies finding between 4 and 53% of autism or autistic traits within female ED populations (Dell'Osso et al., 2018; Gesi et al., 2017; Huke et al., 2013; Kerr-Gaffney et al., 2021; Tchanturia et al., 2019; Westwood & Tchanturia, 2017).

The Role of Autism and Autistic Traits Within Eating Disorder Populations

Determining the true prevalence of autistic women across different ED populations has so far posed a challenge: Most studies in this field have either relied on various versions of semi-structured observational assessments such as the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2000) without an additional thorough investigation of a participant's developmental history or on self-report measures such as the Autism Spectrum Quotient (AQ-50; Baron-Cohen et al., 2001) or have employed structured clinical interviews such as the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2008), which rely heavily on the subjective recollection of the person being interviewed, and were thus at most able to report on current 'autistic traits' in their participants (Kerr-Gaffney et al., 2021; Mandy & Tchanturia, 2015; Sedgewick et al., 2019; Tchanturia et al., 2019; Vagni et al., 2016; Westwood et al., 2017a). Although instruments such as the ADOS-2 or the RAADS-R can aid in the diagnostic process, a comprehensive clinical assessment, including a thorough investigation of the patient's developmental history, ideally along with the report of someone who knew the participant during childhood and adolescence, is essential to determine whether someone is autistic (NICE, 2012). A thorough diagnostic assessment is especially important when investigating the presence of autism in ED populations, as certain neurocognitive and behavioral traits in women with AN have been found that resemble characteristics of autistic individuals: Difficulties with cognitive flexibility, great attention to detail and difficulties 'seeing the bigger picture' (i.e. weak central coherence), compulsive behaviors, obsessions and rituals around food along with impairments in emotion recognition and empathic abilities can also be the consequences of a prolonged starved state or being underweight and might resolve with nutritional recovery (Courty et al., 2013; Danner, Sanders, et al., 2012; Kerr-Gaffney, Harrison, et al., 2020; Kerr-Gaffney, Mason, et al., 2020; Keys et al., 1950; Oldershaw et al., 2011; Pooni et al., 2012; Treasure, 2013; Westwood et al., 2016, 2017b).

To determine whether such traits were already present before the onset of the ED and to investigate which role they play in the development, maintenance and recovery of the ED, a comprehensive diagnostic assessment is needed. Otherwise, it remains unclear whether these traits are related to the ED or whether these traits have a neurobiological underpinning and thus need to be addressed from that standpoint (i.e., working with the problems, not against them, not trying to change them). Interestingly, studies who have utilized both an observational measure such as the ADOS-2 as well as a thorough developmental anamnesis (by interviewing the parents, e.g., with the Developmental Diagnostic Dimensional Interview-short version; 3Di-sv; Santosh et al., 2009) have found much lower prevalence rates of autism in ED samples, namely between 4 and 10% (Bentz et al., 2022; Pooni et al., 2012; Rhind et al., 2014). These percentages are in contrast with those stemming from studies who did not employ comprehensive diagnostic assessments, demonstrating the risk of an overestimation of autism prevalence in ED populations (Huke et al., 2013; Vagni et al., 2016; Westwood et al., 2017a).

Another reason why it is difficult to determine the prevalence of autism across different ED populations is that most information comes either from the same Swedish community sample of women with adolescent-onset anorexia nervosa (AN) or have investigated the presence of autism solely in girls or women with AN (Anckarsäter et al., 2012; Gillberg et al., 1995; Nielsen et al., 2015; Postorino et al., 2017; Rhind et al., 2014; Sedgewick et al., 2019; Westwood et al., 2017a). Only a few studies have included women with other EDs such as bulimia nervosa (BN) or binge-eating disorder (BED), so it remains unclear whether autism or autistic traits are overrepresented in girls and women with other EDs than AN, as traits like cognitive inflexibility, attention to detail and emotion regulation difficulties have also been found in other EDs than AN (Dingemans et al., 2015; Keegan et al., 2021; Mandy & Tchanturia, 2015; Pooni et al., 2012; Vagni et al., 2016; Wentz et al., 2005). At present, comorbid autism seems to be more commonly diagnosed in girls and women with restrictive types of EDs, such as AN or atypical AN, though some studies have found no difference between different EDs (Nickel et al., 2019; Vagni et al., 2016).

Impact of Autism on Eating Disorders

The clinical implications of co-existing autism in women with EDs and the necessity to study them further are illustrated by a recent publication of Nielsen et al. (2022), which followed 51 women with adolescent-onset AN and 51 matched controls over the course of 30 years to investigate the long-term consequences of comorbid autism in women with AN. The presence of autism was assessed at four different timepoints using a developmental assessment with the mother of the patient at timepoint 1, as well as a variety of diagnostic tools (i.e., different structured interviews) reflecting a change in diagnostic criteria (i.e., the update from DSM-III-R to DSM-4 and DSM-5), yielding different rates of autism across the four timepoints. Those with a stable autism diagnosis across all timepoints presented with worse outcomes in psychiatric-, psychosexual and socio-economic state as measured by the Morgan-Russel outcome assessment schedule (MROAS; Morgan & Russell, 1975) than those without a stable diagnosis. In addition, results on ED-specific outcomes on the MROAS were only improving for those with AN that were not autistic. Although there is still a lack of knowledge into why autistic women with an ED seem to fare worse on mental health outcomes, there are some indications that autism or autistic traits in women with EDs are associated with a more complex or serious presentation of the ED, along with poorer daily functioning and a longer duration of the ED (Nielsen et al., 2015; Saure et al., 2020; Tchanturia et al., 2019). In addition, autism or autistic traits in women with EDs are theorized to be one of the most important predictors of a chronic course of the ED (Nielsen et al., 2022; Wentz et al., 2005). In order to understand the role of autism in the development and maintenance of the ED, Brede et al. (2020) have proposed a model of autism-specific mechanisms underlying disordered eating behaviors. In this model, a range of autism characteristics such as sensory sensitivities (i.e., general and food specific sensory sensitivities as well as difficulties with interoceptive abilities regarding bodily changes), certain cognitive and

behavioral patterns (i.e., cognitive rigidity, restricted interests as well as ritualized behavior) as well as social-emotional difficulties (e.g., understanding and regulating emotions or difficulties establishing social relationships) are proposed to, directly and indirectly, give rise to disordered eating behaviors and help maintaining them. For instance, increased cognitive rigidity is suggested to directly contribute to the development and maintenance of routines and rituals around food, in conjunction with sensory sensitivities directly stimulating the development of food selectivities and other restrictive eating behaviors (Kinnaird, Norton, Stewart, et al., 2019; Kuschner et al., 2015; Westwood et al., 2017b). Social-emotional difficulties associated with autism may result in negative emotional consequences and can thus indirectly also contribute to the development of disordered eating behaviors, which serve as a maladaptive way to cope with such negative emotional consequences, such as restrictive eating or bingeing and purging behaviors (Kinnaird, Norton, Stewart, et al., 2019).

This combination of direct and indirect routes in which autism or autistic traits can lead to disordered eating behaviors, might not only result in very complex ED presentations that are a mixture of more “traditional” ED presentations (such as AN) as well as more “ARFID-like” ED presentations, but can also have the consequence that autistic women or women with high autistic traits are insufficiently profiting from existing ED treatments (Nazar et al., 2018; Nielsen et al., 2015, 2022). Even though research into the effectiveness of recommended ED treatments of autistic women with an ED are still lacking, some qualitative studies have reported that in some autistic women, “traditional” ED motivations, such as a desire to lose weight or a low self-esteem because of body image issues were less relevant in the development of the ED than other motivations, such as a need for control, sensory sensitivities, or organizational problems around cooking and food shopping or the ED as a special interest (Kinnaird, Norton, Stewart, et al., 2019). Another recent narrative review has reported that autistic individuals or individuals with high autistic traits and AN seem to benefit less from cognitive remediation therapy (CRT) and cognitive remediation therapy and emotional skills training (CREST) (Saure et al., 2022). The authors argue that this could possibly be linked to autistic traits such as difficulties in social cognition and emotion processing, cognitive inflexibility and sensory processing. The authors of this review propose a range of possible treatment modifications, such as offering individual CRT or CREST sessions instead of group therapy to account for social difficulties, modifications for communication styles, longer treatment to account for information processing difficulties or offering extra support before or after therapy sessions to help generalize what has been learned in therapy to real-life-situations. The included studies of this review however did not apply comprehensive diagnostic assessments to determine an autism diagnosis, making it difficult to attribute any difficulties benefitting from treatment to the presence of autism. There are currently no studies investigating the effectivity and possible adaptations of cognitive behavioral therapy (CBT) for autistic individuals with an ED, a therapy that is commonly used in the treatment of AN, targeting body image issues as well as the over-evaluation of shape, weight and strict control over food (Fairburn, 2008).

Even though there is an urgent need for guidelines on how to best approach and support the needs of autistic individuals with an ED according to major stakeholders (such as patients themselves, their carers and clinicians), current National Institute for Health and Care Excellence (NICE, 2017) guidelines make no differentiation between autistic and non-autistic individuals with EDs and therefore do not yet recognize and acknowledge the complex interplay of autism and EDs (Adamson et al., 2020; Babb et al., 2021; Kinnaird et al., 2017). Recently, a novel pathway has been developed aiming to improve the support for autistic individuals or individuals with high autistic traits with an ED (Tchanturia et al., 2020, 2021). This pathway consists of various adaptations on how to make ED treatment more autism-friendly, by for example offering a specialized menu addressing sensory sensitivities around food or making communication passports that are designed to aid in the support and treatment of the patient.

Taken together, there is still a lot unknown about EDs in autistic women, how they develop, how they are maintained and how these women are best supported on their way to recovery. The majority of studies that have been done so far have lacked appropriate autism assessments and were thus not able to determine to which extent autism spectrum disorders were present in ED populations and whether the difficulties to benefit from treatment lead back to the neurobiological underpinnings of autism. Nevertheless, the need for adaptations of current ED treatments is clear, and first efforts have been made to improve the support and treatment of autistic individuals struggling with an ED, by proposing various treatment modifications ranging from changing the color scheme of wards and offering alternative menus to take sensory sensitivities into account to providing individual therapy sessions of CRT and CREST adapted to the individual needs of the autistic patient (Dandil, Baillie, et al., 2020; Saure et al., 2022; Tchanturia et al., 2020). As no studies have been done so far examining the effectiveness of other ED treatments for autistic individuals, such as CBT for AN, BN or BED, it is still unclear whether adaptations have to be made in the protocols of these treatments. As in some autistic women with an ED, autistic eating behaviors (e.g., those related to sensory sensitivities) seem to overlap with disordered eating behaviors (e.g., the restriction of food due to a fear of gaining weight), new protocols might have to be developed that take the complex interplay of both into account (Nielsen et al., 2022; Nimbley et al., 2025). In the case of CBT, this could mean that parts of CBT specifically developed for ARFID could be paired with the CBT protocol for AN, BN or BED, to account for the specific needs of these patients.

Thus, there is a need for future research to shed light on what underlies the eating behaviors of autistic women with an ED, in order to help to adapt current treatment modalities that meet the unique needs of these women.



Chapter 4:

Eating Behaviors of Autistic Women with an Eating Disorder

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ABSTRACT

Background: Autistic women with eating disorders (EDs) often present with more complex EDs and may not fully benefit from current treatments, yet the reasons for this remain unclear. This study aims to examine the eating behaviors of autistic women with EDs and how these differ from those of (1) non-autistic women with EDs, (2) autistic women without EDs, and (3) non-autistic female controls. It investigates autism-related eating behaviors, traditionally disordered eating behaviors, and avoidant–restrictive food intake disorder (ARFID)-related behaviors to better understand their complex ED presentations.

Methods: A cross-sectional study was conducted with 30 autistic women with EDs, 30 non-autistic women with EDs, 29 autistic women without EDs, and 60 non-autistic female controls. Participants completed questionnaires assessing eating behaviors, quality of life, and comorbid psychological symptoms.

Results: Autistic women with EDs exhibited higher levels of both autism-related and disordered eating behaviors than all other groups, including food selectivity, mealtime rigidity, and sensory-related eating difficulties. They also reported notable weight and shape concerns. Additionally, they showed higher levels of comorbidity and reported lower mental health-related quality of life compared to all other groups.

Conclusions: These findings suggest that the overlap of autism-related and disordered eating behaviors contributes to the complexity and severity of EDs in autistic women, potentially limiting the effectiveness of current treatment approaches. Developing autism-informed interventions that address sensory sensitivities, rigidity, and cognitive differences may improve treatment outcomes. Future research should explore how these factors interact in maintaining ED pathology and identify strategies to distinguish adaptive from maladaptive eating behaviors.

AUTHOR CONTRIBUTIONS

Sabrina Schröder: Conceptualization, Formal Analysis, Investigation, Methodology, Writing – Original Draft Preparation, Writing – Review & Editing

Unna Danner: Conceptualization, Formal Analysis, Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annelies Spek: Conceptualization, Formal Analysis Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annemarie Van Elburg: Conceptualization, Formal Analysis Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing



INTRODUCTION

The treatment of eating disorders (ED) is inherently challenging. Recent studies have suggested that the presence of autism spectrum disorder (ASD) exacerbates treatment complexity, although the underlying reasons remain unclear (Nielsen et al., 2022; Nimbley et al., 2025). Problematic eating behaviors are well-documented in autistic¹² individuals, but far less is known about eating behaviors in those with a co-occurring ED diagnosis. This knowledge gap is particularly concerning, as this comorbidity appears to contribute to a more complex clinical presentation of the ED, which may, in turn, warrant more tailored treatment approaches to address the specific needs of those with comorbid autism (Nimbley et al., 2025; Zhang et al., 2022).

The complexity may, in part, be linked to the high prevalence of distinct feeding and eating behaviors observed in autistic individuals, which themselves are associated with an increased risk of developing feeding and eating disorders (Schröder et al., 2022). These behaviors can include food selectivity (e.g., eating a restricted range of foods), food neophobia (e.g., avoiding unfamiliar foods), meal-related rigidity (e.g., insistence on using specific utensils), and atypical dietary intake (e.g., excessive fluid consumption) (Bourne et al., 2022; Mari-Bauset et al., 2014). While some of these eating patterns may serve adaptive functions, such as managing sensory sensitivities or alleviating social challenges, they can also increase the risk of nutritional deficiencies and other health complications (e.g., weight problems, type II diabetes and cardiovascular issues) (Croen et al., 2015; Kinnaird, Norton, Pimblett, et al., 2019; Leader et al., 2021). Collectively referred to as autism-related eating behaviors¹³, these eating patterns are thought to arise from core-autism related characteristics, including altered sensory processing, differences in social communication, and a heightened need for sameness, structure, and predictability (Adams et al., 2024; Black & Bölte, 2025). Notably, several of these behaviors overlap with symptoms of avoidant/restrictive food-intake disorder (ARFID), which is increasingly recognized as being particularly common in autistic individuals (Bourne et al., 2022).

Autistic women in particular report high levels of autism-related eating behaviors alongside greater engagement in traditionally disordered eating behaviors (Schröder et al., 2022), and these may be linked to their heightened sensory sensitivity (Lai et al., 2015; Spek et

12 While we acknowledge that individual preferences vary across autistic communities, this paper adopts “identity-first” language (i.e., “autistic person”) rather than “person-first” language (i.e., “person with autism”) in line with the preferred terminology of the English-speaking autism community (Bury et al., 2023; Kenny et al., 2016). Notably, in the Netherlands - the country of origin of the authors and participants - “person first” language is preferred over “identify-first” language (Buijsman et al., 2023).

13 While we recognize that eating behaviors such as food neophobia or selectivity are not exclusive to autistic individuals, we use the term ‘autism-related eating behaviors’ to enhance readability and emphasize their markedly higher prevalence in autistic individuals compared to those with other developmental conditions such as ADHD or intellectual disabilities (Malhi et al., 2017; Mayes & Zickgraf, 2019).

al., 2020), greater cognitive and behavioral rigidity (Bitsika & Sharpley, 2018), increased difficulties with emotion regulation (Wallace et al., 2021), and heightened challenges in social situations involving food (Lundin Remnélius et al., 2022). These eating behaviors may include restricting certain food groups (e.g., avoiding high-carbohydrate or high-sugar foods due to fears of weight gain), binge eating, and purging behaviors, placing them at greater risk for developing EDs (Schröder et al., 2023; Spek et al., 2020). To help conceptualize the interplay between autism traits and disordered eating, Brede et al. (2020) proposed a model in which sensory sensitivities, cognitive rigidity, and social-emotional difficulties are thought to directly and indirectly contribute to the development and maintenance of disordered eating behaviors in autistic women. For example, heightened sensory sensitivity may lead to avoidance of certain textures or temperatures, which over time could contribute to restrictive eating patterns. While our study focuses on these autism-related traits, it is important to note that other contextual factors – such as traumatic experiences or masking ones autistic characteristics as a way to cope with neurotypical social demands (“camouflaging”) – may also contribute to disordered eating in autistic individuals, as such behaviors may serve as coping strategies, emotional distractions, or arise when cognitive and emotional resources are depleted (Bradley et al., 2024; Carpita et al., 2022).

Once established, EDs in autistic women often present with greater complexity and severity, longer illness duration, poorer daily functioning, and worse long-term psychological outcomes than EDs in non-autistic women (Nielsen et al., 2022; Nimbley et al., 2025). Their treatment is suggested to frequently involve intensive interventions, such as prolonged inpatient stays or tube feeding, and autistic women frequently report negative experiences with ED treatments (Nimbley et al., 2025; Zhang et al., 2022).

To develop treatments tailored to the unique needs of autistic women with EDs, it is crucial to gain further insight into their specific eating behaviors. The often more complex and severe clinical presentation of EDs in this group may stem from an interplay between autism-related and traditionally disordered eating behaviors, making it difficult to distinguish adaptive from maladaptive patterns (Longhurst et al., 2024; Nimbley et al., 2023). Current treatment protocols, such as cognitive behavioral therapy for EDs (CBT-E; NICE, 2017; Fairburn, 2008) do not account for the co-occurrence of autism-related and traditionally disordered eating behaviors and primarily target weight and shape concerns — key drivers of disordered eating behaviors in non-autistic women (Kinnaird, Norton, Stewart, et al., 2019; Lundin Remnélius & Bölte, 2025). However, recent research suggests these concerns may play a lesser role in autistic women, who more often attribute their eating difficulties to autism-related challenges, such as sensory sensitivities or cognitive and behavioral rigidity (Kinnaird, Norton, Stewart, et al., 2019; Lundin Remnélius & Bölte, 2025). This mismatch may contribute to poorer treatment outcomes in this population (Nimbley et al., 2025;

Zhang et al., 2022). Understanding the unique eating behaviors of autistic women is therefore essential to inform the development of more targeted, autism-informed interventions.

In addition to treatment mismatches, further challenges arise from how autism is defined and operationalized in ED research. Many studies rely on samples of women with autistic traits, subthreshold autism, or suspected autism (Nimbley et al., 2025). While research including individuals across the autism spectrum increases inclusivity, it also raises the risk of misattributing common personality traits or psychiatric symptoms to autism, despite their presence in other conditions such as schizophrenia or obsessive-compulsive disorder (Bertelli et al., 2025). Given that an autism diagnosis requires the presence of interrelated core symptoms rather than isolated traits, distinguishing autism from other psychiatric conditions is essential to accurately understand eating behaviors in autistic women. Without studies focusing specifically on formally diagnosed autistic women, it remains unclear whether their eating behaviors align with or differ from those of non-autistic women with an ED. Formally diagnosed samples are therefore essential to ensure that observed eating behaviors are truly autism-specific, rather than reflective of overlapping features of other psychiatric conditions. For example, social withdrawal in individuals with anorexia nervosa may resemble autistic social difficulties, but can stem from body-related shame or a desire to avoid eating in front of others, rather than from autism itself (Spek et al., 2021).

In response to Sharp's (2025) call for high-quality research on EDs in autistic individuals, this study aims to investigate the eating behaviors of autistic women with EDs. It compares their behaviors to those of 1) non-autistic women with EDs, 2) autistic women without (lifetime) EDs, and 3) non-autistic female controls. Using a set of questionnaires, this study examines a broad range of eating behaviors, including autism-related eating behaviors, traditionally disordered eating behaviors and eating behaviors often observed in people with ARFID. We hypothesize that autistic women with EDs will report (1) more autism-related eating behaviors, (2) more traditionally disordered eating behaviors, and (3) more ARFID-related eating behaviors (including more picky eating) compared to non-autistic women with EDs, autistic women without EDs, and controls.

MATERIALS AND METHODS

Study Design

This study employed a cross-sectional design with a single time-point measurement. Participants completed several questionnaires assessing various eating behaviors using Qualtrics software (Versions 2020–2023; Copyright © 2024 Qualtrics). The study was approved by the Medical Research Ethics Committee in Utrecht, the Netherlands (NL74635.041.20)

and by the Institutional Review Board of the Altrecht Mental Health Institute. Additionally, it was pre-registered with the Overview of Medical Research in the Netherlands (OMON; Overzicht van medisch-wetenschappelijk onderzoek in Nederland; NL-OMON20463).

Participants

The sample size was determined based on both statistical considerations and recruitment feasibility. Given the exploratory nature of the study and the limited prior data on comparable populations, a formal power analysis indicated that group sizes of approximately 30 participants would allow detection of medium effect sizes (Cohen's $d = 0.36$ or larger) with 80% power at an alpha level of 0.05. Feasibility estimates were based on annual patient flows at the participating centers and suggested that the proposed group sizes were realistic within the study's time frame, including the more difficult-to-recruit ASD+ED group, which required additional diagnostic assessment.

A total of 149 women participated in the study, divided into four groups: autistic women with EDs (ASD+ED group, $n = 30$), non-autistic women with EDs (ED group, $n = 30$), autistic women without EDs (ASD group, $n = 29$), and non-autistic female controls (control group, $n = 60$), matched for age. Participants in the ASD+ED, ED, and ASD groups were recruited from two centers in the Netherlands: Altrecht Eating Disorders Rintveld, a specialized center for the assessment and treatment of EDs (ASD+ED and ED groups), and the Autism Expertise Centrum, a center specialized in the assessment and treatment of autism spectrum disorders (ASD group). Control participants were recruited via Utrecht University. All participants were 18 years of age or older. Before inclusion, they received a letter containing detailed information about the study and provided written informed consent.

Inclusion and Exclusion Criteria

Potential participants were not included if they had a level of education below basic primary education, a mental disability, or insufficient proficiency in Dutch. No participants were excluded based on these criteria.

ASD+ED and ED Groups

To be included in the ASD+ED and ED groups, participants had to meet the DSM-5 diagnostic criteria for an ED (American Psychiatric Association, 2013). Participants in the ASD+ED group required an additional confirmed autism spectrum disorder diagnosis. Altrecht Eating Disorders Rintveld does not provide treatment for individuals with binge eating disorder (BED) or pica; therefore, participants with these EDs were not included. Those diagnosed with an unspecified feeding or eating disorder (UFED) were also excluded, as this is a temporary diagnosis at Rintveld. Patients with ARFID were not included because the present study focused specifically on autistic women who exhibit both autism-related eating behaviors and traditionally defined ED symptoms such as weight and shape concerns. Including individuals with



ARFID, whose restrictive eating is typically not driven by such concerns, would have limited our ability to examine this specific interaction. To maintain a clear distinction between autistic and non-autistic participants, individuals in the ED group who exhibited autistic traits, as measured by the Autism Spectrum Quotient (AQ-50; Baron-Cohen et al., 2001), were excluded. The ASD+ED group consisted of participants diagnosed with anorexia nervosa (AN) binge-purge type (n = 4), AN restrictive type (n = 14), bulimia nervosa (BN; n = 3), and other specified feeding and eating disorder (OSFED; n = 9). The ED group consisted of participants with AN binge-purge type (n = 3), AN restrictive type (n = 12), BN (n = 7), and OSFED (n = 8).

ASD Group

Participants in the ASD group were eligible for inclusion if they had an autism spectrum disorder diagnosis according to DSM-5 criteria (American Psychiatric Association, 2013). Those with a current or past ED were excluded.

Control Group

Control participants were included if they had no history of psychiatric illness, as determined by the M.I.N.I. International Neuropsychiatric Interview (Sheehan et al., 1998), and had never been diagnosed with autism spectrum disorder. Those who exhibited autistic traits, as measured by the AQ-50, were excluded.

Procedure

ASD+ED Group and ED Group (Altrecht Eating Disorders Rintveld)

Participants at Rintveld underwent standard diagnostic procedures, including the Eating Disorder Examination interview (EDE; Cooper & Fairburn, 1987), a psychiatric interview, a medical examination and a heteroanamnesis with a caregiver or close contact. These assessments were conducted by experienced clinicians (psychiatrists and clinical psychologists), who established ED diagnoses. Autism diagnoses were determined using a screening procedure, regardless of whether the participant had a prior autism diagnosis. The screening included clinician behavioral observations and three diagnostic questions assessing socio-communicative development, social-emotional reciprocity, and cognitive and behavioral flexibility. These questions were answered by both the participant and a caregiver. Screening results were categorized as positive (indicating possible autism), negative (no indication of autism), or unclear. Participants with a positive or unclear screening result underwent a full autism diagnostic assessment. This assessment followed the Dutch Multidisciplinary Guidelines for Diagnostics and Treatment of Autism Spectrum Disorders in Adults (Kan et al., 2013) and included a semi-structured diagnostic interview, a developmental anamnesis, and a heteroanamnesis, conducted by trained clinicians. Participants who screened negative for autism completed the AQ-50. Those in the ED group who scored above the AQ-50 cut-off of 112 (Wouters & Spek, 2011) were excluded from the study.

This procedure ensured a rigorous and careful diagnostic process for both autism and ED diagnoses, allowing for an accurate classification of participants.

ASD Group (Autism Expertise Centrum)

Participants in the ASD group underwent a similar diagnostic procedure at the Autism Expertise Centrum. To screen for EDs, they completed the SCOFF Questionnaire (Morgan et al., 1999) and additional ARFID-related questions based on the DSM-5 criteria (American Psychiatric Association, 2013). If necessary, the Structured Clinical Interview for DSM-5 (SCID-5-CV; First et al., 2016) was administered. Those with a lifetime ED diagnosis were excluded.

Once diagnoses were confirmed, all participants completed the same online assessment battery. Data collected included demographic information (age and years of education), clinical characteristics (age of ED onset, illness duration, and age of autism diagnosis), as well as self-reported height and weight measurements, by means of which the Body Mass Index (BMI) was later calculated.

Instruments

Six validated instruments were used to assess eating behaviors, quality of life for people with mental health problems and clinically relevant psychological symptoms.

The Dutch version of the Eating Disorder Examination-Questionnaire (EDEQ; Aardoom et al., 2012; Fairburn & Beglin, 1994) was used to measure ED pathology. This measure consists of 28 items with a variety of different answer possibilities, such as Likert scales or open-ended questions, asking about the frequency with which a patient engages in behaviors indicative of an ED over a 28-day period. There is a global score as well as four subscales: Restraint, Eating Concern, Shape Concern and Weight Concern. Higher scores indicate greater eating pathology. All Cronbach's alpha scores were good: $\alpha > .88$.

To measure the level of eating and mealtime problems in autistic individuals without an intellectual disability (i.e. autism-related eating behaviors), a Dutch translation of the Swedish Eating Assessment for Autism Spectrum Disorders (SWEAA; Karlsson et al., 2013) was employed. This measure consists of 60 items comprising eight subscales, two single items, five autism-specific items, as well as demographic and medical background questions, by means of a five-point Likert scale. Scores are added to subscores within their respective subscale: Perception, Motor Control, Purchase of Food, Eating Behavior, Mealtime Surroundings, Social Situation at Mealtime, Other Behavior Associated with Disturbed Eating and Hunger/Satiety. The questionnaire also contains two single-item subscales, Simultaneous Capacity and Pica. Most Cronbach's alphas were acceptable or good: $\alpha > .73$, except for the Social Situation at Mealtime subscale ($\alpha = .63$), which was excluded from further analyses.



A Dutch translation of the Adult Picky Eating Questionnaire (APEQ; Ellis et al., 2017) was used to measure picky eating behavior in adults. This multidimensional measure of adult picky eating attitudes and behaviors consists of 16 items and can be answered by means of a five-point Likert scale. There is a global score and four subscales, with higher scores indicating greater adult picky eating: Meal Presentation, Food Variety, Meal Disengagement and Taste Aversion. Most Cronbach's alphas were good: $\alpha > .70$, except for the Taste Aversion subscale ($\alpha = .50$), which was subsequently excluded from further analyses.

To measure the level of ARFID symptomatology, a Dutch translation of the Nine Item ARFID Screen (NIAS; Zickgraf & Ellis, 2018) was used. This brief multidimensional construct consists of nine items, which are answered by means of a six-point Likert scale. Items are divided into three subscores, Fear, Lack of Interest and Picky Eating, from which a global score can be calculated. Higher scores reflect more ARFID symptoms. All Cronbach's alphas were good: $\alpha > .88$.

The Mental Health Quality of Life questionnaire (MHQoL; van Krugten et al., 2019) is a measure of quality of life specifically developed for use in people with mental health problems. The MHQoL consists of two parts: the MHQoL-7D scale and a corresponding visual analogue scale. In this study, only the MHQoL-7D scale was used. It comprises seven questions pertaining to seven dimensions (self-image, independence, mood, relationships, daily activities, physical health, and future), each with four response levels (e.g., ranging from very satisfied to very dissatisfied). Higher scores on the MHQoL-7D indicate better quality of life. The Cronbach's alpha was good: $\alpha = .86$.

The Dutch version of the Brief Symptom Inventory (BSI; De Beurs & Zitman, 2006; Derogatis & Melisaratos, 1983) was used to assess comorbid psychological symptoms. The BSI consists of 53 items and comprises nine different symptom dimensions: somatic complaints, cognitive problems, interpersonal sensitivity, depressed mood, anxiety, hostility, phobic anxiety, paranoid thoughts and psychoticism. Items are answered by means of a four-point Likert scale (e.g., ranging from not at all to very much), with higher scores indicating more severe symptoms. In the present study, only the BSI total score was used. Additionally, a global severity index (GSI; De Beurs & Zitman, 2006) was calculated, which is considered to be the most sensitive indicator of the participant's level of distress as it combines information about the number of symptoms and the intensity of distress. On top of that, the number of present symptoms on the BSI was counted, which is referred to as the number of positive symptoms (PTS). Finally, the severity of the symptoms was determined using the Positive Symptom Distress Index (PSDI). The reliability of the BSI total scale in the present study was excellent: $\alpha = .97$.

Data Analysis

All questionnaire data were complete, with no missing responses across participants or measures. Therefore, no imputation procedures were required. Statistical analyses were conducted using IBM SPSS Statistics (Version 29). Univariate ANOVAs and independent-samples t-tests were used to compare demographic and clinical characteristics between groups. Univariate ANOVAs were also used to compare outcomes on eating behavior questionnaires, with Tukey's post hoc pairwise comparisons employed to examine significant group differences. Given the exploratory nature of the study, the modest sample size, and the conceptual overlap across several outcome measures, no correction for multiple comparisons was applied. All results, including effect sizes, are reported to support interpretation.

RESULTS

Demographics and Clinical Characteristics

Table 4.1 presents demographic and clinical characteristics of each group. Participants in the ASD group were significantly older than those in the ASD+ED group and had completed more years of education. As expected, both the ASD+ED and ED groups had significantly lower BMI values than the ASD and control groups. No significant differences were observed between the ASD+ED and ED groups regarding ED onset or illness duration. Participants in the ASD group received their autism diagnoses significantly later in life than those in the ASD+ED group. Results from the BSI revealed that participants in the ASD+ED group reported higher levels of clinically relevant psychological symptoms (BSI total score), greater psychological distress (BSI global severity index), increased severity of psychological symptoms (BSI PSDI), and a greater number of reported symptoms (BSI PTS) compared to all other groups. The ASD+ED group also reported significantly lower mental health-related quality of life, as assessed by the MHQoL.

Eating Behaviors

Table 4.2 presents the outcomes on all eating behavior instruments.

Eating Pathology – EDEQ

Regarding ED pathology, participants in the ASD+ED group exhibited higher overall eating pathology (EDE-Q global score) than all other groups. They also reported significantly greater concerns regarding weight and shape compared to participants in the other groups.

Autism-Related Eating Behaviors – SWEAA

Participants in the ASD+ED group reported higher levels of autism-related eating and meal-time problems (SWEAA total). Specifically, they exhibited greater food selectivity (SWEAA

Table 4.1 Means (and SD) of Descriptive Variables: Demographic and Clinical Characteristics per Group (ED Group, ED+ASD Group, ASD Group and Control Women), and Group Differences.

	ED+ASD (n = 30)		ED (n = 30)		ASD (n = 29)		Controls (n = 60)		F (3,145)	p	η_p^2	t
	Mean	SD	Mean	SD	Mean	SD	Mean	SD				
Age	24.23 ^c	7.36	31.13	13.29	34.72 ^b	12.11	29.40	9.71	5.01*	.002	.09	
Years of Education	13.63 ^c	3.30	15.92	2.77	17.00 ^d	3.85	16.10 ^c	3.76	5.08*	.002	.10	
BMI	18.82 ^{c,d}	3.92	18.78 ^{c,d}	2.93	24.36 ^b	4.24	23.20 ^b	3.36	21.88**	<.001	.31	
Age of Onset of ED	16.60	4.45	18.63	6.54	-	-	-	-	-	.164	-	1.41
Illness Duration of ED (years)	7.63	6.21	12.50	13.05	-	-	-	-	-	.007	-	1.84
Age of Autism Diagnosis	20.97 ^c	8.12	-	-	33.10 ^b	11.62	-	-	-	.037	-	4.64**
BSI Total	55.17 ^{b,c,d}	31.33	30.03 ^d	19.71	19.72 ^d	20.97	5.20 ^{b,c}	8.45	44.54**	<.001	.48	
BSI GSI	1.04 ^{b,c,d}	0.59	0.57 ^{b,d}	0.37	0.37 ^{b,d}	0.40	0.10 ^{b,b,c}	0.16	44.54**	<.001	.48	
BSI PST	28.10 ^{b,c,d}	11.90	18.07 ^{a,c,d}	9.11	11.86 ^{a,b,d}	9.75	3.57 ^{a,b,c}	5.25	58.10**	<.001	.55	
BSI PSDI	1.83 ^{b,c,d}	0.43	1.54 ^a	0.32	1.46 ^a	0.39	1.36 ^a	0.43	8.34**	<.001	.17	
MHQoL	8.30 ^{b,c,d}	3.10	10.43 ^{b,d}	2.97	12.41 ^{a,d}	3.31	15.92 ^{b,c}	2.79	50.46**	<.001	.51	

Note: * $p < .05$, ** $p < .001$. BMI, body mass index. BSI TOT, Brief Symptom Inventory total score. BSI GSI, Brief Symptom Inventory Global Severity Index. BSI PST, Brief Symptom Inventory Positive Symptom Total. BSI PSDI, Brief Symptom Inventory Positive Symptom Distress Index. ED, eating disorder. MHQoL, Mental Health Quality of Life Index. ^a Different from ED+ASD group; ^b Different from ED group; ^c Different from ASD group; ^d Different from control group.

Table 4.2 Mean (and SD) of Eating Behavior Variables per Group (ED+ASD Group, ED Group, ASD Group and Control women), and Group Differences.

		ED+ASD (n = 30)		ED (n = 30)		ASD (n = 29)		Controls (n = 60)		F (3,145)	p	η_p^2	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD				
EDEQ	Global	4.22^{b,c,d}	1.12	3.39^{a,c,d}	1.36	1.06^{a,b}	0.86	0.74^{a,b}	0.72	111.63**	< .001	.70	
	Restraint	3.83^{c,d}	1.46	3.22^{c,d}	1.58	0.72^{a,b}	0.90	0.62^{a,b}	0.92	70.65**	< .001	.59	
	Eating Concern	3.43^{c,d}	1.26	2.81^{c,d}	1.33	0.57^{a,b}	0.72	.25^{a,b}	0.46	109.64**	< .001	.69	
	Shape Concern	4.99^{b,c,d}	1.06	4.04^{a,c,d}	1.58	1.69^{a,b}	1.40	1.16^{a,b}	1.14	77.90**	< .001	.62	
	Weight Concern	4.62^{b,c,d}	1.33	3.50^{a,c,d}	1.56	1.25^{a,b}	1.11	.94^{a,b}	1.11	73.19**	< .001	.60	
SWEAA	Global	163.93^{b,c,d}	34.11	124.50^{a,d}	26.90	136.38^{a,d}	31.36	91.67^{a,b,c}	15.05	57.68**	< .001	.54	
	Perception	32.50^{b,d}	9.98	20.83^{a,c}	6.53	29.86^{b,d}	9.60	17.90^{a,c}	5.84	31.51**	< .001	.40	
	Motor Control	12.03	3.98	10.23^c	3.55	13.34^{b,d}	4.06	10.42^c	2.75	6.10**	< .001	.11	
	Purchase of Food	11.43^{b,d}	2.60	8.60^{a,d}	2.88	9.69^d	3.31	6.58^{a,b,c}	2.52	22.46**	< .001	.32	
	Eating Behavior	17.87^{b,c,d}	5.71	14.43^{a,d}	5.07	13.90^{a,d}	5.12	8.82^{a,b,c}	2.73	31.01**	< .001	.39	
	Mealtime Surroundings	35.80^{b,c,d}	9.20	24.40^{a,d}	9.07	25.21^{a,d}	10.14	13.42^{a,b,c}	3.07	61.79**	< .001	.56	
	Social Situations at Mealtime	25.43^d	4.76	22.50^d	4.76	24.83^d	4.33	19.85^{a,b,c}	4.43	13.49**	< .001	.22	
	Other Behavior Associated with Disturbed Eating	18.67^{b,c,d}	5.41	15.30^{a,c,d}	4.22	10.45^{a,b}	2.57	9.07^{a,b}	1.58	62.78**	< .001	.57	
	Hunger/Satiety	6.57^d	1.50	5.60^d	1.98	5.69^d	1.75	3.40^{a,b,c}	2.04	33.22**	< .001	.41	
	Simultaneous Capacity	2.63^{b,d}	1.33	1.50^{a,c}	0.90	2.38^{b,d}	1.24	1.22^{a,c}	0.49	19.72**	< .001	.29	
	Pica	1.00	0.00	1.10	0.55	1.03	0.19	1.00	0.00	1.14	.337	.02	
	APEQ	Global	2.95^{b,c,d}	0.78	2.18^{a,d}	0.50	2.24^{a,d}	0.62	1.67^{a,b,c}	0.46	35.24**	< .001	.42
	Meal Presentation	3.02^{b,c,d}	0.85	2.32^{a,d}	0.47	2.44^{a,d}	0.67	1.78^{a,b,c}	0.54	27.09**	< .001	.36	
Food Variety	2.83^{b,c,d}	0.65	1.97^{a,d}	0.74	2.38^{a,d}	0.67	1.55^{a,b,c}	0.53	31.37**	< .001	.39		
Meal Disengagement	2.78^{b,c,d}	1.08	2.06^{a,d}	0.80	2.18^{a,d}	0.78	1.58^{a,b,c}	0.66	15.02**	< .001	.24		
Taste Aversion	3.20^{b,d}	1.03	2.27^{a,d}	0.83	2.79^d	0.93	1.70^{a,b,c}	0.67	25.17**	< .001	.34		



		ED+ASD (n = 30)		ED (n = 30)		ASD (n = 29)		Controls (n = 60)		F (3,145)	p	η_p^2
		Mean	SD	Mean	SD	Mean	SD	Mean	SD			
NIAS	Global	21.43^{b,c,d}	9.58	15.40^{a,d}	9.45	13.79^{a,d}	8.89	4.58^{a,b,c}	5.36	33.83**	< .001	.41
	Picky Eating	6.43^d	3.78	4.77^d	3.27	6.69^d	4.50	2.40^{a,b,c}	2.83	14.21**	< .001	.23
	Lack of Interest	8.37^{c,d}	3.66	6.63^{c,d}	3.61	4.34^{a,b,d}	3.98	1.42^{a,b,c}	2.37	36.20**	< .001	.43
	Fear	6.63^{b,c,d}	4.64	4.00^{a,d}	4.16	2.78^{a,d}	3.27	0.77^{a,b,c}	1.70	21.95**	< .001	.31

Note: * $p < .05$, ** $p < .001$. APEQ, Adult Picky Eating Questionnaire. EDEQ, Eating Disorder Examination Questionnaire. NIAS, Nine Item ARFID Screen. SWEAA, Swedish Eating Assessment for Autism. ^a Different from ED+ASD group; ^b Different from ED group; ^c Different from ASD group; ^d Different from control group

Eating Behavior), more symptoms commonly associated with “traditional” EDs like bingeing and purging (SWEAA Other Behavior Associated with Disturbed Eating) and a heightened need for mealtime routines (SWEAA Mealtime Surroundings). In terms of sensory-related eating difficulties, participants in the ASD+ED group reported similar levels of difficulties with the sensory input related to food (SWEAA Perception) and the need for control over food-related purchases (SWEAA Purchase of Food) to those in the ASD group, but significantly higher levels than those in the ED group and controls. In terms of being able to do two things simultaneously during a meal (SWEAA Simultaneous Capacity), both the ASD+ED and ASD groups experienced greater difficulties than the ED group and controls. Across all diagnostic groups, similar difficulties were reported in recognizing sensations of hunger and satiety, with higher scores than those observed in controls. No significant group differences were found in the presence of pica-related behaviors.

Adult Picky Eating Behaviors and Attitudes – APEQ

Participants in the ASD+ED group exhibited significantly elevated overall picky eating (APEQ global score) compared to all other groups. They also displayed greater rigidity regarding meal presentation and preparation (APEQ Meal Presentation), increased food neophobia (APEQ Food Variety), and more pronounced issues with mealtime disengagement and avoidance (APEQ Meal Disengagement) than all other participants. Additionally, the ASD+ED group demonstrated a greater tendency to reject bitter and sour foods (APEQ Taste Aversion) compared to the ED group and controls, though their scores did not differ significantly from those of the ASD group.

ARFID-Associated Eating Behaviors – NIAS

Participants in the ASD+ED group showed elevated ARFID symptomatology (NIAS global score), particularly greater fear of choking, vomiting, or gastrointestinal distress (NIAS Fear). All three diagnostic groups (ASD+ED, ED, and ASD) had similar levels of food avoidance due to sensory sensitivities (NIAS Picky Eating), which were significantly higher than

those observed in the control group. Finally, participants in both the ASD+ED and ED groups reported comparable patterns of food avoidance or reduced intake due to a lack of appetite or interest (NIAS Lack of Interest), with scores significantly higher than those in the ASD and control groups.

DISCUSSION

The findings of this study provide important insights into the eating behaviors of autistic women with EDs, highlighting both shared and unique patterns compared to non-autistic women with EDs, autistic women without EDs, and non-autistic controls. In line with our hypotheses, autistic women with EDs reported (1) significantly higher levels of autism-related eating behaviors, (2) more traditionally disordered eating behaviors, and (3) elevated ARFID-related symptoms and picky eating compared to all other groups. Specifically, they experienced more food-related sensory difficulties, food selectivity, meal-related rigidity, food neophobia, and disengagement from and avoidance of mealtimes. While their interoceptive challenges (e.g., recognizing hunger/satiety cues) were similar to those of non-autistic women with EDs, they were more impaired than autistic women without EDs. Notably, autism-related eating behaviors were significantly more prevalent in autistic women with EDs than in autistic women without EDs. These findings align with those of Brede et al. (2024), who found that autistic women with restrictive EDs also displayed higher levels of autism-related eating behaviors than both non-autistic women with restrictive EDs and autistic women without EDs. According to the authors, this suggests that such autism-related eating behaviors are not merely general features of autism but are, in fact, characteristic of the subgroup of autistic women who develop EDs.

Contrary to prior suggestions, this study found that autistic women with EDs exhibited not only elevated disordered eating behaviors, but also greater weight and shape concerns than all other groups (Kinnaird, Norton, Stewart, et al., 2019; Lundin Remnélius & Bölte, 2025). These findings challenge the assumption that weight and shape concerns play a lesser role in the development and maintenance of EDs in autistic women. They also contrast with Brede et al. (2024), who reported lower levels of disordered eating and fewer weight and shape concerns in autistic women with restrictive EDs compared to their non-autistic counterparts. A potential explanation is that Brede et al. (2024) grouped autistic women with ARFID and (atypical) AN, meaning some exhibited restrictive eating not driven by weight and shape concerns. One possible explanation for the heightened weight and shape concerns in our study is that autistic women may view their weight and shape as a means of social integration. Previous qualitative research suggests that some autistic women focus on their weight and shape as a way to conform to neurotypical social norms (Brede et al., 2020; Healy et al., 2021). Additionally, cognitive styles common in autism, such as literal



thinking and black-and-white reasoning, may exacerbate these concerns, reinforcing rigid perceptions of what to weigh and how to look (e.g., “If I’m not thin, then I’m fat and horrible”) (Brede et al., 2020; Longhurst, 2023). However, it is important to note that the Dutch validation study of the EDE-Q (Aardoom et al., 2012) did not support the instrument’s theorized four-factor structure, including the subscales for weight and shape concern. This limitation warrants caution in interpreting these subscales. Nevertheless, given the assumption that autistic women with EDs experience weight and shape concerns differently, our findings underline the need for further research to critically assess this belief and clarify their role in this population.

Our results confirm clinical and empirical observations that ED presentations in autistic women tend to be particularly severe and complex (Nimbley et al., 2025; Zhang et al., 2022). This complexity appears to stem from the interplay of high levels of autism-related and disordered eating behaviors, where both adaptive (e.g., food selectivity to manage sensory issues) and maladaptive behaviors (e.g., food restriction due to weight and shape concerns) are simultaneously present. The co-occurrence of ARFID symptoms, such as a fear of choking or gastrointestinal distress, further complicates this clinical picture. This overlap poses significant clinical challenges. On the one hand, some autism-related eating behaviors may be mistakenly pathologized as disordered eating behaviors. On the other, ED pathology may be misattributed to autistic characteristics, leading to potential misdirection in treatment (Longhurst et al., 2024). Moreover, findings on the BSI and MHQoL suggest that autistic women with EDs experience particularly severe psychological distress, with higher levels of comorbid symptoms and a significantly lower mental health-related quality of life than all other groups.

The findings highlight the pressing need for tailored treatment approaches that consider the unique eating behaviors observed in autistic women with EDs. Standard ED treatments, such as CBT-E, may require modifications to accommodate altered sensory processing, differences in information processing, rigid thinking styles and differences in social communication. A critical component of autism-informed ED care is distinguishing adaptive eating behaviors (e.g., food selectivity to manage sensory sensitivities or difficulties with novelty) from maladaptive behaviors that contribute to ED pathology (e.g., restriction due to weight concerns). Developing additional treatment modules focused on this distinction could help clinicians validate and support beneficial eating strategies while effectively addressing harmful behaviors such as bingeing, purging, or extreme dietary restriction. In this context, clinicians should remain cautious not to over-attribute eating behaviors to autism alone, as weight and shape concerns might remain a significant factor in this group despite previous assumptions. While some autistic women with EDs may benefit from adapted interventions - such as sensory-informed strategies or modifications to cognitive-behavioral approaches - clinical experience also shows that others respond

well to standard treatments without the need for adjustments. This subgroup may have lower levels of sensory sensitivity or greater cognitive flexibility, which could reduce the need for modifications. Additionally, some may prioritize weight and shape concerns over autism-related challenges, making traditional ED treatment targets possibly more relevant and effective. Recognizing this variability is essential in tailoring care without assuming that all autistic individuals require fundamentally different approaches.

Beyond identifying adaptive and maladaptive behaviors, practical modifications to ED treatment may help autistic women engage more effectively in therapy. These could include providing a structured and predictable treatment environment, adapting therapy pace to accommodate information processing differences, or offering sensory-informed nutritional rehabilitation, taking into account individual sensory profiles (Tchanturia et al., 2020). By implementing these modifications and creating an autism-friendly treatment environment, clinicians may improve treatment accessibility and outcomes for autistic women with EDs. Future research should explore how such autism-adapted interventions impact treatment efficacy and long-term recovery trajectories. Additionally, ensuring participatory approaches in treatment development is crucial (Lundin Remnélius et al., 2022). Autistic individuals need to be actively involved in discussions on how to incorporate autism-specific factors into therapy, particularly sensory sensitivities and cognitive rigidity. Moreover, their perspectives could provide valuable insights into how weight and shape concerns should be interpreted and addressed in treatment, ensuring that interventions align with their lived experiences and clinical needs.

Strengths, Limitations, and Future Directions

This study has several methodological strengths, including thorough diagnostic assessments to confirm autism diagnoses and the inclusion of both autistic and non-autistic control groups. However, several limitations should be acknowledged. First, height and weight data were self-reported rather than clinically measured. While this approach ensured consistency across all groups, it may have introduced bias. The use of self-report measures may have also influenced how participants interpreted questionnaire items, making it difficult to determine whether certain behaviors reflect autism-related behaviors or disordered eating behaviors. Second, while our sample size was adequate for the planned group comparisons, it was not sufficient to conduct covariate-adjusted or mediation analyses, nor to explore differences between ED subtypes within groups. Although our inclusion of various ED subtypes reflects the clinical reality that comorbid autism occurs across ED diagnoses, it is likely that additional factors — such as ED subtype and symptom severity — may further shape the eating behaviors of autistic women with EDs. The current study was not designed to examine such differences, and this represents an important avenue for future research. Relatedly, we did not control for potentially confounding variables such as age and education, which may have influenced the findings. Future research should investigate whether age-related

factors — such as increased life experience or improved coping mechanisms — help buffer against the development of disordered eating in autistic individuals without EDs. Third, although we observed similar picky eating patterns across the three diagnostic groups, this study was not designed to disentangle whether these behaviors are autism- or ED-driven, nor to identify the underlying mechanisms linking sensory sensitivities, ARFID symptoms and traditional ED pathology. We also did not include individuals with ARFID to focus on autistic women with traditional ED profiles. While this was a deliberate decision, it limits the conclusions about the overlap between ARFID symptoms and autism-related eating behaviors. Additionally, given that cultural context may shape eating behaviors and weight and shape concerns, the use of a Dutch-only sample may limit generalizability and partially may explain differences from studies conducted in other countries, such as Brede et al. (2024). Finally, as multiple statistical comparisons were conducted without formal correction, there is a risk of type I error. However, this decision was based on the exploratory aim of the study and the interdependence of the measures, which made conservative corrections, such as Bonferroni correction, inappropriate due to the risk of overlooking meaningful effects.

Future research may want to investigate eating behaviors and potential mechanisms underlying weight and shape concerns in autistic women with various subtypes of EDs and consider how autistic characteristics (such as altered sensory processing or differences in thinking styles) and comorbid symptoms interact in the development and maintenance of ED pathology (Black & Bölte, 2025; Brede et al., 2024). Additionally, future work should explore how overlapping or co-occurring symptoms (e.g., ARFID symptoms and autism-related eating behaviors) interact with traditionally disordered ED behaviors and influence treatment response. Investigating whether sensory accommodations in treatment may inadvertently reinforce restrictive eating would also be valuable. Finally, research should evaluate how specific treatment adaptations — such as sensory informed interventions, or modifications to CBT-E — can be matched to individual profiles, supporting a flexible, personalized approach to care.

CONCLUSIONS

This study highlights the complex and multifaceted nature of ED presentations in autistic women, emphasizing both shared and distinct features, compared to nonautistic women with EDs and autistic women without EDs. The findings challenge previous assumptions about the limited role of weight and shape concerns and underscore the importance of tailored interventions that address both autism-related and traditionally disordered eating behaviors. By developing strategies to distinguish between adaptive and maladaptive behaviors and fostering a more autism-friendly treatment environment, clinicians and researchers can improve treatment effectiveness and better meet the needs of this population.



Chapter 5:

The Association Between Cognitive Flexibility and Eating Behaviors in Autistic Women with Eating Disorders

Schröder, S. S., Danner, U. N., Spek, A. A., & van Elburg, A. A. (2025). The association between cognitive flexibility and eating behaviors in autistic women with eating disorders. Submitted for publication.



ABSTRACT

Background: Reduced cognitive flexibility is a trait often associated with autism and has also been implicated in eating disorders (EDs). However, most studies have not distinguished between autistic and non-autistic individuals in ED samples, potentially obscuring group-specific patterns. This study investigated cognitive flexibility and its association with eating behaviors — including traditional ED pathology and ARFID symptomatology — across four groups: autistic women with EDs (ASD+ED), non-autistic women with EDs (ED), autistic women without EDs (ASD), and non-autistic controls.

Method: Participants included 30 ASD+ED, 30 ED, 29 ASD, and 60 control women (N=149). All completed the Detail and Flexibility Questionnaire (DFlex), the Eating Disorder Examination Questionnaire (EDE-Q), and the Nine Item ARFID Screen (NIAS). Group comparisons were conducted on cognitive flexibility (cognitive rigidity, attention to detail) and eating behaviors (ED pathology, ARFID symptoms). Associations between cognitive flexibility and eating behaviors were examined across and within groups.

Results: ASD+ED and ASD groups showed significantly greater impairments in cognitive flexibility than ED and control groups, which did not differ from each other. Attention to detail was associated with ED pathology in the ASD+ED group, and with ARFID symptomatology in the ASD+ED, ASD, and control groups — but not in the ED group.

Conclusion: These findings suggest that reduced cognitive flexibility — particularly attention to detail — may play a more central role in the eating behaviors of autistic individuals than in EDs alone, challenging assumptions in standard ED treatment approaches.

AUTHOR CONTRIBUTIONS

Sabrina Schröder: Conceptualization, Formal Analysis, Investigation, Methodology, Writing – Original Draft Preparation, Writing – Review & Editing

Unna Danner: Conceptualization, Formal Analysis, Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annelies Spek: Conceptualization, Formal Analysis Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Annemarie Van Elburg: Conceptualization, Formal Analysis Methodology, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

INTRODUCTION

The presentation of eating disorders (EDs) is often complex – particularly in individuals with co-morbid autism spectrum disorder (henceforth autism). People with both disorders frequently exhibit a combination of traditionally disordered eating behaviors such as restriction driven by weight or shape concerns, and behaviors often associated with autism, including food selectivity, rigid meal routines, and sensory-related eating difficulties. This group tends to benefit less from standard interventions and exhibits poorer treatment outcomes (Nimbley et al., 2025; Zhang et al., 2022).

A complicating factor for treatment related to both conditions is reduced cognitive flexibility (CF) — the ability to shift between mental tasks, perspectives, or strategies in response to changing demands (Dajani & Uddin, 2015). CF comprises two interrelated components: set-shifting — the ability to switch between mental sets — and central coherence, the tendency to process information globally rather than locally (Happé & Frith, 2006; Miles et al., 2020). Deficits in these domains are thought to underlie a rigid, repetitive, and detail-focused cognitive style, commonly observed in both autism and EDs (Lang et al., 2014; Sternheim et al., 2022).

Reduced CF has been described as a defining feature of autistic individuals (Happé & Ronald, 2008; Van Eylen et al., 2011). Autistic individuals frequently engage in restrictive and repetitive patterns of interest and activity (American Psychiatric Association, 2013) and show a preference for sameness and heightened attention to detail (Petrolini et al., 2023). Reduced CF has been proposed to be related to the eating behaviors of autistic individuals, including selective eating, food aversions, and a heightened need for predictable meal routines (Schröder et al., 2022). These behaviors may reflect a broader difficulty adapting to change or novelty in the sensory or social aspects of eating.

Similar reduced CF has been reported in individuals with EDs, though findings vary depending on factors such as illness duration, age, or symptom profile (Miles et al., 2020). Nonetheless, reduced CF is suggested to contribute to rigid eating behaviors such as strict food rules, compulsive exercise, or perseverative thinking around food and weight, and has been linked to poorer treatment engagement and increased relapse risk (Danner, Sanders, et al., 2012; Sternheim et al., 2022; Treasure & Schmidt, 2013).

Importantly, most prior research has not separated autistic from non-autistic individuals in ED samples, potentially obscuring meaningful group differences in cognitive traits. Given that reduced CF is a trait often associated with autism, distinguishing between diagnostic subgroups may offer a clearer understanding of how specific cognitive styles relate to eating behaviors. This study examines the association between CF and eating behaviors in autistic



women with EDs, compared to non-autistic women with EDs, autistic women without EDs, and non-autistic controls.

METHOD

Study Design

This study used data from a larger cross-sectional project (Schröder et al., 2025) on eating behaviors in autistic women with EDs. Participants completed several questionnaires. The study was approved by the Medical Research Ethics Committee in Utrecht, the Netherlands (NL74635.041.20), Altrecht Mental Health Institute's Institutional Review Board and pre-registered with the Dutch OMON registry (NL-OMON20463).

Participants

Participants included 30 autistic women with EDs (ASD+ED), 30 non-autistic women with EDs (ED), 29 autistic women without EDs (ASD), and 60 age-matched non-autistic female controls. Clinical participants were recruited through Altrecht Eating Disorders Rintveld (ASD+ED and ED) and the Autism Expertise Centrum (ASD). Controls were recruited via Utrecht University. All were 18+ and provided informed consent. Exclusion criteria were: education below primary level, intellectual disability, or insufficient Dutch language skills. No participants were excluded on this basis.

ASD+ED and ED Group

Women in the ASD+ED and ED group were included if they had both an autism spectrum disorder and an ED diagnosis (ASD+ED group) or a sole ED diagnosis (ED group), according to DSM-5 criteria (American Psychiatric Association, 2013). Participants in the ED group who scored above the Autism Spectrum Quotient-50 (AQ-50; Baron-Cohen et al., 2001) cut-off of 112 (Wouters & Spek, 2011) were excluded from study participation. The ASD+ED group consisted of a total of four participants with anorexia nervosa (AN) binge-purge type, 14 with AN restrictive type, three with bulimia nervosa (BN) and nine with other specified feeding or eating disorder (OSFED), whereas the ED group consisted of three participants with AN binge-purge type, 12 with AN restrictive type, seven with BN and eight with OSFED.

ASD group

The ASD group included women with a DSM-5 ASD diagnosis (American Psychiatric Association, 2013). Those with a (lifetime) ED, were excluded from study participation (see below).

Control Group

Controls were eligible for inclusion if they had no current or past psychiatric illnesses as determined by the M.I.N.I International Neuropsychiatric Interview (Sheehan et al., 1998) and if they did not have a previous ASD diagnosis. Those who scored above the AQ-50 cut-off of 112 were excluded from the study.

Procedure and Instruments

All participants underwent standardized diagnostic procedures to confirm ED and/or autism diagnoses according to DSM-5 criteria. Eligibility was verified through structured interviews and screening protocols. After diagnostic confirmation, participants completed an online assessment battery covering eating behavior, cognitive traits, and clinical characteristics. CF was assessed with the Detail and Flexibility Questionnaire (DFlex; Roberts et al., 2011; Sternheim et al., 2022), yielding two subscales: cognitive rigidity and attention to detail (Cronbach's $\alpha > .89$). ED pathology was measured using the global score of the Eating Disorder Examination Questionnaire (EDE-Q; Aardoom et al., 2012; Fairburn & Beglin, 1994; $\alpha = .98$). ARFID symptomatology was assessed with the Nine Item ARFID Screen (NIAS; Zickgraf & Ellis, 2018), using the total score ($\alpha > .89$). See Schröder et al. (2025) for full scoring details.

Data Analysis

Statistical analyses were performed using IBM SPSS Statistics version 29. Demographic and clinical characteristics were compared between the four groups using univariate ANOVAs and independent samples t-tests. Outcomes on eating behavior (ED pathology and ARFID symptomatology) and CF (cognitive rigidity and attention to detail) were compared using univariate ANOVAs and Tukey's post-hoc pairwise comparisons to examine significant group differences. To examine associations between CF and eating behavior, four separate regression analyses with the General Linear Model were conducted, with each DFlex subscale as predictor for each type of eating behavior.

RESULTS

Demographics and Clinical Characteristics

Demographic and clinical characteristics are shown in **Table 5.1**. ASD participants were older and had more years of education than the ASD+ED group. As expected, ED and ASD+ED groups had lower BMI than ASD and control groups. Age of ED onset and illness duration did not differ between ED and ASD+ED groups. ASD participants received their autism diagnosis later than ASD+ED participants.



Table 5.1 Mean (and SD) of Descriptive Variables: Demographic and Clinical Characteristics per Group (ED Group, ED+ASD Group, ASD Group and Controls), and Group Differences on DFlex, EDE-Q And NIAS.

	ED+ASD (n = 30)		ED (n = 30)		ASD (n = 29)		Controls (n = 60)		<i>F</i> (3,145)	<i>p</i>	η^2	<i>t</i>
	Mean	SD	Mean	SD	Mean	SD	Mean	SD				
Age	24.23^c	7.36	31.13	13.29	34.72^a	12.11	29.40	9.71	5.01*	.002	.09	
Years of Education	13.63^c	3.30	15.92	2.77	17.00^{a,d}	3.85	16.10^c	3.76	5.08*	.002	.10	
BMI	18.82^{c,d}	3.92	18.78^{c,d}	2.93	24.36^{a,b}	4.24	23.20^{a,b}	3.36	21.88**	< .001	.31	
Age of Onset of Eating Disorder	16.60	4.45	18.63	6.54	-	-	-	-	-	.164	-	1.41
Illness Duration of Eating Disorder (years)	7.63	6.21	12.50	13.05	-	-	-	-	-	.007	-	1.84
Age of Autism Diagnosis	20.97^c	8.12	-	-	33.10^a	11.62	-	-	-	.037	-	4.64**
EDE-Q Global	4.22^{b,c,d}	1.12	3.39^{a,c,d}	1.36	1.06^{a,b}	0.86	0.74^{a,b}	0.72	111.63**	< .001	.70	
NIAS Total	21.43^{b,c,d}	9.58	15.40^{b,d}	9.45	13.79^{a,d}	8.89	4.58^{a,b,c}	5.36	33.83**	< .001	.41	
DFlex CR	54.17^{b,d}	8.74	36.60^{a,c}	7.01	51.93^{b,d}	7.23	32.32^{a,c}	9.85	61.34**	< .001	.56	
DFlex AD	52.03^{b,d}	9.58	32.90^{a,c}	9.14	49.83^{b,d}	7.54	28.72^{a,c}	10.40	58.83**	< .001	.55	
DFlex Total	106.20^{b,d}	17.21	69.50^{a,c}	14.24	101.76^{b,d}	13.44	61.03^{a,c}	18.90	70.49**	< .001	.59	

Note: * $p < .05$, ** $p < .001$. BMI, body mass index. DFlex CR, Detail and Flexibility Questionnaire cognitive rigidity subscale. DFlex AD, Detail and Flexibility Questionnaire attention to detail subscale. DFlex total, Detail and Flexibility Questionnaire total score. ^A Different from ED+ASD group; ^b Different from ED group; ^c Different from ASD group; ^d Different from control group.

Eating Behaviors (EDEQ and NIAS)

On the EDE-Q global score, the ASD+ED group reported the highest ED pathology, followed by the ED group. ASD and control participants showed similar, lower scores. On the NIAS, ASD+ED participants reported the highest ARFID symptomatology, while ASD and ED groups scored similarly and higher than controls.

Cognitive Flexibility — DFlex

Regarding overall CF (DFlex total), the ASD+ED as well as the ASD group showed similar impairments in CF, both greater than the ED group and controls, which in turn did not differ from each other. In terms of the subscales *cognitive rigidity* (DFlex CR) and *attention to detail* (DFlex AD), similar results were observed: ASD+ED and ASD groups reported similar levels of cognitive rigidity and attention to detail, and more than the ED group and controls, which did not differ on these subscales.

Association Between Cognitive Flexibility and ED Pathology

Across all groups, analyses showed a main effect of overall CF (DFlex total) on ED pathology (EDE-Q global), $F(3,141)=3.20$, $p=.025$, $\eta_p^2=.06$. When examining the DFlex subscales separately, analyses revealed a main effect of attention to detail on ED pathology, $F(3,141)=3.60$, $p=.015$, $\eta_p^2=.07$, but no main effect of cognitive rigidity on ED pathology (EDE-Q global), $F(3,141)=2.53$, $p=.060$, $\eta_p^2=.05$. When looking at each group separately, analyses revealed a main effect of overall CF on ED pathology in the ASD+ED and in the control group, $F(1,28)=31.22$, $p<.001$, $\eta_p^2=.53$ and $F(1,58)=6.31$, $p=.015$, $\eta_p^2=.10$ respectively. No effects were observed in the ASD and ED group, all $p's>.09$. Additionally, a main effect of attention to detail on ED pathology was found within the ASD+ED group $F(1,28)=30.99$, $p<.001$, $\eta_p^2=.53$, but not within the other groups, all $p's>.06$.

Association Between Cognitive Flexibility on ARFID Symptomatology

Across all groups, a main effect of overall CF (Dflex total) on ARFID symptomatology (NIAS total) was found, $F(3,141)=3.24$, $p=.024$, $\eta_p^2=.07$. When examining the DFlex subscales separately, analyses revealed a main effect of attention to detail, $F(3,141)=3.63$, $p=.015$, $\eta_p^2=.07$, but no effect of cognitive rigidity on ARFID symptomatology, $F(3,141)=1.78$, $p=.153$, $\eta_p^2=.04$. When looking at each group separately, there was a main effect of attention to detail on ARFID symptomatology in the ASD+ED, ASD and control group, $F(1,28)=12.05$, $p=.002$, $\eta_p^2=.30$, $F(1,27)=20.28$, $p<.001$, $\eta_p^2=.43$ and $F(1,58)=10.90$, $p=.002$, $\eta_p^2=.16$ respectively. No effect was found in the ED group, $p=.16$.

DISCUSSION

This study investigated CF and its association with eating behaviors (ED pathology and ARFID symptomatology) in autistic women with EDs. Autistic women, regardless of ED status, reported greater impairments in CF — in both cognitive rigidity and attention to detail — than non-autistic women with EDs and controls. Attention to detail was associated with ED pathology in the ASD+ED group, and with ARFID symptomatology in the ASD+ED, ASD, and control groups — but not in the ED group — suggesting that this trait may reflect autism-related or general cognitive styles rather than ED-specific pathology.

Contrary to prior research suggesting widespread impairments in CF in ED populations, this study found no evidence of such impairments in non-autistic women with EDs. This raises the possibility that previous findings were influenced by undetected autism within ED samples. Given that autism and EDs can co-occur — and may obscure or mimic each other's presentation — it is critical to assess both when examining cognitive traits (Schröder et al., 2023). These findings also call into question the assumption that impairments in CF are intrinsic to EDs, suggesting that interventions such as Cognitive Remediation Therapy

(CRT) – a structured intervention originally developed for longstanding EDs to improve CF – may not be appropriate for all individuals.

Among autistic women with EDs, attention to detail emerged as a key factor associated with increased ED pathology and ARFID symptomatology. This supports prior work suggesting that heightened focus on features of food — such as calorie content, texture, or visual appearance — may be associated with disordered eating behaviors (Wang et al., 2021). This may be especially relevant for autistic individuals, where pre-existing impaired cognitive flexibility may increase vulnerability to rigid or restrictive eating patterns (Schröder et al., 2023). Moreover, attention to detail may promote fixation on ED-relevant rituals such as calorie counting, body checking, or scrutinizing body parts, which can perpetuate symptoms and impede treatment (Wang et al., 2021). In contrast, cognitive rigidity showed no consistent associations, highlighting the importance of examining attention to detail and cognitive rigidity as distinct dimensions of CF in ED research.

Clinically, these findings support the need for differentiated assessment and treatment approaches in ED populations. Routine assessment of autism and related cognitive traits may help identify individuals who respond less well to standard interventions and inform the development of autism-sensitive interventions (Nimbley et al., 2025; Schröder et al., 2025). Originally developed for individuals with longstanding EDs and later adapted for autistic populations, CRT has shown promising results when autism-specific adaptations are made (Dandil, Baillie, et al., 2020; Dandil, Smith, et al., 2020; Tchanturia et al., 2016). By enhancing perspective-shifting and reducing over-focus on detail, CRT may help reduce rigid eating behaviors and enhance treatment engagement. Controlled studies are needed to evaluate the effectiveness of autism-adapted CRT in this subgroup.

Beyond the modest sample size, other limitations include the heterogeneity of the sample that may obscure subtype-specific patterns, and the Dutch nature of the sample, limiting generalizability across cultural or healthcare contexts. Future studies should assess whether targeting reduced CF can improve outcomes in autistic individuals with EDs. Overall, this study highlights the importance of considering comorbid autism in ED research and suggests that cognitive inflexibility may be more strongly linked to autism than to EDs alone.



Chapter 6:

General Discussion



MAIN QUESTION AND AIMS

This thesis aims to address gaps in the understanding of EDs in autistic women by systematically examining how their eating behaviors compare to those of non-autistic women with EDs, autistic women without EDs, and non-autistic controls. The primary focus is on comparing a broad range of eating behaviors — including traditionally disordered eating behaviors, autism-related eating behaviors, ARFID symptomatology, and picky eating — across these groups. In addition, an exploratory assessment of psychological distress and mental-health related quality of life is included in order to better contextualize the clinical complexity of this group. Additional attention is paid to the role of cognitive flexibility, a neurocognitive trait known to differ in both autistic and ED populations, in shaping these patterns. The overarching goal is to generate a more nuanced understanding of how EDs present in autistic women — one that reflects the interplay between autism characteristics and ED symptomatology, and that can inform more appropriate and effective forms of care. This thesis explores these questions through a combination of theoretical, empirical, and clinical perspectives, with each chapter contributing to a more integrated understanding of EDs in autistic women.

Every chapter contributes uniquely to building this broader understanding. **Chapter 2** highlights that, although problematic eating behaviors in autistic women are increasingly acknowledged, the empirical literature remains limited and fragmented — often excluding autistic adults or failing to consider gender-specific presentations. **Chapter 3** offers a conceptual paper that explores the intersection of autism and EDs, drawing on clinical experience, research, and theoretical reasoning to argue that traditional ED models often fail to account for the lived experiences of autistic women. It also discusses implications for assessment, diagnosis, and treatment adaptation. **Chapter 4** presents empirical evidence showing that autistic women with EDs report both traditionally disordered and autism-related eating behaviors, along with elevated ARFID symptomatology, higher psychological distress, and lower mental health–related quality of life compared to other groups. **Chapter 5** examines one potential underlying mechanism — cognitive flexibility — and finds it to be more strongly linked to eating difficulties in autistic than in non-autistic women. Collectively, these findings underscore that current diagnostic frameworks may not fully account for the complexity of ED presentations in autistic women, and point toward the need for personalized, autism-informed approaches in both research and care.



SUMMARY OF KEY FINDINGS

Dual Presentation of Eating Behaviors in Autistic Women with EDs

The clearest theme emerging from this thesis is that autistic women with EDs present with a dual pattern of eating behaviors. **Chapters 2** and **4** provide converging evidence that autistic women with EDs exhibit a dual presentation, characterized by both autism-related behaviors (e.g., food related sensory difficulties, food selectivity or meal-related rigidity), and traditionally disordered eating behaviors (e.g., dietary restraint, fear of weight gain, bingeing or purging). Notably, **Chapter 4** shows that autistic women with EDs score higher than all other groups — including non-autistic women with EDs — on measures of disordered eating, autism-related eating behaviors, ARFID symptomatology, and picky eating. This pattern not only underscores the complexity of their eating difficulties but also suggests a high level of clinical need that may not be adequately addressed by standard assessment and treatment approaches. Such approaches typically conceptualize eating behaviors primarily through an ED lens — focusing on weight and shape concerns as core drivers of pathology (NICE, 2017; Fairburn, 2008) — and may misinterpret autism-related eating behaviors such as food avoidance due to sensory sensitivities, as disordered rather than adaptive (Kinnaird, Norton, Stewart, et al., 2019; Lundin Remnélius & Bölte, 2025). They also tend to overlook autism-specific features, including literal thinking, black-and-white reasoning, differences in social communication, and altered sensory processing, which can shape how eating difficulties are experienced and maintained in this group (Brede et al., 2020). Together, these findings point to the need for more nuanced conceptualizations of eating difficulties in autistic women with EDs — models that move beyond traditional ED frameworks.

This mismatch is further echoed in the voices of autistic women themselves. As reviewed in **Chapter 2**, many report feeling misdiagnosed, misunderstood, or poorly served by current treatment systems. They describe falling between the cracks of services that are not designed to accommodate the interplay of autism-related traits and ED symptoms. These experiences reinforce calls in the clinical literature (e.g., Brede et al., 2020, 2024; Kinnaird, Norton, Stewart, et al., 2019) for more personalized and autism-informed assessment approaches that can better capture the complexity of this population.

While a range of factors may contribute to these complex eating profiles, this thesis empirically examines one mechanism in particular — cognitive flexibility — a trait frequently implicated in both autism and EDs.

The Role of Cognitive Flexibility

Chapter 5 explores the role of cognitive flexibility in shaping eating behaviors. Impairments in this domain — suggested to be common in both autistic and ED populations — may play a

more central role in the eating difficulties (ED pathology and ARFID symptoms) experienced by autistic individuals than in non-autistic individuals with EDs. Both autistic groups — regardless of ED status — reported significantly more impaired cognitive flexibility than non-autistic groups, reinforcing its relevance as a core neurocognitive feature in autistic individuals.

In this context, attention to detail — assessed as a subcomponent of cognitive flexibility — was associated with both ED pathology and ARFID symptoms in autistic individuals, but not in non-autistic individuals with EDs. This suggests that attention to detail may become clinically relevant when it contributes to maladaptive eating behaviors, particularly in combination with other autism-related traits such as black-and-white thinking, cognitive rigidity, or sensory sensitivities. In such cases, a strong detail focus may reinforce rigid food rules or obsessive calorie tracking, and clinicians may need to differentiate when this trait supports helpful structure versus when it maintains distress — adapting interventions accordingly. While cognitive rigidity was also elevated in autistic individuals, it did not show a direct association with eating difficulties in this study, indicating that different facets of impaired cognitive flexibility may have distinct roles depending on the behavioral context.

These cognitive mechanisms appear to not only influence the form eating behaviors take, but also how they are maintained over time, highlighting the need for tailored interventions. The findings support and extend the model proposed by Brede et al. (2020), which posits that EDs in autistic individuals may be maintained through a combination of sensory sensitivities, cognitive rigidity, and detail-oriented processing. **Chapter 2** similarly emphasizes that traditional ED models often overlook these features. Incorporating autism-specific cognitive and sensory mechanisms into both theoretical models and clinical formulations may improve our ability to understand and support this population.

High Psychological Burden and The Need for Broader Support

Crucially, this complexity is compounded by a high level of psychological burden, which may further interfere with recovery and help-seeking. **Chapter 4** shows that autistic women with EDs score higher than all other groups on measures of relevant psychological symptoms, reporting greater overall distress as well as a broader and more severe range of comorbid symptoms. They also reported significantly lower mental health–related quality of life. These findings are consistent with studies showing elevated rates of anxiety, depression, emotion regulation difficulties, trauma exposure, and PTSD symptomatology in this group (Bruggink et al., 2016; Hollocks et al., 2019; Rumball et al., 2021). The literature reviewed in **Chapter 2** likewise highlights how these individuals often face chronic invalidation, exclusion from services, and a sense of being “too complex” for treatment settings (e.g., Babb et al., 2021, 2022; Tchanturia et al., 2020).



These findings underscore the importance of developing care pathways that are both autism-informed and sensitive to the high psychological burden reported by this group. Clinicians should anticipate co-occurring emotional and psychological challenges alongside the ED and systematically assess psychological distress across different symptom domains. In addition, clinical experience suggests that many autistic women with EDs struggle not only with psychological symptoms but also with broader challenges in daily life — such as finding structure, coping with overwhelming life demands, or navigating questions of identity and meaning. While these issues are not directly assessed in the current research, they are frequently observed in clinical practice and may shape the context in which ED behaviors emerge. ED services might therefore benefit from working collaboratively with autism-specialized care to offer broader, life-oriented support that addresses daily functioning and sources of meaning, in addition to ED symptomatology.

Weight and Shape Concerns

A further layer of complexity emerges in relation to weight and shape concerns — an area long debated in the context of autism and EDs. Contrary to longstanding assumptions that these issues are marginal in autistic individuals with EDs (e.g., Kinnaird, Norton, Stewart, et al., 2019; Lundin Remnélius & Bölte, 2025), our findings show that such concerns are clearly present and notably elevated in this group. In the general population, concerns about weight and shape are often rooted in internalized sociocultural ideals that equate thinness with attractiveness, success, and self-worth (Evans, 2003; Jankauskiene & Baceviciene, 2022; Thompson & Stice, 2001). Such ideals are reinforced through media, peer comparison, and dominant health narratives, and are known to contribute to body dissatisfaction and the development of disordered eating (Frayn & Knäuper, 2018; Marks et al., 2020). While these frameworks help explain body image disturbance in many individuals, the elevated weight and shape concerns observed in autistic women with EDs raise the possibility that additional or alternative mechanisms may be at play in this group.

Our findings warrant greater clinical attentiveness to the presence of weight and shape concerns in autistic individuals — rather than assuming their absence — and suggest that such concerns may manifest in distinct ways. They also underscore the importance of moving beyond surface-level assumptions about what drives weight and shape concerns in autistic women with EDs. While some individuals may indeed internalize societal ideals, others may pursue weight and shape goals for reasons rooted in autistic cognition — such as a need for predictability, a tendency toward black-and-white reasoning, or a desire to fit in. Misinterpreting these underlying motivations could result in interventions from which patients cannot sufficiently benefit. Future theoretical models should therefore incorporate autism-specific cognitive and social mechanisms when conceptualizing weight and shape concerns in this group, with particular attention to how these factors interact with ED pathology over time. In parallel, empirical research should further examine the specific content, function,

and developmental course of weight and shape concerns in autistic individuals to better inform targeted treatment approaches.

These layers of complexity raise important questions about how to best identify autism in ED populations before tailoring interventions.

DIAGNOSTIC CONSIDERATIONS

Before such personalized treatment can be delivered, however, it is crucial to ensure thorough and careful diagnostic assessment — particularly given the significant symptom overlap between autism and other psychiatric conditions. Clinicians should be mindful of the ways in which autism may present differently in women, often with subtler, camouflaged traits that can be easily misinterpreted as symptoms of other conditions, or the ED itself (Attwood, 2006; Hull, Lai, et al., 2020; Mandy et al., 2012; Oswald et al., 2016). A key part of this process is the inclusion of a developmental anamnesis. Carefully exploring functioning and behavior prior to ED onset can help distinguish enduring autistic traits from state-dependent symptoms — such as rigidity due to malnutrition or social withdrawal secondary to the ED. This distinction is vital not only for making a correct diagnosis, but also to avoid overdiagnosing autism in individuals whose presentation may be better explained by other conditions. While there is growing attention to the presumed high prevalence of autism in ED populations (e.g., Vagni et al., 2016; Westwood & Tchanturia, 2017), this suggestion does not hold up when looking at studies that employ comprehensive autism assessments, including developmental anamneses, as described in **Chapter 3**. At Rintveld, a structured autism screening procedure was implemented in routine clinical practice: all patients entering care were screened using the screening questions described in **Chapter 4**. Those who screened positive were referred for comprehensive autism assessments. Even within this pre-screened group, only a small proportion (approximately 15 to 20%) ultimately received an autism diagnosis. The majority were more accurately diagnosed with other conditions — such as avoidant personality disorder, obsessive-compulsive personality disorder or attachment-related difficulties. These observations underscore the need for assessors to have specific expertise in both autism and EDs, as well as a nuanced understanding of how autism — and its differential diagnoses — may present in this population. Inaccurate or premature labeling may not only lead to overdiagnosing autism but also obscure the individual's actual needs and hinder engagement with appropriate care.



CLINICAL IMPLICATIONS AND TREATMENT INNOVATIONS

Ultimately, this thesis advocates for a shift in perspective: from asking how autistic women fit into existing ED models, to asking how ED care can better fit the lived experiences of autistic women. This vision reflects a necessary shift away from one-size-fits-all treatment models toward a more person-centered and precise approach — one that honors individual variation, validates autistic experiences, and supports both recovery and long-term well-being.

The PEACE Pathway in the UK (Tchanturia et al., 2020) provides a strong example of a service-level response to improving care for autistic individuals with EDs. The program includes autism training for staff, sensory-friendly adaptations, and collaborative care planning. Early evaluations show promising results in improving patient experience and treatment outcomes, highlighting the value of integrating autism-informed principles into mainstream ED services (Li et al., 2024).

While promising, such interventions are still emerging and not yet common practice. Future treatment programs may benefit from being designed with flexibility, co-creation, and autism-informed principles at their core. This includes the recognition — also echoed in the conclusion — that for some autistic patients, standard ED treatments may be entirely appropriate, provided they are delivered with suitable adaptations. For others, a hybrid or entirely different care pathway may be more suitable.

An integrated care model for autistic individuals with EDs would ideally include early autism screening, opportunities for shared formulation, and tailored treatment plans that incorporate autism-informed adaptations. These adaptations may address sensory sensitivities, core cognitive traits, and communication preferences. Crucially, such care would also consider the broader life context — supporting patients in building a life that fits, not just reducing symptoms. Multidisciplinary teams with expertise in both EDs and autism are well-positioned to offer this kind of holistic, person-centered support.

Our findings converge on a core implication: current ED treatment models require thoughtful adaptation to address the nuanced needs of autistic women. Effective care begins with a solid diagnostic foundation. When autism has not yet been formally assessed, clinicians may want to initiate appropriate diagnostic evaluations — ideally before commencing ED treatment — to better understand the full picture.

From there, a key step is individualized formulation: clinicians are encouraged to collaboratively explore whether standard ED treatment is appropriate for the individual at hand, or whether a different or additional approach is required. For some autistic patients, disordered eating may dominate, with only minor, adaptive autism-related eating behaviors.

For others, a complex, intertwined pattern of maladaptive ED and autism-related behaviors may require dual focus and integrated intervention. These questions are best explored jointly with the patient through psychoeducation and shared formulation, supporting the development of personalized and achievable goals that honor both the eating difficulties and the broader neurodevelopmental context.

In practice, several domains require attention:

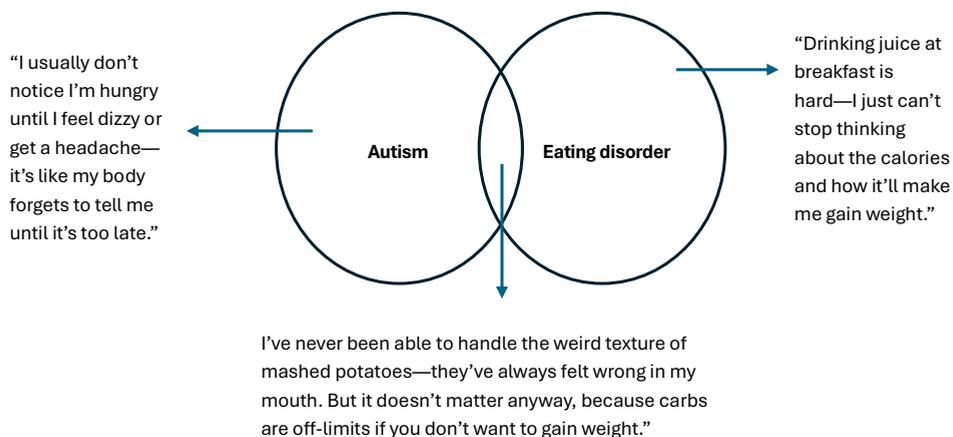
- **Autism-informed assessment and treatment planning**, including exploration of sensory sensitivities (What was present before the ED? What may be ED-related?) and core cognitive styles (e.g., black-and-white thinking, rigidity, detail focus).
- **Respecting autism-specific communication and information-processing styles** and adapting the therapeutic frame where helpful — for example by offering structure, clarity, or visual supports.
- **Expanding the focus beyond eating behaviors**, by asking: Does this person have a life that suits them? Are they overwhelmed, socially isolated, or lacking in meaning? In many cases, an ED may serve as a coping mechanism for deeper unmet needs. Collaboration with autism-specialized coaches or clinicians can be key — particularly when life struggles related to autism are hindering ED recovery or engagement in treatment.

To support such tailored work, specific psychoeducational tools can be helpful. One example is the autism-ED psychoeducational module currently used at Altrecht Eating Disorders Rintveld. This module helps patients and clinicians disentangle ED-related and autism-related eating behaviors, using structured exercises and mapping tools (see **Figure 6.1**). By jointly exploring how autistic traits (e.g., sensory processing, routines, interoception) intersect with ED symptoms, treatment can be directed at the most distressing and maladaptive elements, while respecting and accommodating adaptive autism-related needs. This approach is complemented by a peer-led psychoeducational group for autistic women with EDs, in which shared experiences often foster self-understanding and reduce isolation.



Figure 6.1

Psychoeducational profile template for disentangling autism-related and ED-related eating behaviors.



Concluding Remarks

This thesis sets out to deepen our understanding of EDs in autistic women — a group long underrepresented in ED research and care. Through a combination of conceptual, empirical, and clinical work, it sheds light on the distinct and often dual nature of eating difficulties in this population, highlighting the co-occurrence of traditionally disordered and autism-related eating behaviors.

Rather than reinforcing binary distinctions between “ED” and “autism,” the findings presented here point to a more layered clinical reality — one in which the same behavior can hold different meanings depending on its cognitive, sensory, and emotional context. A behavior like food avoidance, for example, may be driven by body image concerns, sensory sensitivities, or both. These complexities call for more precise, autism-informed assessments and formulations that can meaningfully distinguish between adaptive traits and symptoms requiring intervention.

The thesis also provides concrete pathways forward. By identifying cognitive flexibility as a potentially important mechanism and illustrating how autism-specific features shape eating difficulties, it offers clinicians both insight and direction. The proposed clinical recommendations — including individualized formulation, autism-informed adaptations, and integration of broader life context — are not intended as a new “protocol,” but as a call for flexible, person-centered care. The work aligns with and complements other emerging initiatives, such as the PEACE pathway (Tchanturia et al., 2020), and contributes to a growing movement toward inclusive and autism sensitive ED services.

In sum, this thesis highlights the need for more tailored, autism-informed approaches to ED care — and offers practical steps for moving in that direction. To illustrate how these insights can translate into clinical practice, we return to the story of Eva.

EVA'S CASE REVISITED: A PERSONALIZED PATH FORWARD

Revisiting Eva's story brings the clinical implications of this thesis into focus. After a comprehensive intake and shared formulation process, it was collaboratively decided that she would begin CBT-E — not because it is universally optimal, but because its structured and predictable format matched her cognitive style and need for clarity. Crucially, this was complemented by two tailored additions: participation in a psychoeducation group specifically designed for autistic women with EDs, and individual sessions aimed at disentangling the interplay between her autism and ED symptoms. In the group setting — where many participants shared a dislike for conventional group therapy — Eva found meaningful peer support. For the first time, she experienced resonance rather than alienation, hearing others voice challenges she had long considered uniquely her own. These shared reflections, together with her individual work, helped to formulate treatment goals that truly fit her, rather than asking her to fit the treatment. Throughout the process, autism-informed adaptations were woven into the therapeutic structure. Sensory sensitivities were actively assessed and addressed — from practical adjustments such as removing the batteries from ticking clocks or changing seating orientation, to more fundamental considerations during nutritional planning (e.g., distinguishing pre-existing sensitivities from ED-related avoidances). Sessions were kept relatively short, supported with visual materials, and consistently closed with a summary of key takeaways — both verbally and via emailed session notes for later review. Together with Eva, an autism coach was introduced into the treatment trajectory to support the transition to life outside the clinic. This included pragmatic planning around shopping, meal preparation, and daily structure — domains that often remained unaddressed in earlier treatment attempts. Session times were scheduled to avoid rush-hour travel, and the flexibility to hold appointments online when needed further supported her engagement. Importantly, Eva's autism was not only a source of difficulty — it also served as a strength in recovery. Her strong sense of reliability, exceptional honesty, and black-and-white thinking (“if I say I'll do it, I do it”) allowed for a transparent therapeutic relationship and consistent follow-through on behavioral goals. These traits created a solid foundation for exploring her ED thoughts and routines in detail, and for gradually experimenting with change. Rather than asking Eva to suppress her autism in order to recover, treatment focused on building a path that honored her way of processing the world. While the road remains complex, this integrated approach allowed space not only for symptom change, but also for self-understanding, agency, and hope.

“I still don't have the manual, but now I have a map that makes sense to me.”





Chapter 7:

Summary in Dutch

(Nederlandse Samenvatting)



ACHTERGROND VAN DIT PROEFSCHRIFT

Eetstoornissen behoren tot de meest complexe psychiatrische stoornissen om te behandelen¹⁴. Hoewel evidence-based behandelingen beschikbaar zijn, blijft het herstel voor veel cliënten uit — in het bijzonder voor volwassenen met een meer atypische presentatie. Eén groep die hierbij opvalt, zijn personen met autisme. Autisme wordt beschreven als neurobiologische ontwikkelingsstoornis, maar ook wel als neurodivergentie, en wordt onder andere gekenmerkt door bijzonderheden in de sociale communicatie. Binnen deze groep komen specifieke en bijzondere eetgedragingen relatief vaak voor. Zo geven veel mensen met autisme de voorkeur aan voorspelbaarheid in maaltijden, vermijden zij bepaalde texturen of smaken vanwege sensorische gevoeligheden, of houden zij vast aan vaste routines en rituelen rondom eetmomenten. Dergelijk gedrag is op zichzelf niet per definitie problematisch — het kan zelfs belangrijke sensorische, emotionele of sociale functies vervullen. Onder bepaalde omstandigheden kunnen deze eetgewoonten echter versterkt raken en overgaan in eetgestoord gedrag.

Bij vrouwen met autisme blijken naast dit soort eetgedragingen ook vaker klassieke eetstoornissymptomen voor te komen, zoals restrictie, eetbuien of compensatiegedrag. Wanneer een eetstoornis zich ontwikkelt in deze groep, wijzen klinische observaties en eerste onderzoeksbevindingen op een ernstigere en complexere klinische presentatie van de eetstoornis, met een langere ziekteduur, verhoogde kans op terugval, en vaker de noodzaak tot intensieve zorg zoals een opname of sondevoeding.

Het blijft vooralsnog onduidelijk waarom eetstoornissen bij vrouwen met autisme gemiddeld ernstiger verlopen, en waarom zij minder lijken te profiteren van standaardbehandelingen voor eetstoornissen. Eén hypothese is dat deze groep gekenmerkt wordt door een 'duale presentatie' van eetgedrag: zowel eetgestoord gedrag dat voortkomt uit bijvoorbeeld zorgen over figuur en gewicht, als gedrag dat nauw samenhangt met het autisme, zoals rigide eetrouines of voedselvermijding op basis van sensorische gevoeligheden. Deze overlap maakt het lastig om goed te onderscheiden welk gedrag voortkomt uit de eetstoornis, en welk gedrag juist een helpende functie vervult binnen het dagelijks functioneren. Binnen bestaande behandelmodellen zoals Cognitieve Gedragstherapie voor Eetstoornissen (CBT-E), ligt de nadruk echter vaak op zorgen over gewicht en figuur als drijvers van eetgestoord gedrag. Bij mensen zonder autisme is dit vaak terecht. Maar bij mensen met autisme is het de vraag in hoeverre deze assumptie klopt. Eerste kwalitatieve studies

14 In dit proefschrift verwijst de term *eetstoornissen* specifiek naar stoornissen die worden gekenmerkt door restrictief eetgedrag, compensatie gedrag en/of zorgen over figuur en gewicht — namelijk anorexia nervosa (AN), boulimia nervosa (BN) en andere gespecificeerde voedings- en eetstoornissen (OSFED). Hoewel ook *binge eating disorder* (BED) en *avoidant/restrictive food intake disorder* (ARFID) formeel onder de DSM-5 vallen, zijn deze stoornissen niet opgenomen in de empirische studies in dit proefschrift. ARFID wordt wél besproken, vanwege de conceptuele relevantie voor autisme-gerelateerd eetgedrag.



suggereren dat eetgedrag bij hen dus ook andere functies kan vervullen — zoals prikkelregulatie, controlebehoefte of het vermijden van sociale spanning. Er is dus mogelijk sprake van een discrepantie tussen standaardbehandelingen voor eetstoornissen en de manier waarop eetstoornisklachten zich manifesteren bij vrouwen met autisme — een mogelijke factor in de slechtere behandeluitkomsten bij deze groep. Een tweede factor ligt mogelijk in de behandelcontext zelf. Klinische settingen binnen de reguliere eetstoorniszorg zijn vaak onvoldoende afgestemd op de sensorische, cognitieve en communicatieve behoeften van mensen met autisme. Daarnaast spelen ook diagnostische uitdagingen een rol. Autismen — zeker bij vrouwen — wordt regelmatig niet of pas laat herkend, mede doordat zij vaker camoufleren en hun klachten internaliseren. In sommige gevallen worden autistische trekken verward met andere stoornissen, zoals persoonlijkheidsproblematiek of trauma. Hierdoor ontvangen veel vrouwen mogelijk eetstoorniszorg zonder dat hun neurodivergente behoeften worden meegenomen.

Ondanks de toegenomen aandacht voor deze doelgroep, blijft er nog veel onbekend. Een groot deel van het bestaande onderzoek naar de samenhang tussen autisme en eetstoornissen is bovendien gebaseerd op vragenlijstonderzoek, waarbij geen formele autisme diagnostiek is toegepast. Hierdoor is onduidelijk hoe eetstoornissen zich manifesteren bij vrouwen met een klinisch vastgestelde autismediagnose, en in hoeverre hun eetgedrag overeenkomt met dat van vrouwen met een eetstoornis zonder autisme. Ook is nog weinig bekend over de onderliggende mechanismen die een rol spelen binnen hun eetgedrag. Eén mogelijk mechanisme dat in dit proefschrift verder wordt onderzocht, is beperkte cognitieve flexibiliteit — het vermogen om gedrag en denkwijzen aan te passen aan veranderende omstandigheden. Cognitieve flexibiliteit is vaak beperkt bij zowel mensen met autisme als mensen met eetstoornissen, maar is in deze specifieke combinatie tot nu toe nauwelijks onderzocht.

Tegen deze achtergrond is het doel van dit proefschrift om meer inzicht te krijgen in het eetgedrag van vrouwen met autisme, met en zonder eetstoornis, en te onderzoeken in hoeverre dit verschilt van andere groepen. Daarbij wordt specifiek gekeken naar cognitieve flexibiliteit als mogelijk onderliggend mechanisme dat samenhangt met eetgedrag in deze groep. Daarnaast wordt exploratief aandacht besteed aan psychische lijdensdruk en mentale gezondheidsgerelateerde kwaliteit van leven, om de klinische complexiteit en beleving van hun problematiek beter te begrijpen. In de volgende hoofdstukken wordt dit thema vanuit verschillende invalshoeken benaderd — variërend van literatuuronderzoek en theoretische reflectie tot empirisch vergelijkend onderzoek — met als doel te komen tot een meer genuanceerde en autismsensitieve benadering van eetstoornissen bij vrouwen met autisme.

Bevindingen per Hoofdstuk

In aansluiting op deze achtergrond, start het proefschrift met een systematische verkenning van de bestaande literatuur. **Hoofdstuk 2** presenteert een scoping review naar het eetgedrag van vrouwen met autisme zonder verstandelijke beperking — een groep die in eerder onderzoek nauwelijks is onderzocht. De meeste studies tot nu toe richten zich op kinderen, mannen of mensen met autisme én een verstandelijke beperking, waardoor de aard en achtergrond van eetgedrag bij deze specifieke groep grotendeels onderbelicht zijn gebleven. Het doel van de review is om systematisch in kaart te brengen welke eetgerelateerde gedragingen bij deze vrouwen worden beschreven, welke terminologie en theoretische kaders worden gebruikt, en waar lacunes in de literatuur bestaan. Slechts vijf studies voldeden aan de inclusiecriteria. De resultaten laten zien dat vrouwen met autisme zowel gedrag vertonen dat typisch is voor autisme — zoals voedselselectiviteit en sensorische gevoeligheden — als symptomen die passen bij eetstoornissen, waaronder restrictie en compensatiegedrag. Tegelijkertijd ontbreekt er kennis over de onderliggende functies of mechanismen die dit gedrag aandrijven. Een belangrijk aandachtspunt is dat de methodologische kwaliteit van de studies sterk varieerde. Veel onderzoek maakt gebruik van zelfrapportage-instrumenten om autistische trekken te meten, zonder dat sprake was van formele diagnostiek. De review concludeert dan ook dat er dringend behoefte is aan meer onderzoek binnen klinisch bevestigde populaties, om beter zicht te krijgen op de aard, functie en onderliggende processen van eetgedrag bij vrouwen met autisme.

Waar **Hoofdstuk 2** laat zien dat er nauwelijks empirische kennis is over eetgedrag bij vrouwen met een formele autisme diagnose, biedt **Hoofdstuk 3** een verdiepend, theoretisch perspectief. In dit hoofdstuk staat een conceptuele verkenning centraal van de overlap tussen autisme en eetstoornissen. Bestaande literatuur en klinische observaties worden geïntegreerd om te onderzoeken waarom traditionele modellen en behandelprotocollen vaak onvoldoende aansluiten bij de klinische werkelijkheid van vrouwen met autisme en een eetstoornis. Een belangrijk uitgangspunt in deze modellen is de veronderstelling dat autisme relatief veel voorkomt binnen eetstoornispopulaties — een aanname die breed wordt gedeeld in zowel de wetenschappelijke literatuur als de klinische praktijk. Prevalenties lopen uiteen van 4 tot wel 50%, maar zijn vaak gebaseerd op screeningsvragenlijsten voor autistische trekken, zonder gebruik van ontwikkelingsanamnese — een cruciaal onderdeel van betrouwbare autismediagnostiek. Zonder die anamnese blijft onduidelijk of autistische trekken al vóór de eetstoornis aanwezig waren, of het gevolg zijn van toetsfactoren zoals ondervoeding of sociale terugtrekking. In studies waarin wél gebruik wordt gemaakt van formele diagnostiek, liggen de prevalenties aanzienlijk lager, doorgaans tussen de 4 en 10%. Bij deze subgroep blijkt dat eetstoornissen vaak ernstiger en complexer verlopen. **Hoofdstuk 3** stelt daarom dat klassieke verklaringsmodellen — zoals de nadruk op eetgestoord gedrag vanuit zorgen over gewicht en figuur — mogelijk onvoldoende toepasbaar zijn op deze doelgroep. In plaats daarvan kunnen eetgedragingen voortkomen



uit andere functies, zoals het reguleren van sensorische gevoeligheden, spanningreductie of behoefte aan voorspelbaarheid. Daardoor bestaat het risico dat gedrag onterecht wordt geïnterpreteerd als eetstoornissymptoom, terwijl het in feite samenhangt met het autisme. Tegelijkertijd kunnen klassieke eetstoornisgedragingen juist extra hardnekkig zijn in deze groep, bijvoorbeeld door beperkte cognitieve flexibiliteit of moeite met gedragsverandering. Het hoofdstuk wijst op de valkuil dat behandelaars het eetgedrag van vrouwen met autisme interpreteren vanuit standaardmotieven, zonder oog voor de onderliggende functie of context. Diagnostiek en behandeling sluiten daardoor mogelijk vaak onvoldoende aan bij de specifieke behoeften en beleving van vrouwen met autisme. Tot slot pleit het hoofdstuk voor meer autismesensitieve conceptualisaties van eetstoornissen, waarin ruimte is voor alternatieve verklaringmodellen en beter passende vormen van zorg.

Hoofdstuk 4 bouwt voort op de conceptuele verkenning van **Hoofdstuk 3** en presenteert een empirische studie waarin het eetgedrag van vrouwen met autisme en een eetstoornis systematisch wordt vergeleken met drie andere groepen:

- (1) vrouwen zonder autisme met een eetstoornis,
- (2) vrouwen met autisme zonder eetstoornis, en
- (3) neurotypische vrouwen zonder eetstoornis.

In deze cross-sectionele studie wordt gekeken naar verschillende vormen van eetgedrag:

- traditioneel eetgestoord gedrag (zoals restrictie om af te vallen, angst om aan te komen of compenseren),
- autisme-gerelateerd eetgedrag (zoals eten vermijden vanwege sensorische gevoeligheid of rigide eetpatronen), en
- ARFID-gerelateerde kenmerken (inclusief picky eating).

In dit onderzoek rapporteerden vrouwen met autisme en een eetstoornis op al deze domeinen hogere scores dan vrouwen in de andere drie groepen. Zij vertoonden zowel meer klassiek eetgestoord gedrag dan vrouwen met een eetstoornis zonder autisme, als meer autisme- en ARFID-gerelateerd eetgedrag dan vrouwen met autisme zonder eetstoornis. Opvallend is dat zij ook meer zorgen over gewicht en figuur rapporteerden dan alle andere groepen — inclusief vrouwen met een eetstoornis zonder autisme. Deze bevinding gaat in tegen eerdere veronderstellingen dat zorgen over gewicht en figuur bij mensen met autisme slechts een marginale rol zouden spelen, en benadrukt dat ook deze elementen een centrale plek kunnen innemen in hun eetproblematiek. De combinatie van traditioneel verstoord, autisme-gerelateerd en ARFID-gerelateerd eetgedrag, in samenhang met verhoogde zorgen over gewicht en figuur, wijst op een ernstig en complex klinisch beeld. Vrouwen met autisme en een eetstoornis vormen daarmee een subgroep die vraagt om een zorgvuldig afgestemde, autismesensitieve benadering van diagnostiek en behandeling. Als aanvullende uitkomstmaten werd gekeken naar psychische lijdensdruk en mentale ge-

zondheidsgerelateerde kwaliteit van leven. Op beide domeinen scoorde de groep vrouwen met autisme en een eetstoornis het meest ongunstig, wat de klinische complexiteit en het belastende karakter van deze dubbele diagnose verder onderstreept.

Hoofdstuk 5 verdiept zich in één van de mogelijke onderliggende mechanismen die kunnen bijdragen aan de eetproblematiek bij vrouwen met autisme en een eetstoornis: cognitieve flexibiliteit. Cognitieve flexibiliteit verwijst naar het vermogen om gedrag of denkpatronen aan te passen aan veranderende omstandigheden. Aangezien deze executieve functie vaak beperkt is bij zowel mensen met autisme als bij mensen met een eetstoornis, wordt in dit hoofdstuk onderzocht in hoeverre beperkte cognitieve flexibiliteit samenhangt met eetgedrag bij vrouwen bij wie beide diagnoses samen voorkomen. De resultaten laten zien dat vrouwen met autisme — ongeacht of zij wel of geen eetstoornis hadden — significant lagere cognitieve flexibiliteit rapporteerden dan vrouwen met een eetstoornis zonder autisme en niet-autistische controlepersonen. Deze laatste twee groepen verschilden niet van elkaar, wat erop wijst dat beperkte cognitieve flexibiliteit niet per definitie kenmerkend is voor eetstoornissen op zichzelf, maar mogelijk eerder samenhangt met autisme. Dit nuanceert de aanname dat beperkingen in cognitieve flexibiliteit een universeel kenmerk zijn van eetstoornissen, en roept de vraag op in hoeverre eerdere bevindingen op dit gebied deels beïnvloed zijn door onderliggend autisme — een hypothese die verder onderzoek verdient. Binnen de groep vrouwen met autisme en een eetstoornis bleek met name het aspect ‘aandacht voor detail’ samen te hangen met ernstiger eetgestoord gedrag. Daarnaast hing aandacht voor detail samen met ARFID-symptomen bij vrouwen met autisme — zowel met als zonder eetstoornis — en bij controlepersonen, maar niet bij vrouwen met een eetstoornis zonder autisme. Deze bevindingen suggereren dat verhoogde aandacht voor detail mogelijk een grotere rol speelt in het eetgedrag van vrouwen met autisme dan in dat van vrouwen met alleen een eetstoornis. Dit roept ook vragen op over de geschiktheid van interventies zoals cognitieve remediatetherapie (CRT), die specifiek gericht zijn op het verbeteren van cognitieve flexibiliteit: dergelijke interventies zijn mogelijk niet voor alle cliënten met een eetstoornis passend. Hoewel deze studie verkennend van aard is, onderstrepen de bevindingen het belang van meer aandacht voor neurocognitieve processen binnen zowel de diagnostiek als behandeling van deze groep. CRT zou, mits aangepast aan het cognitieve profiel van vrouwen met autisme, mogelijk kunnen bijdragen aan het verminderen van rigide eetpatronen en het versterken van behandelbetrokkenheid.

CONCLUSIES

Dit proefschrift brengt het eetgedrag van vrouwen met autisme in kaart en laat zien hoe hun eetstoornissen zich onderscheiden van andere groepen — in gedrag en onderliggende cognitieve processen. De bevindingen tonen een dubbele presentatie: enerzijds klassiek



eetgestoord gedrag zoals restrictie, compenseren en zorgen over figuur en gewicht, anderszinds eetgedrag dat samenhangt met autisme, waaronder sensorische gevoeligheden, voedselselectiviteit en rigide routines. Opvallend is dat vrouwen met autisme én een eetstoornis zelfs meer zorgen over figuur en gewicht rapporteerden dan vrouwen met een eetstoornis zonder autisme — een bevinding die eerdere aannames nuanceert en onderstreept dat ook deze elementen een centrale rol kunnen spelen in hun eetproblematiek. Daarnaast blijkt uit dit proefschrift dat cognitieve flexibiliteit, en specifiek aandacht voor detail, mogelijk een belangrijk mechanisme is dat samenhangt met eetgedrag bij vrouwen met autisme. Aandacht voor detail hing samen met zowel klassieke eetstoornissymptomen als ARFID-symptomen, maar alleen bij vrouwen met autisme en niet bij vrouwen met eetstoornissen zonder autisme. Deze bevinding suggereert dat bepaalde cognitieve kenmerken bij autisme kunnen bijdragen aan de complexiteit van de klinische presentatie — en dat hier in de behandeling rekening mee gehouden moet worden.

Deze inzichten komen samen in een centrale implicatie: huidige behandelmodellen voor eetstoornissen vragen om zorgvuldige aanpassing om recht te doen aan de specifieke behoeften van vrouwen met autisme.

Voor de klinische praktijk betekent dit onder meer:

- **Een zorgvuldig diagnostisch proces**, met aandacht voor het vroegtijdig herkennen van autisme bij vrouwen — ook bij subtiele of gemaskeerde presentaties — waarbij altijd een ontwikkelingsanamnese wordt afgenomen en expliciet wordt gekeken naar functioneren en gedrag vóór de ontwikkeling van de eetstoornis. Dit helpt om autistische kenmerken te onderscheiden van toestandsfactoren (zoals rigiditeit door ondervoeding of sociale terugtrekking als gevolg van de eetstoornis), en draagt bij aan het voorkomen van overdiagnostiek;
- **Functieanalyse van eetgedrag**, waarin gezamenlijk met de cliënt onderscheid wordt gemaakt tussen eetstoornisgedrag en gedrag dat voortkomt uit sensorische, regulerende of voorspelbaarheidsgerichte functies;
- **Gedeelde besluitvorming en individuele formulering**, waarbij per cliënt wordt bekeken of een standaardbehandeling voor eetstoornissen volstaat, of dat een aanvullende of alternatieve benadering nodig is;
- **Een autisme-vriendelijke behandelomgeving**, met voorspelbaarheid, heldere communicatie en aanpassing aan autisme-specifieke informatieverwerkingsstijlen;
- **Brede, levensgerichte ondersteuning**, met aandacht voor zingeving, structuur, overprikkeling en samenwerking met ervaringsdeskundigen

Dit proefschrift onderstreept dat eetstoornissen bij vrouwen met autisme niet slechts een variatie op het bekende zijn, maar een klinisch beeld met eigen kenmerken, uitdagingen en behoeften. De complexiteit van hun eetgedrag vraagt om meer zorg op maat — waarin

ruimte is voor neurodiversiteit, nuance en verschil in betekenis en herstel. Door eetgedrag niet louter te interpreteren als symptoom, maar ook als uitdrukking van bredere cognitieve, sensorische en sociale processen, kan zorg ontstaan die niet alleen effectiever is, maar ook beter aansluit bij wie de ander is. Dit vraagt om verdere dialoog tussen wetenschap en praktijk, en om samenwerking tussen disciplines, behandelaren en ervaringsdeskundigen. De inzichten uit dit proefschrift kunnen daarin hopelijk richting geven.





Appendices



SUPPLEMENTARY MATERIAL OF CHAPTER 2: PROBLEMATIC EATING BEHAVIORS OF AUTISTIC WOMEN — A SCOPING REVIEW

Full Search Queries for each Electronic Database

For Medline: “exp Feeding Behavior/ OR exp “Feeding and Eating Disorders”/ OR exp Food Fussiness/ OR exp Food Preferences/ OR exp Food/ OR exp Eating/ OR exp Meals/ OR exp Diet/ OR exp Pica/ OR exp Rumination Syndrome/ OR exp Avoidant Restrictive Food Intake Disorder/ OR exp Anorexia/ OR exp Bulimia/ OR exp Binge-Eating-Disorder/ OR exp body weight/ OR exp Obesity/ OR exp Body Weight/ OR exp Body Mass Index/ OR eating*.mp OR feed*.mp OR food*.mp OR meal*.mp OR nutrition*.mp OR diet*.mp OR obes*.mp OR anorexia*.mp OR bulimia*.mp OR binge*.mp OR pica*.mp OR orthorexia*.mp OR ARFID*.mp OR ruminati*.mp AND exp Women/ OR exp Adult/ OR exp Female/ OR women*.mp OR woman*.mp OR female*.mp OR adult*.mp AND exp Autism Spectrum Disorder/ OR exp Autistic Disorder/ OR exp Asperger Syndrome/ OR exp Child Development Disorders, Pervasive/ OR autis*.mp OR asperger*.mp”

For PsychInfo: “exp Eating behavior/ OR exp Eating Disorders/ OR exp Eating Attitudes/ OR exp Appetite/ OR exp Food/ OR exp Food Preparation OR exp Food intake/ OR exp Food Preferences/ Or exp Food Insecurity/ OR exp Food Refusal/ OR exp Nutrition/ OR exp Mealtimes/ OR exp Food Addiction/ OR exp Satiation/ OR exp Neophobia OR exp Anorexia Nervosa/ OR exp Binge Eating/ OR exp Bulimia/ OR exp Binge Eating Disorder/ OR exp Pica/ OR exp Feeding Disorders/ OR exp Obesity/ OR exp Body Weight/ OR exp Diets/ OR exp Body Mass Index/ OR exp Overweight/ OR eating*.mp OR feed*.mp OR food*.mp OR meal*.mp OR nutrition*.mp OR diet*.mp OR obes*.mp OR anorexia*.mp OR bulimia*.mp OR binge*.mp OR pica*.mp OR orthorexia*.mp OR ARFID*.mp OR ruminati*.mp AND exp Human Females/ OR women*.mp OR woman*.mp OR female*.mp OR adult*.mp AND exp Autism Spectrum Disorders/ OR exp Autistic Traits/ OR autis*.mp OR asperger*.mp”

For Cochrane: “Food/ OR Food Preferences/ OR Feeding Behavior/ OR Meals/ OR Eating/ OR Food Fussiness/ OR Avoidant Restrictive Food Intake Disorder/ OR Pica/ OR Anorexia/ OR Bulimia/ OR “Feeding and Eating Disorders”/ OR Rumination Syndrome/ OR Obesity/ OR Body weight/ OR Diet/ OR Body Mass Index/ OR eating* OR food* OR diet* OR feed* OR anorexia* OR bulimia* OR meal* OR pica* OR orthorexia* OR ARFID* OR binge* OR ruminati* OR nutrition* OR BMI* AND exp Women/ OR exp Adult/ OR exp Female/ OR wom* OR adult* OR female*AND exp Autism Spectrum Disorder/ OR exp Autistic Disorder OR exp Asperger Syndrome OR exp Child Development Disorders, Pervasive/ OR autis* OR asperger*”

For PubMed: ““Feeding Behavior”[Mesh] OR “Feeding and Eating Disorders”[Mesh] OR “Binge-Eating Disorder”[Mesh] OR “Eating”[Mesh] OR “Diet”[Mesh] OR “Bulimia”[Mesh] OR “Food Fussiness”[Mesh] OR “Food Addiction”[Mesh] OR “Meals”[Mesh] OR “Diet”[Mesh] OR eating*[tiab] OR food*[tiab] OR diet*[tiab] OR feed*[tiab] OR anorexia*[tiab] OR bulimia*[tiab] OR meal*[tiab] OR pica*[tiab] OR orthorexia*[tiab] OR eating*[tiab] OR feed*[tiab] OR food*[tiab] OR meal*[tiab] OR nutrition*[tiab] OR diet*[tiab] OR obes*[tiab] OR anorexia*[tiab] OR bulimia*[tiab] OR binge*[tiab] OR pica*[tiab] OR ARFID*[tiab] OR ruminat*[tiab] AND “Women”[Mesh] OR “Adult”[Mesh] OR “Female”[Mesh] OR women*[tiab] OR woman*[tiab] OR female*[tiab] OR adult*[tiab] AND “Autism Spectrum Disorder”[Mesh] OR “Autistic Disorder”[Mesh] OR “Asperger Syndrome”[Mesh] OR auti*[tiab] OR asperger*[tiab]” + filter to only include non-Medline articles



ACKNOWLEDGEMENTS (DANKWOORD)

When I moved to the Netherlands nearly a decade ago (omg), I slowly began to live in a world where three languages took turns occupying whatever cognitive capacity I had left on any given day. On good days, this trilingual life felt like a superpower. On other days... was my German during evening phone calls home really still German? Who knows. These acknowledgements reflect that reality. The people who shaped this PhD journey come from different corners of my life and speak different languages — and so these acknowledgements do, too. Each section is written in the language that naturally belongs to the people I am addressing. Just like the past years, it might sometimes switch unexpectedly, but hopefully understandably.

De afgelopen zes jaar heb ik met ontzettend veel plezier, nieuwsgierigheid en af en toe de nodige dosis ‘hoe kan dit nou weer?’ aan mijn promotieonderzoek gewerkt. Dit proefschrift is, naar mijn mening, hard nodig: voor een groep die in zowel onderzoek als klinische praktijk lang onderbelicht is gebleven, en waarover hardnekkige aannames bestaan die niet altijd overeenkomen met hun ervaringen. Dat dit proefschrift er nu ligt, is te danken aan heel veel mensen die op kleine of grote manieren aan deze reis hebben bijgedragen. Een promotietraject doe je uiteindelijk nooit alleen — al voelt dat soms wel zo, vooral tijdens de formatting-fase.

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Lieve **Unna**, in 2016 stapte ik op je af tijdens de thesismarkt, omdat jij de enige docent was die “iets met eetstoornissen” aanbood — een thema dat me al sinds mijn Bachelor in Innsbruck het meest fascineerde. Bijzondere eetgedragingen, onderliggende mechanismen, de vraag waarom mensen doen wat ze doen: daar wilde ik me verder in verdiepen. Dat is nu bijna tien jaar geleden, en sindsdien ben je mijn thesisbegeleider, stagedocent, senior onderzoeker, co-promotor, en vooral mijn mentor geweest. Het is dankzij jouw scherpe blik (en die van Nicole Blom) dat dit onderzoek überhaupt is ontstaan. Jullie herkenden het belang en de urgentie van dit thema op een moment dat het nog nauwelijks aandacht kreeg. Je hebt verreweg de grootste invloed gehad op hoe ik nu als professional in het werkveld sta en op hoe ik ben gevormd als onderzoeker. Jij hebt me geleerd om effectief en efficiënt te werken, syntaxen te schrijven, (amateuristisch) te programmeren, en hoe je binnen de klinische praktijk wetenschappelijk onderzoek zó uitdraagt dat het ook echt landt. Soms was het echt moeilijk: SPSS die maar niet deed wat ik wilde, eindeloze datasets, of het volledig opnieuw moeten programmeren van de Iowa Gambling Task zonder eerdere programmeerervaring (lichtelijk ambitieus, maar oké). Maar zelfs op de pittige momenten voelde ik me gesteund, en tegelijkertijd uitgedaagd om nog nét een stapje verder te gaan. Ik ben onder de indruk van wat je hebt bijgedragen aan het veld en dankbaar voor alles wat ik van je heb mogen leren als senior onderzoeker — inclusief het werken in kamers die stevast een paar graden kouder waren dan mijn persoonlijke voorkeur. Toch voelde ik me altijd welkom om binnen te stappen wanneer ik vastliep. Ik kijk ernaar uit om voort te zetten wat wij zijn begonnen. En tot die tijd: je mag me altijd blijven vragen om het wachtwoord van het wachtwoordbestand.

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ABOUT THE AUTHOR (OVER DE AUTEUR)

Sabrina Stefanie Schröder was born in Wiesbaden, Germany, on the 21st of July 1992. After completing her secondary education, she moved to Innsbruck, Austria, where she earned a Bachelor's degree in Psychology. She later continued her studies at Utrecht University and completed the Master's program in Clinical and Health Psychology. She wrote her Master's thesis in collaboration with Altrecht Eating Disorders Rintveld in Zeist, where she subsequently continued working — first as a research intern and later as a research assistant. During this period, she also worked as a teaching assistant at the Department of Clinical Psychology at Utrecht University. In 2019, she started her PhD project as an external PhD candidate at Utrecht University, based at Altrecht Eating Disorders Rintveld and conducted in collaboration with the Autism Expertise Centre in Eemnes. Alongside her PhD trajectory, she combined her doctoral research with clinical work at both the outpatient and inpatient departments of Rintveld and with teaching duties as a lecturer at the Department of Clinical Psychology at Utrecht University. She will start her postgraduate training as a healthcare psychologist (*GZ-psycholoog*) in January 2026.



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