## Measuring eating disorders in Autistic people: A proposal for future research

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<u>Funding:</u> EN, KGS and FD are funded via EDAC, a jointly funded project by UK Research and Innovation (MRC, ESRC, AHRC), the National Institute for Health and Care Research and the Medical Research Foundation as part of the New Collaborations to support Eating Disorders Research programme (grant number: MR/X03058X/1).

Conflict of interest: The authors declare no conflicts of interest.

#### Abstract

While diagnostic pathways for identifying Autism in eating disorder (ED) populations have been developed, the field continues to lack validated psychometric tools to measure EDs for use in the Autistic population. Many commonly used measures for EDs potentially lack validity and reliability in the Autistic population limiting theoretical and practical advancements in the field. This paper outlines current conflicts in autism and ED research and how these can be addressed through psychometric methodology. We discuss: (1) the lack of differentiation between ED pathology and Autistic eating behaviours, as well as the limited inclusion of autism-specific mechanisms in existing tools; (2) the subsequent theoretical and practical implications for researchers, clinicians, and Autistic people; and (3) future directions for psychometric research. Scholars are encouraged to employ participatory designs *with* autistic people, before carefully considering which analytical strategies are used in the Autistic population.

**Keywords:** Autism; Neurodivergence; Psychometrics; Assessment tools; Eating disorders; Participatory research

### **Clinical implications**

- Current measures have yet to be revised and validated for use in Autistic people
- Measurement may not capture Autism-specific eating disorder pathology
- Bias in measurement may negatively impact effective screening and prevention
- Development necessitates participatory research and appropriate analytical strategy

### 1. Introduction

Autistic individuals experience feeding and eating disorder (ED) pathology (Huke et al., 2013), with elevated Autistic characteristics often reported among individuals with anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and avoidant and restrictive food intake disorder (ARFID) (Huke et al., 2013; Gesi et al, 2020). While Autistic people describe eating difficulties which warrant a diagnosis of an ED, evidence suggests existing theory and practice may also erroneously pathologise Autistic peoples' eating-related needs and experiences (Nimbley et al., 2023). Increasing attention has been paid to the assessment of Autism in the ED population to support adaptations to ED treatments (e.g., Tchanturia et al., 2020), as well as the development of measurement tools for feeding behaviours and/or pathology in autistic groups – namely, autistic children/adolescents (e.g., the Brief Autism Mealtime Behavior Inventory; Lukens & Linscheid, 2008; for review, see Baraskewich et al., 2021). Despite this, to date, there is limited psychometric research for measuring EDs in the Autistic population. The aim of this paper is to provide an overview of the limitations of existing psychometric ED tools, their implications for the Autistic community, and how these may be addressed in future research.

#### 2. Current psychometric limitations

## 2.1. Differentiating Autistic needs from ED pathology

Accumulating evidence has identified Autistic people attribute universal, but also autism-related, experiences to their ED pathology (Nimbley et al., 2023). Despite our enhanced understanding of EDs in this group, many 'traditional' outcomes (e.g., eating intuitively) may be inaccessible, or even a negative experience, for Autistic people in two critical ways. Firstly, research has established a clear association between Autistic peoples' sensory and emotional processing differences and their body image and eating-related concerns (Longhurst, 2023). 69-94% of Autistic people describe differences in sensory responsivity (MacLennan et al., 2022), and commonly describe having difficulties interpreting their internal states/cues (e.g., hunger, affect), which often lead to inadvertent neglect of their body (e.g., forgetting to eat), and reduced food intake to manage their sensory challenges (Kinnaird et al., 2019). Secondly, many '(neuro)normative' eating-related behaviours (e.g., planning/eating a flexible diet) require processes and/or skills which differ in this group (Longhurst & Burnette, 2023).

Preliminary qualitative research suggests Autistic people employ adaptive strategies to 'compensate' for these difficulties: for example, following a repetitive diet containing sensory-congruent foods, eating alone or with headphones to reduce environmental sensory input, using certain utensils, and refer to external cues (e.g., alarms) and/or meal plans to remind them to eat (Kinnard et al., 2019; Longhurst et al., 2023; Park-Cardoso & da Silva, 2021). Resultantly, health-care providers are found to misattribute autistic characteristics or needs to ED pathology (Field et al., 2023). While these findings have been used to support adapting ED treatment for Autistic people (see Kinnaird & Tchanturia, 2021), scholars have yet to extend this toward existing measures for EDs. Moreover, research has yet to explicitly explore adaptive eating behaviours and/or positive food-related experiences (e.g., intuitive eating) in the Autistic population (Longhurst & Burnette, 2023), limiting our ability to meaningfully distinguish their adaptive and maladaptive behaviours (e.g., Tylka & Wilcox, 2006). Many existing scale items (e.g., EAT-26; Garner et al., 1982) may therefore assume potentially adaptive eating-related attitudes and/or behaviours in Autistic people to represent ED symptomatology (see Table 1).

## 2.2. Understanding and including underlying processes

Existing ED measures for Autistic people commonly lack the inclusion of potentially pertinent constructs (for interested readers, see Brede et al., 2020; Field et al., 2023; Nimbley et al., 2023). One, but non-exhaustive, example: despite being captured in most ED measures (Prnjak et al., 2022), body dissatisfaction has yet to be included in measures developed for Autistic people (e.g., SWEAA; Karlsson et al., 2013). While some Autistic people perceive body dissatisfaction as being impertinent to their ED, the literature has yet to examine the relationship between negative body image and EDs in this group (Longhurst, 2023). It is therefore possible that negative body image is currently framed in a way which does not accord with Autistic people's experience. Relatedly, commonly used ED measures do not reflect Autism-specific processes: in addition to feeling dissatisfied with the appearance of their body (e.g., weight/shape), Autistic people also attributed negative sensory (e.g., overstimulation) and socio-cognitive factors (e.g., discrimination, masking) with their negative body image (Longhurst et al., 2023). Such sensory and social factors were also perceived as underlying mechanisms for the development and maintenance of Autistic peoples' ED (Nimbley et al., 2013).

Another important psychometric limitation has been the focus on developing self- and parent-reporting tools for feeding problems (e.g., food refusal, food over selectivity), particularly among autistic children and adolescents (Baraskewich et al., 2021). Similarly, existing measures currently refer to certain EDs more than others – namely AN and ARFID in the Autistic population (Schroder et al., 2022). While research has investigated the relationship between Attention Deficit Hyperactivity Disorder (ADHD) and BED and BN (Nazar et al., 2016), such efforts have yet to be fully translated to Autistic people. This is despite preliminary evidence suggesting BED pathology in Autistic people may be associated with seeking sensory stimulation from certain food tastes (MacLennan et al., 2022). Further, the ED literature has disproportionately extrapolated findings in Autistic sub-populations – namely, White children or women (e.g., Schröder et al., 2022).

### 2.3. Language and practicalities

Guidance has recently been published for developing measures for Autistic people (Nicolaidis et al., 2020); however, these have not yet been embraced by ED research. Many existing ED-related measures may be inaccessible to Autistic people by using ambiguous language. For example, response options (i.e., "Never" to "Always") can be problematic for Autistic people, particularly when asking for memory recall (e.g., "In the last 28 days, how much have you been upset by your weight?"). Current ED measures may also refer to relevant constructs for Autistic people but may lack semantic equivalence. For instance, binge eating may be assessed by perceived loss of control (e.g., EDE-QS; Gideon et al., 2016), yet this assumes 'accurate' interoceptive awareness and may conceptually overlap with certain Autistic experiences (e.g., sensory overwhelm; MacLennan et al., 2022). Relatedly, single items containing several components can be problematic when the Autistic person agrees with one part of the item but not the other (e.g., NIAS item, "I have to push myself to eat regular meals throughout the day, or to eat a large enough amount of food at meals"; Zickgraf & Ellis, 2018).

The inaccessibility of ED related measures for Autistic people is also magnified when considering intersectionality. While research has identified *some* gender differences in eating difficulties (e.g., Spek et al., 2019), both the general Autistic and ED literature currently lacks the inclusion of Autistic men, as well as other marginalised identities (e.g., gender, sexual, and racial minorities; for discussion, see Mallipeddi & VanDaalen, 2022). In turn, potential differences in ED pathology across Autistic sub-groups is poorly understood. Furthermore, a considerable proportion of the Autistic population will also have an intellectual disability (Leitner, 2014); however, studies have historically relied on measures developed for parents

or caregivers, including reports of health-care providers (Nicolaidis et al., 2020). With treatment evaluation being dependent on available validated measures, this may decrease the validity of findings, but also raise ethical concerns by excluding Autistic people with an intellectual disability in research (McDonald & Raymaker, 2013).

## 3. Implications for Autistic people

The limitations of accurate measurement of EDs in Autistic populations has significant theoretical and practical implications. The clinical literature frequently refers to the high prevalence of Autistic characteristics in ED populations potentially being a transient behavioural consequence of having an ED (e.g., starvation effects), as opposed to a true aetiological overlap (e.g., Treasure, 2013). Although recent longitudinal studies have challenged this concept (Solmi et al, 2021), one area of research which requires further investigation is diagnostic overshadowing. As we previously highlighted, there is a tendency for assuming Autistic eating behaviours as being ED pathology. At the same time, however, ED pathology may be misattributed to Autistic characteristics and needs. In both scenarios, risk factors and behaviours associated with Autistic experiences of EDs are commonly overlooked, thus limiting Autistic peoples' access to ED treatment (Babb et al., 2021). Indeed, such limited consideration in existing measures may lead to the underdiagnosis of EDs in Autistic populations, in both research (e.g., prevalence studies) and practice. Developing more sensitive measures may therefore support accurate differentiation between Autistic characteristics and needs and ED symptomatology and extend our understanding of the prevalence of ED's in Autistic populations. More importantly, such efforts will help guide ED treatment by accurately identifying treatment targets and evaluation of the efficacy of prevention and intervention strategies.

## 4. Future directions for research

### 4.1. Refer to Autistic voices

Historically, autism and ED research has understood Autistic people based on their 'impairments', rather than their abilities. Existing psychometric research has also lacked the meaningful representation of the wider Autistic community (e.g., Pham et al., 2023). Thus, future research needs to centre the meaningful inclusion of Autistic voices. While important insights can be gathered from qualitative studies, a more powerful approach is participatory research, which has been found to generate more effective evidence for theory and practice (Duffy & Gillespie-Smith et al., 2024; Pellicano et al., 2022). Hence, participatory research would be a positive, neuro-affirming step towards addressing the existing psychometric limitations in the ED field.

## 4.2. Employ appropriate methodology

Scholars may decide between: (i) developing a novel scale specifically for Autistic people; or (ii) validate an existing measure using an *emic approach*, whereby constructs that are potentially specific to one population (i.e., non-Autistic people) are applied to another (i.e., Autistic people; Brislin et al., 1973). The latter, however, potentially introduces two related issues: latent concepts may not be comparable between non-Autistic and Autistic people, and thus psychometric validity and reliability may not translate from neurotypical to Autistic populations. Scholars may counteract this by examining an existing measure among Autistic people to determine whether revisions are needed, or even if it suitable for use at all (e.g., Longhurst et al., 2024), using recommended practice for psychometric (Nicolaidis et al., 2020) and participatory research (e.g., Arnold et al., 2023).

Scholars may also (re)consider their analytical approach: exploratory factor analysis (EFA) is commonly cross validated with findings from confirmatory factor analysis (CFA). However, this is most suitable when supporting *a priori* theoretically-informed rationale and/or validating a unidimensional factor structure, as it may otherwise introduce model misspecification and/or irreplicable factor structure (Morin et al., 2016). Alternatively, exploratory structural equation modelling (ESEM) may be used for predicting a new, or examining an existing, multidimensional factor structure (e.g., EDE-Q), as it integrates elements of EFA (i.e., the relaxation of zero cross-loadings) and CFA (i.e., obtaining goodness-to-fit statistics; Marsh et al., 2014; Morin et al., 2016). This is particularly relevant for assessing a hierarchically superior latent construct (e.g., ED pathology) through separate inferior subscales (e.g., body dissatisfaction, restrictive eating, purging behaviours). In doing so, this could support the conceptualisation of ED pathology in Autistic people by illustrating the relationship between constructs, including their antecedents and outcomes.

### 5. Conclusion

This paper highlights the urgent need for psychometric research to measure EDs in the Autistic population. Through participatory research approaches and gold-standard psychometric practice, this may add essential perspectives for expanding our theoretical and practical understanding of EDs toward Autistic people. Doing so will be crucial for better preventing EDs and improving identification and treatment outcomes in this community. It is hoped that this paper provides readers the theoretical and practical foundations to address the above research limitations and to realise more reliable, neuro-affirming practice.

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| Existing scale items                                                  | Autistic needs and behaviours                                               |
|-----------------------------------------------------------------------|-----------------------------------------------------------------------------|
| EDE-Q item 2: "Have you gone for long periods of time (8              | Difficulties remembering to eat or planning and executing meals,            |
| waking hours or more) without eating anything at all in order to      | limited awareness of internal cues (i.e., hunger, thirst), anxiety over     |
| influence your shape or weight?"                                      | sensory- rather than appearance-related changes in the body (e.g.,          |
| EAT-26 Item 2: "Avoid eating when hungry"                             | worries over feelings of digestion instead of weight gain)                  |
| EDE-Q Item 25/26: "How dissatisfied have you been with your           | Body dissatisfaction being related to negative sensory (e.g., over-         |
| weight/shape?"                                                        | stimulation, digestion) and/or social experiences (e.g., discrimination,    |
| EAT-26 Item 11: " <i>Am preoccupied with a desire to be thinner</i> " | stigma)                                                                     |
| EDE-Q Item 19: "On how many days have you eaten in secret             | Differing motor skills, difficulties shifting between tasks, monotropic     |
| (i.e., furtively)?"                                                   | focus/sensory stimulation, difficulties with enforced (i.e., social) rules, |
| EAT-26 Item 15: "Take longer than others to eat my meals"             | wanting to eat in a sensory-congruent environment (e.g., in a quiet         |
|                                                                       | room)                                                                       |
| EDE-Q Item 3: "Have you tried to exclude from your diet any           | Desire for routine/structure around food/mealtimes, needing sensory-        |
| foods that you like in order to influence your shape or weight        | congruent meal plan, prevent/recover from over-stimulation, sensory-        |
| (whether or not you have succeeded)?"                                 | rather than appearance-related concerns of the body                         |

**Table 1.** Conflicting ED concepts, as captured by the EAT-26 and EDE-Q, with common Autistic needs and behaviours.

| EAT-26 Item 19: "Display self-control around food"              |                                                                          |
|-----------------------------------------------------------------|--------------------------------------------------------------------------|
| EDE-Q Item 6: "Have you had a definite desire to have a totally | Distress over internal sensory changes, concerns over gastro-intestinal  |
| flat stomach?"                                                  | dysfunction (e.g., difficulties with constipation), altered awareness of |
| EAT-26 Item 24: "Like my stomach to feel empty"                 | internal cues                                                            |
| EDE-Q Item 13: "How many times have you eaten what other        | Altered awareness of internal cues (i.e., satiation), overcompensating   |
| people would regard as an unusually large amount of food?"      | for missed meals due to executive functioning, seeking out sensory-      |
|                                                                 | congruent foods                                                          |

## Citation on deposit:



Longhurst, P., Nimbley, E., Evans, E. H., MacLennan, K., Gillespie-Smith, K., & Duffy, F. (in press). Measuring eating disorders in Autistic people: a proposal for future research. Eating Disorders, 1-10.

https://doi.org/10.1080/10640266.2024.2416340

For final citation and metadata, visit Durham Research Online URL: <a href="https://durham-repository.worktribe.com/output/2981579">https://durham-repository.worktribe.com/output/2981579</a>

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