Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment?

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Research suggests that up to one in four individuals with anorexia nervosa (AN) may be on the autistic spectrum, and that these autistic traits may not have been recognized or diagnosed prior to eating disorder (ED) treatment. Significantly, these heightened autistic traits are associated with poorer treatment outcomes, suggesting that treatment may need to be adapted for this population. The purpose of this study was to explore with people with AN on the autistic spectrum their experiences of ED treatment, and their views on what needs to be changed.

Women with AN (n = 13), either with an autism diagnosis or presenting with clinically significant levels of autistic traits, were interviewed on their experiences of treatment and potential improvements. Interviews were analysed using thematic analysis. The findings suggest that this population experience unique needs associated with their autism that are not being met by standard ED treatments, and recommendations are made for potential future adaptations.

Future research into a more systematic approach for treatment adaptations for this population, including education programmes for clinicians, could potentially lead to better treatment experiences.
processing that may persist following recovery (Harrison, Mountford, & Tchanturia, 2014; Lang et al., 2016a, 2016b; Lang, Lopez, Stahl, Tchanturia, & Treasure, 2014; Leppanen, Sedgewick, Treasure, & Tchanturia, 2018; Westwood, Lawrence, Fleming, & Tchanturia, 2016; Westwood, Stahl, Mandy, & Tchanturia, 2016). Significantly, heightened autistic traits in people with AN are associated with more severe presentations and poorer treatment outcomes (Nielsen, Anckarsater, Gillberg, Rastam, & Wentz, 2015; Tchanturia, Adamson, Leppanen, & Westwood, 2017; Tchanturia, Larsson, & Adamson, 2016), leading to suggestions that traditional treatment approaches may need to be adapted for this population (Dudova, Kocourkova, & Koutek, 2015; Stewart, McEwen, Konstantellou, Eisler, & Simic, 2017; Treasure, 2013). Although at present there is a lack of research in this area, potential contributors behind these poorer outcomes could reflect the heightened rigidity and difficulties with introspection seen in autism, making it difficult for patients to engage in treatment (Dudova et al., 2015). Similarly, autistic people with co-occurring AN could experience factors motivating their ED behaviours that are related to their autism, rather than the traditional shape and weight concerns associated with AN: studies of food selectivity in autistic individuals suggest that factors impacting eating in this population could include sensory sensitivity, a need for routine and difficulties with coordination (Cermak, Curtin, & Bandini, 2010). A study interviewing clinicians on their views on treating AN in autistic patients found that clinicians felt that this population was particularly difficult to treat (Kinnaird, Norton, & Tchanturia, 2017). Problems inhibiting treatment included rigid thought patterns, difficulties with emotion identification, and communication. Clinicians identified the importance of understanding the role of autism in the ED, and the identification of autistic traits and referral for diagnosis if necessary. However, many clinicians felt that they did not have enough information or training in this area.

Consequently, previous research indicates that people with AN on the autistic spectrum could benefit from treatment adaptations (Kinnaird et al., 2017). Nonetheless, at present there is a lack of literature on the needs of this population, and how treatment should, therefore, be adapted. At present, any changes to treatment are typically made on the basis of individual clinician experience, rather than representing a systematic approach (Kinnaird et al., 2017). Research has explored how treatment for other psychological conditions should be adapted for autistic people, including adapting cognitive behavioural therapy for anxiety and depression, but no research has explored treatment adaptations for AN (Moree & Davis, 2010; Spain, Sin, Chalder, Murphy, & Happe, 2015). Therefore, the aim of this study was to examine the possibility of treatment adaptations for this population by exploring the views and experiences of individuals with AN on the autistic spectrum.

Method

Study design

Semi-structured interviews were conducted with women with AN and high levels of autistic traits between August 2017 and May 2018. The study received ethical approval from London-City and East Research Ethics Committee and South London (18/LO/0050) and Maudsley Clinical Audit & Effectiveness Committee.

Participant selection

Patients with AN receiving treatment with the National Eating Disorder Clinical Service in South London and Maudsley NHS Foundation Trust were invited to participate in the study by their clinicians if they had a diagnosis of autism or had scores indicative of high autistic traits on the Short Autism Spectrum Quotient (AQ-10) or the Autism Diagnostic Observation Schedule (ADOS) (Allison, Auyeung, & Baron-Cohen, 2012; Lord et al., 2000). The AQ-10 is a brief screening instrument designed to measure autistic traits and guide decision-making around referral for a formal diagnosis. Participants were invited to the study if they scored above the previously established clinical cut-off (6). The ADOS is a structured interview designed for the direct observation of characteristics associated with autism. Participants were considered eligible if they scored above the threshold for being on the autism spectrum. Eligible patients were informed that they were being invited to participate in an interview on their treatment experiences. If patients expressed interest and gave verbal consent, a meeting at their place of treatment with the study’s researcher (EK) was arranged to discuss the study and, if the patient was still interested, conduct the interview.

In addition, participants were invited through a separate online study on autism and eating behaviours if they self-reported having both a diagnosis of autism and AN, and having previously experienced AN treatment. Potential participants were contacted by the first author and invited to participate in an interview.
on their ED treatment experiences. Interested participants were then interviewed face to face, over the phone, Skype, or instant messenger, depending on participant preference. This recruitment process continued until authors EK and KT judged that data saturation had been reached.

**Participant characteristics**

In total, 16 people were invited to participate in the study; three declined, two without giving a reason and one person due to their social anxiety making interviewing prohibitive. The final study sample consisted of 13 participants who had previously received treatment for AN, with a mean age of 28.46 years (SD = 7.21). Five participants were recruited through the inpatient service, with the remaining eight recruited online. Eleven participants identified as female, whilst two identified as non-binary. Nine participants had been diagnosed with autism. Four participants exhibited high levels of autistic traits, but no confirmed diagnosis: three of these participants scored above cut-off on the TQ-10, and one participant met the threshold for autism on the ADOS. Out of the nine participants with diagnosed autism, the average age of diagnosis was 23.56 years (SD = 8.17). Individuals in the study had received treatment in varying geographical locations across the UK, the US, and Western European countries.

Participants had been ill with AN for an average of 8.42 years (SD = 7.03), with the majority (n = 10, 77%) of participants receiving treatment on multiple occasions over the course of their illness. Twelve out of the 13 participants (93%) had also been diagnosed with other psychiatric illnesses: eight with depression, eight with anxiety, six with obsessive compulsive disorder, two with bipolar disorder, two with post-traumatic stress disorder, and one with Tourette’s. Additionally, two participants had been diagnosed over the course of their treatment with borderline personality disorder, but disputed this diagnosis.

**Data collection**

Interviews were conducted by EK at a time and using a method of the participant’s choosing. Six interviews were conducted face-to-face at the participant’s place of treatment, one over the telephone, three using Skype, and three using an instant messaging service. Prior to each interview, participants were provided with written information on the study and given an opportunity to ask questions before securing written
informed consent. Each interview lasted between 15–45 min and was audio-recorded. The interviews were conducted using a semi-structured topic guide, exploring participant experiences of treatment and what could be improved. If the participant had a diagnosis of autism they were additionally asked to reflect upon how their autism may have affected their treatment, and how treatment could be improved specifically for autistic people with AN in the future. The interview guide was based on topics thought to be relevant to this area based on previous research, and additionally was developed with the help of an autistic individual who had previously received treatment for AN. As interviews progressed and as new, previously unconsidered topics were raised by the participants, these new topics were added to the interview guide. This process continued until no new topics were raised, indicating data saturation.

Analysis

The interviews were transcribed by EK and entered into NVivo (version 11) for analysis. All identifying information was removed at the point of transcription. Interview data was analysed using thematic analysis: first, interview transcripts were read and reread by authors EK and KT to ensure familiarization (Braun & Clarke, 2006). A coding framework was then developed based on the final interview schedule, which had been updated during the interview process to capture all topics raised by participants. A copy of the final interview schedule is available in the Supplementary material for this paper. These codes were then applied line by line to the data. Following coding, data within each code was reread and compared to identify patterns. Three themes were identified as reflecting these patterns: the relationship between autism and anorexia, problems with treatment, and treatment adaptations.

Results

Themes and sub-themes are summarized in a thematic map in Figure 1. Key findings are summarized below under their main theme headings.

Relationship between autism and anorexia

For participants with an autism diagnosis, all saw their AN and their autism as deeply interlinked. First, they felt that traits associated with their autism in turn reinforced their AN, both contributing towards its development and making recovery more challenging. A common difficulty described by participants was that the rigidity and inflexibility associated with their autism had contributed towards the development of fixed routines and rituals around food, and that, once these had developed, this same rigidity made it very difficult for them to change.

Second, participants described how certain traits and behaviours associated with their autism contributed to the development of their AN, but in ways not traditionally associated with ED behaviours and so not addressed or recognised by current treatment models. Participants described how a desire to lose weight, low self-esteem, and body image issues were less relevant in the development of their illness compared to other, non-traditional motivations. Although these varied across participants, motivations included a need for control, rigid thought patterns, sensory difficulties, social confusion or struggling to relate to other people, organizational problems surrounding cooking and food shopping, exercise as a method of stimulation, and the ED acting as a special interest.

For many participants, AN became a way of coping with these difficulties:

I’ve never really had the thoughts of I want to, kind of, I don’t know, be really thin or lose weight. I’ve never really—like it’s always just kind of happened. And I think it’s not like—it is a bit about body image that everything like that but … It’s more kind of a way of dealing with sensory things like, yeah, it’s a massive thing of not knowing that I had sensory issues and it as a way of coping with those (Participant 9).

The majority of participants diagnosed with autism in this study only received their diagnosis upon receiving ED treatment. As highlighted by this participant, the development of AN was not only viewed as a way of coping with autistic traits, but as a way of coping with autistic traits that these participants were not aware they had as they had not yet been diagnosed. Rather, AN became a way of managing these difficulties and, often, a feeling of difference that they did not understand.

Problems with treatment

For the minority of participants who had received an autism diagnosis prior to ED treatment, a common experience was that they found it difficult to access treatment due to their co-occurring autism. Participants described being refused treatment by specialist ED services. Where participants did access ED treatments, they were often seen as difficult or
uncooperative patients due to their (typically undiagnosed) autism, which led to a poor relationship with clinicians and participants leaving or being discharged from services:

The first facility I went to, before the autism diagnosis was problematic because they thought that I was stubborn and lazy and unwilling to help myself, and they let me know it. They ended up asking me not to come back, because my case was too “complex” (Participant 5).

Similarly, participants described struggling to make progress within the typical time frames for treatment, and being discharged for not making enough progress with treatment. In addition to the lack of time, participants highlighted a number of problems with the treatments they were offered for their ED. In particular, they felt that their autistic traits and behaviours made it difficult for them to engage with treatment in ways that were not recognized or misinterpreted by clinicians. Participants described how their sensory and social difficulties made inpatient treatment environments extremely challenging and often upsetting:

I’m very very sensitive to noise. You know, extremely sensitive. Like things like laughter and stuff, I can pick it up so easily and I don’t like loud noises, like when someone’s distressed in the room I get very distressed, it makes me feel distressed … I feel like they didn’t understand that I needed to walk out, because apparently, they handed it over to the other staff for my notes. I feel like they don’t understand I took myself out of the situation because I can’t cope with the noise (Participant 1).

Similarly, participants whose eating behaviours were partially motivated by sensory difficulties around food described struggling with refeeding programmes that did not take these problems into account. Difficulties included sensitivity to taste, smells, texture, aversion to mixing foods, and needing to have foods at certain temperatures. Participants described their frustration when they were willing to eat food whilst adapting around their autism, such as avoiding certain textures or maintaining a routine, and having this misinterpreted by staff as ED behaviours:

It was sensory and texture and just, caused me so much anxiety not because of what food it was but because of like the sensory aspect of that food … it was always kind of acted as though I was just not really aware and it was really the food that was causing me distress. And then that made me more angry because it felt like they were saying I was lying (Participant 10).

Participants described the lack of recognition of the relationship between their autism and their eating behaviours, and an unwillingness to accommodate these difficulties, as a key factor in impeding their nutritional recovery.

Consequently, participants struggled when treatment was aimed at changing apparent ED behaviours that were in fact related to their autism, and felt misunderstood by their clinicians. In some cases, this misinterpretation of autism related behaviours led to what participants felt were misdiagnoses, including autistic meltdowns being misinterpreted as anxiety or borderline personality disorder, leading to inappropriate treatment interventions and continuing deteriorating relationships with clinicians.

**Treatment adaptations**

In the context of these difficulties with treatment, and the relationship between autism and AN, participants reflected on potential treatment adaptations. Participants felt that traditional ED approaches needed to be adapted for people on the autistic spectrum, and described wanting a flexible, individualized approach which recognized the role of their autism in their ED:

Treating the AN as though it exists in a vacuum is incredibly harmful, because it’s demoralizing to the patient, it delays recovery, and it frustrates everyone involved. Emphasis needs to be placed on figuring out which behaviours are anorexia based, and which are autism based. If someone is refusing to eat their dinner, it could be because their eating disorder is telling them that it will make them fat, or, the food could be touching, is an autistic sensory issue. The behaviours are exactly the same, but the causes can be so different. Knowing all of this, if doctors and therapists and dieticians can be flexible regarding autistic patients, they’re going to see much better outcomes (Participant 5).

For many participants a key element in their treatment was having their autism recognized and finally diagnosed. The majority of participants with an autism diagnosis in this study received this diagnosis as a result of accessing ED treatment, where their autism was recognized for the first time. Where clinicians did recognize the presence of autistic traits and refer for a diagnosis, this was viewed as a positive, important experience for participants:

Actually, all this mental health stuff that I’ve had—this is why, this is why I’ve felt like I’ve not fitted into the world for the last 45 years, and actually I’m just different and that’s ok (Participant 10).

Having an autism diagnosis also enabled participants to have better insight into their ED behaviours,
allowing them to explore and understand which behaviours were related to their ED, and which were in fact related to their autism. This gave them more confidence in treatment to voice and describe their own needs to their clinicians, leading to a better overall treatment experience:

I have like sensory issues with touch, for example textures. But that's something, like last time because I think I was masking I wouldn't bring it up. And it takes quite a lot of courage to be honest and say “actually, yeah, that's a sensory thing for me”, or, I don't know if this is sensory but ever since I've been a child I've never really liked my food mixed or touching. But again, like last time I kind of thought “oh well to recover you have to mix your foods” so, I don't know, it was almost like masking the recovery (Participant 9).

Other treatment improvements described by participants included the importance of clinicians having an understanding of autism and its implications for the ED and its treatment, and a willingness to adapt around difficulties relating to the autism. When participants felt that they were being listened to, and able to direct and influence their treatment to adapt to their autism in collaboration with the clinician, they described better treatment experiences and outcomes. Some participants described specific changes or improvements to ED treatment. In particular, participants felt that current treatment approaches did not take into account their autistic traits and behaviours motivating the ED:

I know that their model of therapy is not going to deal with that. I, so, it's not going to address what I think—I think my problem is how I think. I think, I think as somebody who's on the autistic spectrum and who has an ED, I think AN is kind of like a product of who I am and how I think (Participant 6).

Consequently, this participant felt that treatment could be improved by targeting the rigid thought patterns associated with autism. Whilst participants emphasized that the influence of autism on the ED would vary across individuals, other possible improvements included work on identifying and describing emotions, allowing participants who struggled with communication to write things down in between therapy appointments, a sensory space to withdraw to, and occupational therapy support with difficulties surrounding cooking, food shopping, and organization. In addition, participants felt that they potentially needed more time in treatment, due to the difficulty of challenging the rigidity and routine behaviours associated with autism.

Significantly for treatment, participants felt that their underlying autism impacted how they viewed recovery. Some participants felt unsure if they would ever fully recover, as their ED had become a key part of their life. Participants who had recovered described still having certain behaviours around food, such as a need for control, which they viewed as stemming from their autism rather than their AN. Consequently, one participant felt that recovery for autistic people was less associated with eliminating all food related behaviours, and should be focused on working towards a good quality of life:

Obviously people need to be having a good diet, and they need to be getting to a sustainable weight, and like not having everything controlled, but people getting that like someone is going to still have, probably, a rigidity around their food, like and that not being totally—not just in inpatient, in outpatient as well—that's not the battle to be fighting. It should be about how much is that person able to now be like engaging in life (Participant 13).

Discussion

The findings of this study suggest that people with AN on the autism spectrum have unique needs relating to their autistic traits that require treatment adaptations. The participants in this study highlighted the importance of exploring and understanding collaboratively with clinicians the relationship between their ED and their autistic traits, and the need to recognize these traits and make appropriate adaptations in treatment.

Whilst previous research has highlighted the prevalence of autism in people with AN, this present study went further in exploring the role that autistic traits potentially play in the development and maintenance of the ED (Westwood & Tchanturia, 2017). That participants felt that their autistic traits, including difficulties with rigidity, inflexibility, and social processing, contributed to and maintained their illness reflects research suggesting that these cognitive characteristics may act as maintenance factors for AN, leading to poorer treatment outcomes (Schulte-Ruther, Mainz, Fink, Herpertz-Dahlmann, & Konrad, 2012; Treasure, 2013; Treasure & Schmidt, 2013). Moreover, participants highlighted a number of other difficulties associated with their autism that motivated their ED behaviours not addressed by traditional models of AN, including sensory sensitivity, and executive functioning problems creating difficulties around cooking (Cermak et al., 2010; Crane, Goddard, & Pring, 2009; Hill, 2004). That sensory
difficulties were highlighted by the participants in this study is striking in the context of recent literature suggesting that sensory sensitivity to food may be altered in AN, and the possibility that sensory sensitivity could represent a shared mechanism in autism and AN warrants future research (Kinnaird, Stewart, & Tchanturia, 2018).

The findings of this current study examining patient views on treating anorexia in autistic people generally resonate with a previous study exploring clinician views on this same topic, with the experiences of patients giving greater insight into the difficulties raised by clinicians (Kinnaird et al., 2017). One common aspect was that of understanding recovery in the context of autism: both patients and clinicians emphasized that certain behaviours relating to the autism, such as difficulty with rigidity or food sensory issues, may persist following recovery. Consequently, clinicians treating autistic patients should consider how their patient views recovery, which behaviours are ED related and so can be targeted for change, and which behaviours are rooted in the autism and so may require a process of adaptation and acceptance.

A key divergence in the views of the two groups was that of communication difficulties. Clinicians raised the problem of communication problems, describing autistic patients as difficult to functionally communicate with, and highlighting issues such as patients giving only brief responses, being difficult to engage in conversation, or needing clear and unambiguous instructions using literal language. This is in contrast to the interviews conducted in this study: far from being brief, participants often gave lengthy and detailed responses to the interview questions and were highly engaged. This may in part reflect that, rather than using only face-to-face interactions as typical in therapy sessions, the present study allowed participants to choose how they were interviewed, including over instant messenger. That patient interaction may improve through using alternative methods of communication, including writing things down, reflects previous clinician recommendations for autistic patients (Kinnaird et al., 2017).

In contrast to the views of clinicians that patients were uncommunicative, patients highlighted that they also experience communication difficulties in this relationship, but from a perspective of a lack of understanding, describing a feeling of not being listened to or believed, and clinicians not allowing them to have an input into their treatment. That individuals on both sides of the clinician/patient dyad highlight communication problems with their opposite number reflects a growing interest in the ‘double empathy’ problem in autism: that communication difficulties do not stem from the autistic person alone, but rather due to two people with very different experiences interacting (Milton, 2012). In the case of this population, this could reflect a barrier between a clinician with a neurotypical perspective of how an ED typically presents and lacking insight into the autistic experience, and an autistic patient whose ED experiences are in fact deeply informed by their autism. The findings of both this current study and the previous clinician study suggest that an individualized approach, where a clinician informed and trained in working with autistic people prioritizes the patient’s input on their treatment and encourages and values their input, may be vital in addressing these mutual communication difficulties.

Nonetheless, at present clinicians working in ED settings do not typically receive systematic training in autism, and report lacking the knowledge or confidence to make the kinds of adaptations required for this population (Kinnaird et al., 2017). This reflects wider difficulties that autistic people experience in accessing health services, with previous research similarly finding high levels of unmet needs, and the perception of autistic service users that these needs are misunderstood or dismissed (Nicolaidis et al., 2013; Tint & Weiss, 2017). This study also reinforces the finding of past research suggesting that treatment spaces are often not autism friendly, including difficulties with sensory sensitivity and over-stimulation, suggesting that ED treatment spaces—particularly inpatient wards—may need to be adapted for this population (Tint & Weiss, 2017). In the present study, this poor service experience was often related by participants to clinicians not recognizing or understanding the role of their autism in their ED, emphasizing the importance of clinician education in this area (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012).

Unlike previous research on the service needs of autistic adults, a key problem raised in this study unique to this population was that many participants described not realizing they had autism until they accessed ED treatment. This reflects research findings that women are diagnosed with autism at a later age compared to men, and that their autistic traits may go unrecognized (Begeer et al., 2013; Rutherford et al., 2016). In this study, participants directly related their autism being undiagnosed and the development of AN as a coping mechanism for their autistic traits. Consequently, this highlights the importance of autism being recognized and diagnosed in people with
AN to enable effective treatment. Given the heightened prevalence of autism in people with AN, this potentially suggests a need for a systematic screening approach for heightened ASD traits in people seeking treatment (Westwood et al., 2017).

This was a qualitative study, and so only represents the experiences of a minority of people on the autistic spectrum who have received treatment for AN. However, this study did recruit participants from varying geographical locations and health service systems, supporting the generalizability of these findings. Future empirical research should further explore the relationship between autism and AN identified in this study, and how the ED pathology of people on the autistic spectrum differs from those with AN only. In particular, the concept raised by participants in this study that autism contributed to the development of their AN should be explored by longitudinal research. Further research should explore the possibility of developing a more systematic approach to treatment adaptations for people with AN on the autistic spectrum, including clinician training and the possibility of structured interventions for traits such as cognitive rigidity, communication difficulties, or emotional processing. These adaptations could then be evaluated in a controlled study design against standard treatment.

**Clinical implications**

The findings of these paper raise a number of potential treatment adaptations for this population which should be explored in future empirical research. The role of autistic traits in the ED needs to be recognized and addressed in treatment, and emphasizes the importance of clinician education and training in autism and its potential role in the ED. Specific interventions could include cognitive remediation to address rigid and inflexible thought patterns, or work on recognizing and expressing emotions using emotion skills training (Easter & Tchanturia, 2009; Kyriacou, Easter, & Tchanturia, 2011; Money, Genders, Treasure, Schmidt, & Tchanturia, 2011; Tchanturia, Doris, Mountford, & Fleming, 2015). Furthermore, sensory sensitivity to food in autism may indicate a need to adapt refeeding programmes in order to accommodate these sensitivities, and so create a sustainable nutritional recovery (Cermak et al., 2010). Clinician training could also be valuable in addressing the communication difficulties raised in the present study and previous research (Kinnaird et al., 2017). Any adaptations should reflect an individualized, collaborative approach between patient and clinician, with a focus on autism recognition and diagnosis.

**Conclusions**

People with AN on the autism spectrum experience their autism and their ED as deeply interlinked, with their autistic traits motivating apparent ED behaviours in ways that are not accounted for by traditional treatment models. At present, these unique needs are not being met by standard treatment approaches. Consequently, treatment adaptations are required for this population.

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**Informed Consent**

Written informed consent was obtained from all participants prior to data collection.

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