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**A call for autism-led research exploring definitions of recovery in Autistic individuals
with an eating disorder**

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Abstract

Research gap: It is now established that definitions of recovery in eating disorders (EDs) should be informed by the lived/living experience of individuals and consider a broad range of physical, behavioural, and psychological factors. Autism is a common co-occurring condition in EDs reflecting unique needs and experiences; however, very little research to date has explored definitions of recovery from EDs in Autistic populations. The current article will briefly review what we know about autism and EDs, before addressing how we can apply and extend what we know about broader ED recovery research to the unique needs of Autistic individuals with ED.

Suggested approach: We propose that future studies are urgently required exploring definitions and conceptualisations of recovery in Autistic individuals with EDs, rooted in autism-led, participatory research approaches and incorporating physical, behavioural, and psychological factors.

Discussion: Benefits and possible obstacles of implementing the proposed approach are discussed, before the authors outline specific suggestions for participatory designs and targets for future studies. Multi-dimensional and mixed method approaches to ED recovery will work towards integrating clinically measurable outcomes with lived/living experience perspectives.

Public significance statement: EDs are common in Autistic individuals, however very little is known about definitions of ED recovery in this population. Cross-disciplinary, research-driven definitions involving lived/living experience at all stages of the research process will generate meaningful and translational research..

Keywords: eating disorders, autism, recovery, neurodiversity, participatory research

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1. Introduction

Eating disorders (EDs), such as anorexia nervosa (AN), bulimia nervosa (BN) and binge-eating disorder (BED), are serious mental health conditions that typically have poor recovery outcomes (Murray et al, 2018; Linardon et al, 2017; Peat et al, 2017). A recent paper exploring the design and methodologies of recovery research in EDs suggested several novel approaches to capture a broader, more comprehensive account of recovery, including multi-method and multi-perspective study designs across longer spans on time (see Hower et al, 2022). There remain stark gaps in knowledge regarding recovery in subgroups of individuals with EDs, including those with commonly co-occurring conditions such as autism, where a similar application of such innovative methodologies and designs is urgently required.

1.1. Autism and Eating Disorders

Autism Spectrum Disorders are a range of developmental conditions characterised by differences in social interaction and communication, sensory processing, and restrictive and repetitive behaviours (APA, 2013). We will use the terms autism and Autistic for the purposes of this paper. While we acknowledge that individual preferences vary across Autistic communities, our definition adheres to emerging evidence from the Autistic community advocating for identity-first language (e.g., Kenny et al, 2016; Bottema-Beutal et al, 2020).

Autistic people commonly display differences in eating behaviours such as limited food intake, repetitive intake of the same foods, sensory-based selective eating or picky eating (Bandini et al, 2017; Cermak et al, 2010; Baraskewich et al, 2021). Eating disorders have been consistently identified within Autistic populations, with around 27% of Autistic individuals displaying eating disorder symptoms (Nickel et al, 2019). Autistic traits are over-represented across different ED diagnoses, including BN and BED (Gesi et al, 2021), ARFID (Bourne et al, 2022; Inoue et al, 2021), and in around 30% of AN samples (Westwood & Tchanturia, 2017). However, until recently, research settings have typically not assessed or controlled for autism, leading to highly heterogenous picture of treatment and recovery outcomes (Nazar et al, 2018; Leppanen et al, 2022; Li et al, 2022; Tchanturia et al, 2019; Neislen et al, 2022). In order to

support and improve rates of ED recovery in Autistic individuals, it is important to clarify just what is meant by the term “recovery”, and what this means to Autistic individuals.

1.2. Defining recovery from eating disorders in Autistics individuals

Early recovery definitions in the broader ED literature initially drew on physical (e.g., BMI) factors and the return to behavioural “norms” (Bardone-Cone et al, 2010). These definitions face criticism for being aligned with a medicalised approach, focusing predominantly on physical criteria and ignoring psychological factors and personal experiences of recovery (Kenny et al, 2022). Recent evidence emphasises the importance of psychosocial factors (de Vos et al, 2018; Stockford et al, 2018; Richmond et al, 2018), with several studies suggesting that these factors are often sufficient for personal definitions of recovery, despite continued presentation of ED behaviours (e.g., Slof-Op ‘t Landt et al, 2019; Wetzler et al, 2020). It is therefore now well-established that definitions of recovery from EDs should incorporate physical, behavioural, and psychological criteria that are underpinned by the perspectives of those with lived/living experience (Hower et al, 2022).

These multi-faceted and person-centred approaches will form a strong foundation for conducting recovery research in Autistic individuals with EDs. However, Autistic individuals have a range of unique needs and experiences that will require autism-specific approaches in future research. It is important to note that this does not entail that an Autistic individuals’ needs are lesser, or that there should be a lower threshold for recovery. It also does not necessarily entail that Autistic definitions of ED recovery will include new or additional factors. This has been partially supported by Sedgewick, Leppanen, Austin & Tchanturia (2021), the only study to date that has explored ED recovery in Autistic individuals, who identified similar broad themes in definitions of recovery between Autistic and non-autistic individuals. However, the single-item, open-ended survey format of Sedgewick et al (2021) did not allow for follow-up questioning or probing and is likely not an optimal in generating a comprehensive picture of recovery definitions. Instead, it is likely that similar factors associated with broader ED recovery may be defined or interpreted differently between Autistic and non-autistic individuals, while fundamental recovery goals, such as a high quality of life, should remain universal aims. For example, both Autistic and non-autistic individuals may share a similar recovery goal for social connectedness, yet it is likely that there will be differences between Autistic and non-autistic individuals in how they define these social

“norms”. Broader ED recovery definitions assume a return to behavioural and psychological “norms”, which cannot necessarily be applied to the Autistic community where this “norm” may look very different. By adopting a more autism-led, participatory approach, we can begin to work towards definitions and conceptualisations of recovery that are meaningful for, and reflective of, the lived/living experiences of Autistic people.

2. A call for autism-led, participatory research exploring definitions of recovery in Autistic individuals with an ED

Drawing on broader ED recovery research and the accumulating evidence exploring the overlap between autism and EDs, we propose that *future studies are urgently required exploring definitions and conceptualisations of recovery in Autistic individuals with EDs, rooted in participatory research approaches and incorporating physical, behavioural and psychological factors*. Such approaches advocate that Autistic voices should play an active, participatory role in informing, consulting, collaborating and controlling research studies, as well as providing their unique perspectives as participants.

2.1. Benefits

Including Autistic individuals as active participators in the research process opens many novel avenues for autism research and encourages a shift towards research being conducted *by or with* Autistic people as opposed to being conducted *on* them (Milton & Mclean, 2013). Generating clear understandings of recovery in Autistic individuals with EDs will benefit the delivery of ED treatment, something particularly pertinent in light of poorer treatment and recovery outcomes (e.g., Leppanen et al, 2022; Nielsen et al, 2022). Establishing clear recovery definitions prior to ED treatment may improve engagement, reduce potentially harmful practice and improve outcomes for autistic individuals across inpatient, outpatient services and community services. Finally, understandings of recovery definitions could also help inform the development new treatments, operating within a neurodiversity framework and developed specifically by and for Autistic individuals.

2.2. Anticipated obstacles

While research is needed to add to a sparse evidence base about recovery in Autistic individuals with EDs, conceptual and methodological limitations need to be considered. Firstly, could there

be *a lack of recovery*? While recovery is possible without receiving treatment, it could be that many Autistic individuals have received standard ED interventions that have not been modified or adapted to their specific needs. It could be that due to this lack of specialist care, Autistic individuals may not consider themselves to have reached “recovery” and therefore cannot contribute to recovery research. This highlights the importance of developing clinical interventions specifically designed for Autistic people with EDs. An encouraging example is the PEACE Pathway (<https://www.peacepathway.org/>), a new but promising clinical care pathway for Autistic individuals with anorexia. PEACE provides clear guidance for healthcare professionals working with Autistic individuals with anorexia, including possible ED interventions and modifications and suggestions for clinician training and support (see Tchanturia, Smith, Glennon & Burhouse, 2020). Early evidence suggests that pathway promotes favourable treatment outcomes for Autistic individuals, although it was the only intervention identified and thus far no RCT’s have been conducted (Li et al, 2022).

There is also increasing evidence to suggest that Autistic individuals report more severe ED psychopathology and complex psychological comorbidities (Leppanen et al, 2022; Stewart et al, 2017; Tchanturia et al, 2019) and thus may represent some of the most severely ill ED patients. This could provide researchers with challenges regarding *a lack of access to participants*. Autistic individuals may simply be too ill or are too overwhelmed to participate in research. There could also be a lack of access to participants with different subtypes of EDs, limiting recovery definitions beyond AN samples typically prioritised in services due to significant physical health difficulties. Simultaneously, there could be *a lack of access for participants*. Autistic individuals may not be aware of research opportunities, or they may struggle to engage with research. It is important to consider the broad range of physical, verbal, cognitive and social abilities within autism, and many research designs and methodologies do not consider or cater for the full spectrum of these abilities.

2.3. Specific recommendations for future studies

With regards to participatory approaches, involving Autistic individuals as participatory research members should be considered across all stages of the research process. Autistic communities could be consulted and collaborated with during the design of studies to develop research priorities rooted in these community perspectives (e.g., Crane et al, 2019). Autistic individuals could also be identified as advisors or mentors for studies or trials, working to develop research protocols and ensuring that studies are developed and disseminated in ways

are accessible (Long & Clarkson, 2017). Researchers should involve Autistic researchers as active members of the research team, allowing Autistic perspectives to shape the implementation research and taking a leadership role. In doing so, we can work towards a standard of meaningful participation (see Fletcher-Watson et al, 2019), ensuring the autism research is guided, developed and conducted by Autistic individuals.

Efforts should also be made to improve identification of participants in ED services and research studies. This could involve developing and administering autism-specific screening questionnaires of individuals when they access services, such as sensory screeners or restrictive and repetitive behaviour questionnaires, or for assessing and controlling for the presence of autism in ED research. Within clinical services, this could be achieved through promoting closer collaborations across the autism and ED fields. Currently, there is a notable lack of training and/or communication between the two fields, highlighted by ED clinician's reported lack of confidence in treating EDs in Autistic individuals (Kinnaird et al, 2017). Without communication and collaboration between autism and ED fields, the field will remain in its infancy, generating a fractured evidence base and failing to inform any meaningful clinical progression. Efforts should also be made to engage with the broader Autistic communities. Communication and engagement across multiple stakeholders and agencies will further promote awareness of the co-existence of autism and EDs and may allow for a wider and more representative identification of participants for future ED recovery research.

Attempts should also be made to improve recruitment and sampling strategies, recruiting from more diverse and representative samples. These approaches should involve novel research designs that can explore the perspectives of Autistic individuals across the lifespan, across all abilities and across ED subgroups. Studies should seek to utilise multi-perspectives, focusing on the lived/living experience of Autistic individuals with EDs but also including the perspectives of family members, friends and ED healthcare professionals. This approach acknowledges that these perspectives will inform the individuals definitions of and priorities in recovery and will hopefully work towards achieving consensus across all those involved in the recovery process (Hower et al, 2022). These approaches should be informed by both quantitative and qualitative data, adopting multi- and mixed- method approaches to explore recovery outcomes and perspectives and integrating clinically measurable outcomes with lived/living experience perspectives.

There is also a need to learn from existing research methodologies, such as from stronger collaborations from other fields that commonly co-occur with EDs, including anxiety disorders such as OCD or social anxiety (e.g., Mandelli et al, 2020; Kerr-Gaffney, Harrison & Tchanturia, 2018). For Early evidence of exploring behavioural conceptualisations of autism and EDs are emerging, with several lines of research looking to address shared and different mechanisms between the two (e.g., Zucker et al, 2007; Kerr-Gaffney et al, 2021). However, more translational research is needed, seeking to move understandings generated from research studies towards clinical application. This approach could work both ways, with increased awareness of and collaboration with the autism field providing novel insights for broader ED research. Recent evidence suggests that similar neurocognitive profiles, such as cognitive inflexibility and central coherence, are not simply the result of starvation in AN but instead reflect underlying processes (Hill et al, 2022). ED researchers and clinicians could visit broader autism studies and interventions associated with these shared behavioural conceptualisations and apply them to ED populations (See Table 1 for a summary of suggestions for future research studies).

3. Conclusions

By adopting participatory research approaches and incorporating physical, behavioural and psychological factors into generating definitions of ED recovery in Autistic individuals, researchers will add essential perspectives to a sparse evidence base. Gaining a deeper understanding of definitions of recovery will allow ED clinicians to establish clear treatment goals, while including Autistic perspectives in these definitions will encourage trust and communication in the therapeutic relationship. This will hopefully lead to improved short- and longer-term treatment outcomes. This goal will be further supported by increasing cross-disciplinary communication between autism and ED fields, as well as between paediatric and adult health providers, working collaboratively towards building a solid evidence-base of translational research for future clinical interventions. Fundamentally, by placing Autistic voices at the heart of our evidence-base, we will include perspectives that will make a meaningful influence on service provision and the delivery of autism-specific support. If more studies adopt participatory designs with clear parameters and measurable outcomes, we can hope to generate more guidance and support for ED clinicians on implementing such designs. This will hopefully build confidence in healthcare professionals in helping Autistic

individuals with EDs, and will foster meaningful and positive connections between researchers, clinicians and the lived/living experience community.

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