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RESEARCH ARTICLE

Different pathways, same goals: A large-scale qualitative study of autistic and non-autistic patient-generated definitions of recovery from an eating disorder

Felicity Sedgewick^{1,2}  | Jenni Leppanen¹ | Amelia Austin¹ | Kate Tchanturia^{1,3,4} 

¹Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

²School of Education, University of Bristol, Bristol, UK

³South London and Maudsley NHS Trust, London, UK

⁴Department of Psychology, Illia State University, Tbilisi, Georgia

Correspondence

Kate Tchanturia, Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK.
Email: kate.tchanturia@kcl.ac.uk

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Abstract

Background: Definitions of recovery from an eating disorder (ED) have generally been formulated around clinical conceptualisations, rather than based on the views of patients. This paper therefore asked those with lived experience of ED for their own definitions of recovery.

Method: Data were collected as part of an online study looking at EDs, autism and relationships. About 173 participants identified as recovered from ED and gave free-response definitions of recovery. Responses were subject to thematic analysis.

Results: Seven major themes were identified: Weight restoration, lack of ED behaviours, thoughts and behaviours, cognitions, emotional responses, getting on with life, and ongoing challenges.

Conclusions: Many definitions of recovery given by those who have lived experience of ED echoed those used by clinicians and researchers. There were also points of divergence around the ongoing challenges of recovery. Our findings highlight the need for continuing support post-weight restoration to facilitate the successful long-term recovery for those with ED.

KEYWORDS

autism, definitions, eating disorders, recovery

Key points

- Definitions of recovery from ED have traditionally relied on clinical, rather than patient, priorities.
- Both autistic and non-autistic people with a history of ED reported similar definitions of recovery, including weight restoration, lack of ED behaviours and cognitions, improved emotional responses around food and weight, the ability to get on with life, and the fact that they had ongoing challenges.

Abbreviations: AN, anorexia nervosa; ARFID, avoidant restrictive food intake disorder; BMI, body mass index; BN, bulimia nervosa; ED, eating disorder(s); ED-NOS, eating disorder not otherwise specified; OSFED, otherwise specified feeding and eating disorder.

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- The paper highlights that patients often think about recovery in ways which map on to clinical definitions, with some additional factors which could be utilised to support patients in this phase of illness.

1 | INTRODUCTION

The definition of recovery from an anorexia nervosa (AN), or indeed any eating disorder (ED), is somewhat subjective and individual to each patient, and there is no firm consensus as to its definition in research (Berkman et al., 2007; Couturier & Lock, 2006). In the light of recent research showing that up to 23% of those women who are undergoing in-patient treatment for AN meet clinical criteria for an autism diagnosis (Westwood et al., 2017), it is possible that the definition of recovery is even more subjective and varied than previously suggested. Autism is a highly heterogeneous condition, and the experiences of those who are both autistic and have an ED are likely to be different to those who are non-autistic.

These differences have been seen in the realm of treatment already, with patients with higher levels of autistic traits responding less positively to traditional approaches (Okuda et al., 2017; Spain et al., 2015). It may be that this difficulty engaging with established therapies is due to known autism features such as challenges in identifying and describing emotions (Nuske et al., 2013; Tracy et al., 2011; Uljarevic & Hamilton, 2013), or because the factors driving disordered eating are different for autistic people. For example, sensory sensitivities are a recognised diagnostic feature of autism (American Psychiatric Association, 2013) so avoiding unpleasant sensory stimuli may be the cause of under-eating rather than a desire to be thin. Whatever the causes of these differences in response to standard treatment approaches, however, one potential outcome is that autistic patients with anorexia are more likely to struggle to recover and therefore fall into the 'severe and enduring' illness category (Tchanturia et al., 2017) and therefore may need specifically tailored support (Westwood et al., 2017).

An early definition of recovery was 'the absence of all criterion symptoms of AN or bulimia nervosa (BN) for not less than eight consecutive weeks' (Strober et al., 1997), or 'the point at which an individual who was previously diagnosed with the disorder has no current symptoms and is at comparable risk ... as a matched control in the population' (Pike, 1998). Recent work has emphasised that the definition of full recovery should be 'based on physical (body mass index), behavioural (absence of ED behaviours), and psychological indices' (Bardone-Cone et al., 2010). Following a large-scale meta-analysis, a more conservative definition of 'three

asymptomatic years' (Von Holle et al., 2008) has also been used, as defining recovery within shorter periods risks missing relapse events which are most frequent in the first 18 months after weight restoration (Carter et al., 2004). The difficulty in giving an absolute definition is also reflected in the variation seen in assessing recovery, with a wide range of measures and approaches being used in both clinical practice and research (Shanks et al., 2013).

Further work has shown that professionals also feel well-being and quality of life should play a part in a definition of recovery (Dawson et al., 2015). These definitions work well for clinicians who are seeking to judge when to discharge someone from treatment. However, it is possible for the concept of recovery to be unhelpful when it is focussed on clinical interpretations alone, and needs to include the definition of recovery for patients to be meaningful (Slade et al., 2014).

Qualitative research exploring patient experiences of recovery has often focussed on treatment rather than definitions. Challenges in accessing treatment and difficulties in relationships with professionals have been given as factors negatively impacting recovery outcomes by adolescent patients (Offord et al., 2006; Tierney, 2008). Importantly, there have been differences found between the focus of patients and professionals, with patients talking more about psychological aspects of recovery, whereas professionals focus on physical, visible recovery (Sibeoni et al., 2017). Most research finds that patients and professionals concur on key elements of recovery, such as cessation of ED behaviours and cognitions, and some continued ambivalence about the concept of recovery (Darcy et al., 2010; Pettersen & Rosenvinge, 2002). However, these factors are not universally present in definitions such as those given in the *Diagnostic and Statistical Manual – 5th Edition* (DSM-V: American Psychiatric Association, 2013).

The above research exclusively discusses recovery from AN. While this is the ED most commonly co-occurring with autism in the literature, this may be an artefact of the general dominance over other EDs in research more generally. Recent research has shown that autistic people are more likely than non-autistic people to report having all types of EDs (Sedgewick et al., 2020). It is therefore important to look at what is known about recovery from all EDs in non-autistic people, so that this can be properly investigated among autistic people.

Recovery from BN has received less attention generally, although there are a few papers which again focus on treatment experiences and the recovery process. These papers describe frequent instances of relapse (Wasson, 2003), frame recovery as non-linear (Lindgren et al., 2015) and present it as a lifelong challenge with a continuation of symptoms (Broussard, 2005). Interestingly, similar challenges to engaging with treatment emerge, along with a fear of being judged, particularly around purging behaviours (Pettersen et al., 2008; Sánchez-Ortiz et al., 2011).

Patients are the people with the most intimate lived experience of the process and must define for themselves when – or indeed whether – they feel they have conquered their ED, so it is crucial to understand their views. Autistic people, who face a range of additional challenges and experiences relating to disordered eating, have to date had even less voice in the conceptualisation of recovery than non-autistic patients. The lack of integration between research, clinical, and individual perspectives has previously been highlighted (Jarman & Walsh, 1999), but there has been little change to the notion of recovery since their call for synthesis.

Work which has focused on patient and recovered voices has generally constituted small-scale qualitative studies of those with AN (Noordenbos, 2011b). A meta-analysis summarised the common themes as ‘food intake; physical activity; attitudes to food and weight; body evaluation; relaxation; physical recovery; psychological recovery; emotion regulation; social relations; sexual attitude; and comorbidity’ (Noordenbos, 2011b). Many papers also describe a changing sense of self or regaining identity through recovery from AN (Granek, 2007; Lamourex & Bottorff, 2005), with ‘awakening’ to the reality of AN also a core theme throughout all phases of recovery (reacting, acting, maintaining and preventing [relapse]) (Sharkey-Orgner, 1999). Other work has identified key ‘tipping points’ where personal attitudes towards recovery shift, often associated with positive treatment experiences or an outside motivating factor (Hay & Cho, 2013; Nilsson & Hägglöf, 2006).

These studies are, however, limited by their small numbers and their differing methodologies, meaning that the findings are not easily compared or synthesised into a unified view on what recovery may mean to those who have experienced EDs. They also focus primarily on those with AN, understandable considering the high mortality rates of this condition, but which excludes the experiences of those with other EDs. Furthermore, many of these papers sought to focus on which factors support recovery, arriving at a patient definition by accident rather than design, or asked practitioners and family members rather than speaking to patients themselves.

There is one larger-scale online study examining the views on recovery of those with acute AN, where the authors analysed the comments on an online ED discussion group over a 3 month period (Keski-Rahkonen & Tozzi, 2005). Rather than focussing on definitions of recovery, however, participants focussed on whether they were *recovering*, and on which factors were an influence at different stages of that process. They also talked about specific instances – for example, eating certain previously ‘forbidden’ foods – as milestones. These individual successes do not fit neatly into assessment boxes, and yet they are the everyday lived experience of recovery in a way that body mass index (BMI) is not (Espindola & Blay, 2009).

These results suggest that those who are currently ill think less about what recovery ‘is’ and more about the process of ‘recovering’. Recovery is often seen as one part of an amorphous ED journey (Patching & Lawler, 2009). This is important, as without a personal working definition, patients may find themselves feeling constantly as though they are failing to reach a nebulous goal of ‘being recovered’ without having a firm concept of that that will look like or how to know when they reach it. Aiming for what seems like an impossible outcome makes motivation harder and success less likely (Noordenbos, 2011a). Therefore, having a patient-led definition of recovery has the potential to support the actual process for those who are currently ill.

The current study therefore sought to examine the self-reported definitions of recovery from a large number of autistic and non-autistic people with EDs or who have recovered from ED, of all genders and ages.

Our research questions were:

- What are the themes in recovery definitions generated by those with current or previous ED?
- Are there differences between the recovery definitions generated by autistic and non-autistic ED patients?
- Do these patient generated definitions of recovery differ from clinical views of recovery?

As this was an exploratory study, we had no a priori expectations of the themes which would be identified. Instead, following from literature outlined above, we expected responses to fall into three main categories – nutritional intake, physical recovery, psychological/social recovery – but were interested in the presentation of these topics, whether there were any other clear themes in how individuals who have experience of EDs define their recovery, whether there were any differences between autistic and non-autistic responses, and whether these differed from clinical definitions.

2 | METHODS

2.1 | Participants

As part of a larger online study examining eating behaviours, mental health, and relationships of autistic people in comparison to non-autistic people, 187 participants gave their own definitions of recovery. Participants were drawn from across the United Kingdom and were not linked to specific ED treatment units, with adverts for the research having been posted on social media. Recruitment was open between December 2017 and April 2018. Fourteen of these definitions were removed from the analysis because they came from participants who reported being non-autistic but who scored 21 or above on the Autism Quotient-Short version (Hoekstra et al., 2011), indicating the possible presence of underlying autism. This measure is a 10-item questionnaire where participants indicate the extent to which they agree or disagree with statements relating to classic autism symptoms, with higher scores indicating a greater likelihood of the person being autistic. Of the remaining 173, 125 (72.25%) participants reported being autistic. Ages ranged from 18 to 71, with mean ages by group along with age of diagnosis for both autism and ED given in Table 1. About 100 (57.80%) participants reported having a diagnosis of AN, 37 (21.39%) reported having a diagnosis of BN or binge eating disorder, 30 (17.34%) reported having a diagnosis of either ED – not otherwise specified (ED-NOS) or otherwise specified feeding and eating disorder (OSFED), and 6 (3.47%) reported having a

diagnosis of avoidant restrictive food intake disorder (ARFID). Of these 173 people, 117 (67.63%) identified as female, 9 (5.20%) as male, and 47 (27.17%) as non-binary or transgender.

Ethnicity information was also recorded – 128 (73.99%) participants were of White ethnicity, 2 (1.16%) participants were of Asian ethnicity, 1 (0.58%) was of Black ethnicity, 3 (1.73%) were of Latinx ethnicity, 11 (6.36%) were of mixed ethnicity and 28 (16.18%) declined to provide this information.

Ethical approval for this study was given by the King's College London Psychiatry, Nursing and Midwifery Research Ethics Committee (Ref No: LRS-17/18-5292). All participants completed a consent page and were aware that completion of the survey was considered consent to use the data provided. All procedures were conducted in accordance with the latest version of the Declaration of Helsinki.

2.2 | Measures

The data presented here were collected online as part of a larger testing battery, no data from which has yet been published. That larger study examined differences in mental health, disordered eating and relationships between autistic and non-autistic people. General mental health data is not included here as there is no way to meaningfully compare quantitative questionnaire scores to qualitative written responses in this context. Relationship data, asking about broad friendship experiences,

TABLE 1 Demographic information by group

	Age Mean (SD) Range	Age of autism diagnosis Mean (SD) Range	Age ED diagnosis Mean (SD) Range	BMI Mean (SD) Range
Neurotypical women (<i>n</i> = 41)	30.77 (9.65) 20.85–61.96	–	15.43 (2.93) 8.00–23.00	22.85 (6.45) 15.43–46.69
Neurotypical men (<i>n</i> = 2)	25.05 (2.18) 23.51–26.60	–	15.00 (2.82) 13.00–17.00	20.24 (2.31) 18.61–21.88
Neurotypical non-binary (<i>n</i> = 5)	27.10 (7.44) 19.29–37.64	–	13.80 (3.56) 11.00–19.00	31.09 (10.02) 19.51–46.88
Autistic women (<i>n</i> = 76)	38.22 (12.19) 20.69–71.53	32.04 (13.18) 10.00–70.00	16.85 (5.28) 4.00–38.00	25.79 (7.33) 16.61–55.07
Autistic men (<i>n</i> = 7)	24.63 (7.37) 18.57–40.66	17.14 (10.27) 4.00–38.00	11.57 (3.64) 4.00–15.00	23.84 (5.18) 17.99–32.70
Autistic non-binary (<i>n</i> = 42)	28.09 (8.21) 18.94–51.31	21.45 (10.03) 2.00–49.00	16.43 (4.59) 11.00–29.00	26.25 (8.18) 14.69–48.76

Abbreviations: BMI, body mass index; ED, eating disorder.

is not included here because it was not seen as being related to patient-generated definitions of recovery from ED.

Participants were asked whether they had experienced an ED, what diagnoses they had received, whether they considered themselves to be recovered, and for their own definition of recovery. This was a free response box, with participants being able to write as much as they wanted.

2.3 | Data analysis

Responses were subject to thematic analysis, following Braun and Clarke (2006). Thematic analysis was chosen as similarities and differences in the broad themes of experiences was the topic of interest, rather than specific semantic analysis. The phases of thematic analysis include: (1) data familiarisation, (2) generation of initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6) report production.

Felicity Sedgewick conducted initial thematic analysis, with Jenni Leppanen and Amelia Austin carrying out reliability coding blind to the codes and themes identified by Felicity Sedgewick. We used an inductive approach, starting with research questions exploring what the common patterns were in how those with ED defined recovery. Data were analysed at the semantic level, with the themes being collapsed based on overarching similarities, in a manner similar to axial coding. The authors then met to discuss codes and agree on common themes, presented below. All authors were confident that theoretical saturation was reached in their independent analyses. There was agreement among the authors as to saturation according to the definition given by Urquhart that ‘there are mounting instances of the same codes, but no new ones’ (Urquhart, 2013) from the definitions given.

All authors agreed that there were no significant differences between the definitions of recovery given by autistic and non-autistic participants, or by type of ED they had experienced, and therefore all answers were analysed as a single group.

3 | RESULTS

The themes arising from the free response answers regarding definition of recovery can be visualised in Figure 1. We identified seven major themes: *weight restoration*, *lack of ED behaviours*, *thoughts and behaviours*, *cognitions*, *emotional responses*, *getting on with life* and *ongoing challenges*.

The most common definition of recovery from an ED given by participants was *weight restoration*. More than half of participants referenced weight restoration in some way, either phrasing it precisely so (‘weight restored’), or similarly (‘reaching a healthy weight’). The idea of maintaining weight restoration was key for many participants – ‘maintaining a healthy weight for several months’, ‘staying at a BMI of more than 18.5’, ‘not been underweight for 20 years’.

A *lack of ED behaviours* was often linked to weight restoration and was similarly prevalent. Participants gave answers which divided into two categories. First was a *lack of physical behaviours*, such as ‘not bingeing/purging any more’, ‘not starving myself to match my mental image’ and ‘not restricting calories’. Second was a *lack of monitoring behaviours*, for example ‘not weighing myself obsessively’ and ‘not tracking calories’.

Just as many participants focussed on ceasing to engage in outward behaviours of an ED as a definition of recovery, a similar number focussed on ceasing to have the *cognitions* associated with an ED. Mostly, discussions of these took the form of talking about ‘obsessive’ or ‘disordered ideas about food’, or about not ‘being

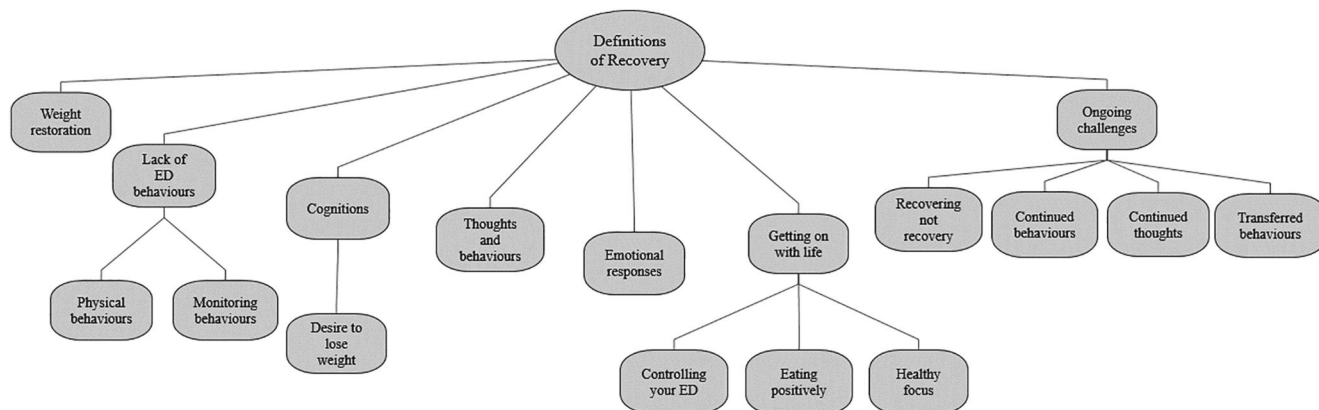


FIGURE 1 Map of themes arising from participant responses

interrupted with thoughts of calories and food'. The persistent nature of these cognitions was also mentioned by several participants, who talked about how they were no longer 'constantly thinking about food and/or my weight' and that 'thoughts about food are no longer constant for me'.

Within the *cognitions* theme, some participants also talked about changes in how they thought about their body and thinness, and a loss of the *desire to lose weight*. As well as recounting recovery from body dysmorphia, participants said they were 'no longer looking at "thinspo"', 'no longer trying to be underweight' and 'I no longer constantly want to be thinner'. The desire to 'attain slenderness' was discussed by these participants as a driving factor in their illness, so a reduction in those cognitions was felt to represent a chance at long-term maintenance of recovery.

Interestingly, few participants gave responses which covered both *thoughts and behaviours* associated with EDs, instead tending to focus on one aspect or the other. Those who did cover both concepts gave definitions including 'recovery is healthy thinking patterns as well as healthy weight' and 'not occupied by ED thoughts and consequently not engaging in disordered behaviours'. Two participants explicitly referenced the work of Carolyn Costin, with one giving an extensive quote and another giving their own summary: 'no longer having a destructive relationship with food, exercise or my body. To no longer live a life preoccupied with my weight or my body and altering either through unhealthy means'.

Definitions which included participants' *emotional responses* around recovery were also a clear theme. These took two forms: increase in positive emotions, and decrease in negative emotions. An increase in positive emotional experiences was exemplified by phrases such as '[I'm] focussed on being happy [now]', 'feeling safe and comfortable' and 'I feel worthy of food'. Similarly, the concept of 'learning to love yourself and being 'relax[ed] around food and my body shape' showed a move towards positive feelings about the self during the recovery process. A decrease in negative emotions was typified by answers such as 'I can eat without enormous amounts of anxiety and shame', 'I can eat without guilt' and '[I] can eat on a regular basis without fear'. One respondent mentioned that they now 'get scared about losing weight', which was the only instance where a negative emotion was mentioned as being a positive element of recovery.

Many participants talked about '*getting on with life*' as part of their definition of recovery. The idea that 'food does not control me anymore' and of 'no longer being controlled by an ED' came up frequently, emphasising that participants felt recovery represented an opportunity

to build and enjoy a life free of ED. The ways in which they did this varied and are described below.

First, *controlling your ED* involved recognising that while the cognitions around an ED may remain or may 'flare up', you could live your life without acting on them – 'being able to deal with symptoms' or 'my symptoms are now less intense ... I know how to manage it'. One participant articulated this as 'to be able to binge once without causing a chain of negative behaviour', showing their focus on being able to manage their own behaviours even in the face of relapse.

Second, *eating positively* was a common theme among participants, reflecting that their eating habits and food choices are very different to when at the height of their ED. These changes ranged from the very simple – 'I eat food now – to broader responses – 'having a fully healthy eating schedule', 'I can enjoy unhealthy foods', 'eating whatever I want when I want to'. Several participants highlighted that this was something which was still an ongoing and conscious effort – 'I do my best to eat 3x a day minimum', 'actively trying to keep a standard eating schedule'.

Third, a *healthy focus* was another way in which participants talked about their life after recovery. Having a 'healthy relationship with food', 'no longer choos[ing] food based exclusively on nutritional value', and being a 'healthy weight [and] able to eat freely' were all ways in which participants focussed on regaining a healthy lifestyle and body as central to moving on from their ED.

Despite the many ways in which participants talked positively about recovery, many also highlighted that they had *ongoing challenges*. The main theme was that this is a process of *recovering not recovery*, and would potentially be lifelong. For example, one person described it feeling 'more like a remission in a chronic issue with the ever-possible potential of a flare up'. Another said 'I don't believe I can be recovered anymore than a sober alcoholic can be not an alcoholic'. Several talked about 'still struggl[ing] sometimes', and one summed up this feeling as 'one is never 'recovered', but rather 'in recovery' because there is an active process of resisting relapse.

Several participants highlighted having *continued behaviours* despite being in recovery. These mostly took the form of restriction ('I still can't eat many kinds of food') and binge/purge cycles ('binging less but not fully recovered') although to a lesser extent. Some of those who were not acting on their ED impulses said that they retained 'some disordered habits' or 'an unhealthy relationship with food'.

Along with continued behaviours, some participants talked about *continued cognitions* associated with their ED. The continuation of 'cravings and self-loathing', and

that ‘there are times that I can still feel it’s grip on me’ emphasised that even when weight restored, underlying ED cognitions can remain. What was important for these participants, however, was that they could recognise these cognitions for what they were – ‘actively living with disordered thoughts while being able to overcome those urges’.

For a minority of those who talked about ongoing challenges as part of their experiences of recovery, identifying *transferred behaviours* was also important. One participant said they have ‘probably substituted food for smoking’ instead of learning to ‘deal with emotions in more productive ways’. Others talked about having gone from restricting to overeating. Still others discussed how they now ‘hyper-fixate on the healthiness of something’, and one gave a long list of her new rules for ‘acceptable’ eating: ‘following guidelines from fitness magazines, and now online blogs on vitamin sufficiency, (drink a gallon of water per day, herbal teas, no sugar, minimal pre-packaged food, steam/boil/ or bake lean meats or grains, make 2/3s of any plate serving ‘living’ fresh fruits and vegetables, if your body feels worse after eating than when you were hungry then don’t eat it)’.

There were many areas where the definitions of recovery given by our participants agreed with those from other patient accounts, from clinicians, and from research, visualised in Figure 2. These are considered further within the Section 4, but the comparisons between our findings and the literature on ED recovery are enlightening as to where disconnects may occur between clinicians and patients during the recovery process.

4 | DISCUSSION

The findings of this study show that ED patients have a wide range of definitions of recovery, that those definitions do not differ by either autism or ED diagnosis, and that only some of those definitions map directly onto those used by clinicians. In the face of a historic focus on autism and AN, making sure to include the voices and experiences of those with a range of EDs can help to redress this imbalance and lead to a better understanding of the overall picture of the relationships between autism and EDs. The lack of differences between autistic and non-autistic participants in terms of thinking about recovery was an unexpected and fascinating finding. Interestingly, most participants focussed on one aspect of recovery – either physical or cognitive – although many also talked about their lived experience of being recovered and the ongoing challenges of the recovery process.

The similarities in the definitions of recovery given by autistic and non-autistic participants were so striking that it was not possible to meaningfully separate the groups. Considering that there is research showing that autistic AN patients are likely to experience and respond to treatment differently (Okuda et al., 2017; Spain et al., 2015), this was somewhat surprising. In many ways though, it is also promising. As autistic patients are thinking about recovery – and its challenges – similarly to non-autistic patients, clinicians can be confident in their ability to discuss and present recovery to patients on the spectrum. This is important as there have been several studies showing that medical professionals lack confidence in working with autistic people, from GPs (Unigwe

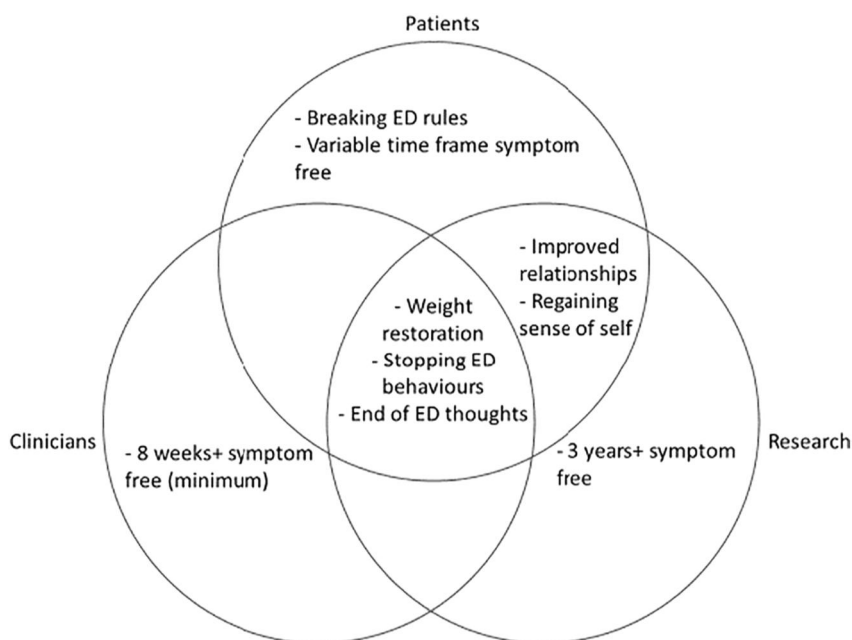


FIGURE 2 Diagram showing areas of agreement and disagreement in conceptualisations of recovery by patients, clinicians, and research literature

et al., 2017) to clinical psychologists (Kinnaird et al., 2017).

The fact that most participants gave a definition of recovery which included weight restoration is unsurprising, as this is the key metric used by clinical services both for initial diagnosis and for determining recovery (American Psychiatric Association, 2013). For example, for those with AN who have been placed on an in-patient ward, weight restoration is the main goal and defining factor in when they are discharged, something which patients themselves have identified as challenging in long-term management of their ED (Bezance & Holliday, 2013). It therefore makes sense that, as the majority of this cohort had a diagnosis of AN, weight restoration and BMI would be central to ideas of recovery, although other patients have argued that clinician focus on physical recovery can be detrimental to their own experiences of the process (Sibeoni et al., 2017).

It is notable that many participants with diagnoses other than AN also had a focus on weight restoration, particularly autistic participants. This may be because the range of sensory sensitivities autistic participants in the sample have led to low bodyweight due to restricted diet, such as those with ARFID (Lucarelli et al., 2017). Those with BN and BED can also experience weight fluctuations, although they tend to maintain a higher BMI, and weight restoration down to a healthy weight was also mentioned by some participants with these diagnoses.

A lack of ED behaviours is also understandable as a predominant element of definitions of recovery. These behaviours have a devastating impact and lead to the high mortality rates associated with EDs such as AN (Birmingham et al., 2005; Papadopoulos et al., 2009). Reaching a point of no longer engaging in those behaviours is clearly important to recovery, hence being such a common theme across the range of ED diagnoses. This is a patient-generated definition which very much mirrors those used by clinicians, such as 'the absence of all criterion symptoms...for not less than eight consecutive weeks' (Strober et al., 1997). In contrast to this relatively short time frame, participants talked about needing to be behaviour-free for several months before they began to 'trust' their recovery.

It is interesting that most participants gave a definition of recovery which focussed on either thoughts or behaviours, rather than combining the two. It is possible that this focus may reflect the type of treatment a person has engaged in – for example, someone who has experience with top-down therapy may focus on the cognitive aspects of their ED. This may also tie into the ongoing challenges many participants described, as a focus on just one aspect of an ED may leave a person struggling with

others, something which is supported by qualitative work with patients who talk about 'reconnecting' their minds and bodies (Jana et al., 2011). While we cannot draw conclusions on this point as we did not collect information on treatment, this would be interesting for future research.

A notable minority of participants gave holistic definitions of recovery encompassing both cognitive and behavioural aspects. This was also a theme among those who talked about overcoming their ED cognitions to refuse to engage in ED behaviours, highlighting the interconnectedness between these two features ED. Studies have shown that those who have cognitive as well as physical recovery from AN are indistinguishable from non-ED controls, whereas those who retain cognitive symptoms continue to score similarly to currently ill patients on a range of symptomatology and personality measures (Bachner-Melman et al., 2006). Those participants who mentioned both aspects were also more likely to be positive about their long-term recovery prospects, as they felt in control of their ED.

These links between cognition and behaviour, as well as encompassing a view of this change as being maintained long term, reflect many of the definitions of recovery used by professionals (Bardone-Cone et al., 2010; Vanderlinden et al., 2007). One potentially concerning finding was that few participants mentioned no longer wanting to be thin or lose weight as part of their definition. A continued desire to be thin and a reluctance to recover has been seen in other work on challenges to recovery (Colton & Pistrang, 2004; Nordbø et al., 2012). Recovery from the desire to be thin or to lose weight may be one of the defining features of a successful recovery and lower chances of relapse, since if someone wants to be thinner, they are always more likely to engage in ED behaviours which help them to achieve that goal. It is important that those supporting people with ED work with their patients to emphasise that it is possible to be happy, healthy, and successful without the ED – something which those participants who talked about 'getting on with life' expressed and which has been seen in other studies (Weaver et al., 2005).

Other research has also emphasised that patients in later stages of recovery may require specialist support with managing the ongoing challenges they experience (Pettersen et al., 2013). The ambivalence towards recovery highlighted both by participants in this study and in work such as that of Darcy (2011) emphasises how AN patients may require support to remain committed to recovery. This is particularly important in light of patients who discussed ongoing behaviours and relapses, something which has been highlighted in previous work (Federici & Kaplan, 2008).

A further finding important for clinical interactions with ED patients was the significant minority of participants who talked about having transferred their behaviours. Adhering to a set of personal rules and rituals around food and eating is a central element of many EDs (Brown et al., 2012), and these rules are something which many treatment programmes work on changing and relaxing. Some participants, however, simply moved from an obsession with a set of rules around restricting to a set of behaviours focussing on the 'healthiness' of food, aligning with the definition of orthorexia nervosa (Donini et al., 2004). It may be that for some patients, a seeming recovery from AN actually represents a move towards a different set of problematic behaviours (Segura-Garcia et al., 2015).

While this research is strong, there are also some limitations. First, the study was conducted anonymously online, meaning that we are dependent entirely on how each participant interpreted the question and how much detail they wanted to give, without the ability to ask follow-up questions. Despite this, the large number of participants and the range of themes which were identified means that we can be confident that the data presented here is representative of the spectrum of community experiences of recovery. Second, the nature of online research means that the sample represent a portion of the population, both autistic and non-autistic, who are literate and comfortable sharing their thoughts in written format. These people do not necessarily represent everyone on the spectrum, but their experiences are still a valuable starting point for guiding research with people who are minimally verbal or who have learning difficulties and are affected by disordered eating. Third, we did not ask about aspects such as treatment experiences and cannot speculate as to how this may shape how individuals define recovery. Exploring the connections between treatment practices and how ED patients conceptualise their own recovery would be an interesting piece of future research and may help guide clinicians in how to support a holistic recovery. We also did not ask participants if they knew which diagnostic criteria had been used in their case, as we felt it was unlikely that patients would be aware of this information. Fourth, the self-report nature of the study means that we are reliant on participants for their diagnostic status. It may be that future work seeks to reproduce our findings through face-to-face interviews where clinician diagnoses – and clinician views – could be collected, which would add richness to the literature.

In conclusion, participants gave a wide range of definitions of recovery from their ED, which were similar regardless of autism or ED diagnostic status. Many

aspects of these definitions aligned with those used by professionals, but not all, and most participants focussed on a single aspect of recovery rather than a holistic definition. While most participants gave positive definitions of recovery and felt that these were achievable, many also highlighted the ongoing challenges of being in the process of recovery, something which clinicians can take in account to prepare patients for before discharging them from support services. The fact that autistic participants gave such similar responses to non-autistic participants should also give clinicians confidence in supporting their autistic patients into and through recovery, rather than being intimidated by an additional diagnostic label.

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CONFLICT OF INTEREST


There are no conflicts of interest to declare for any author.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions

ORCID

Felicity Sedgewick  <https://orcid.org/0000-0002-4068-617X>

Kate Tchanturia  <https://orcid.org/0000-0001-8988-3265>

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