What changes would you like to make to the field of Eating Disorders to help patients and carers better?

While working in inpatient CAMHS Eating Disorders and community CAMHS, I saw the extent that eating disorders (EDs) affect patients and their carers. Some of the most challenging and "stuck" patients I saw were those with both anorexia nervosa (AN) and autistic spectrum disorder (ASD). These patients struggled to engage with their eating disorders-specific management plans and displayed additional difficulties associated with their autism, such as rigid thinking and sensory difficulties.

AN is coded F50.0 in ICD-10. ICD-10 definition: *"Anorexia nervosa, is an eating disorder characterized by a low weight, fear of gaining weight, a strong desire to be thin, and food restriction."* [1] It is estimated that approximately 700,000 people in the UK are living with an eating disorder, 90% of these are female. Anorexia is the psychiatric disorder associated with the highest level of mortality, with a mortality rate of 5.1 deaths per 1000 patients with anorexia nervosa. [2]

ASD is coded F84.0 in ICD-10. ICD-10 definition: *"Autism is a neurodevelopmental disorder characterized by impaired social interaction, verbal and non-verbal communication, and restricted and repetitive behaviour."* [3]

Rates of mental health difficulties are frequently comorbid in adults with autism and are associated with a diminished quality of life.[4] ASD is thought to be present in up to 35% of patients with AN. Women with ASD have been found to be much more likely to develop AN than those who without ASD.[5] Patients with AN and higher levels of autistic traits had poorer treatment outcomes, longer inpatient stays and more severe presentations.[6] There are currently no services or guidelines in the UK for the management of these patients.[7] NICE guidelines for AN or eating disorders do not mention neurodevelopmental disorders, despite having extensive guidance on various physical and psychological comorbidities.[8]

A qualitative study by Brede et al evaluated the perspectives of autistic women, parents of autistic women and healthcare professionals. Six overarching themes were identified: sensory difficulties, social interaction and relationships, self and identity, difficulties with emotions, thinking styles, and needing control and predictability.[9] The thinking styles identified in the study were literal thinking, intense interests and rigid thinking.[9] Cognitive rigidity is a major symptom seen in both AN and ASD.[10] Adamson et al found that traits including attention to detail and routine behaviours also overlapped across ASD and AN.[6] Restricted and repetitive behaviours and interests (RRBIs) are one of the key presenting features seen in ASD.[10] Some of this overlap in symptoms may be due to a "pseudo-autistic" presentation caused by the effects of starvation in AN. This starvation can cause temporary cognitive rigidity and poor mentalising ability, which does not persist once the individual has undergone refeeding. However, many individuals with AN continue to meet criteria for ASD once they have made a full recovery from their eating disorder, or have been reported to show autistic traits in childhood, preceding their anorexia. "Intense interests" seen in ASD relating to eating behaviours contributed to the development of AN. These interests could be directly associated with diet, such as veganism, exercise, nutrition or environmental concerns, or a special interest in numbers extending to counting calories or numbers on the weighing scales. These special interests led to a decrease in patients' anxiety levels and a sense of enjoyment.[9]

Nine women with ASD and AN interviewed in a qualitative study by Kinnaird et al reported feeling that their AN and ASD were heavily connected. RRBIs associated with their autism meant that they had developed strict behaviours and routines around foodbody image issues were less common in the women with autism and they reported their main issues to be a need for control, sensory difficulties, social confusion, organisational problems surrounding cooking and food shopping, exercise as a method of stimulation, and the ED acting as a special interest. [11]

The male to female ratio of autism diagnoses is 3:1 according to a review and meta-analysis conducted in 2017.[12] This contrasts to the 1:9 male to female ratio seen in eating disorders.[2] Differences have been found between how autism presents in females vs males. The review explored perceived barriers to ASD diagnoses in females. Five core themes were identified: compensatory behaviours, parental concerns (parents in general being less concerned about their daughters with ASD), others' perceptions, lack of information/resources and clinician bias. The main issue highlighted was that ASD continues to be seen as a predominantly male disorder.[12] One of the compensatory behaviours highlighted was "masking". "Masking" is more common in females with ASD compared to males. This is the term used to describe the individual's hiding of their symptoms and compensatory behaviours used to diminish social challenges.[12]

A key feature seen in autism is difficulty with social interactions. All women in the Brene et al study with AN and ASD had experienced this, often leading to loneliness, bullying and abuse, which all affected their eating. These difficulties became more apparent as they reached adolescence, coinciding with the onset of their eating disorder. Restricting their eating was both a way of regaining control and numbing emotions, as well as avoiding social interactions.[9] Alexithymia (difficulty identifying and describing emotions[13]) has been associated with both AN and ASD.[14] Of the carers interviewed by Adamson et al, 40% thought that the eating disorder provided a means of coping with the girls' difficulties associated with ASD and 80% of carers in the study described "masking" becoming more difficult as their daughters grew older. As their daughters became less able to cope with ever more complex social circumstances their AN started to emerge and seemed to be related to their reduced coping ability.[6]

A study exploring the relationship between symptoms of ASD and AN in adults with AN concluded that isolation, difficulties in relationships with others, and anxiety around social situations maintain AN and ASD psychopathology. Focussing treatment on these particular difficulties may lead to improvements in AN patients with ASD traits. The symptoms that crossed over between the 2 disorders the most were poor self-confidence, concern around social eating and anxieties around other people seeing the patient's body.[14]

In the Adamson et al study, 40% of carers paid for a private autism assessment. They also observed that those that did receive an autism diagnosis felt that it was a barrier to accessing eating disorder services; they felt that eating disorder services would challenge or refuse to recognise the autism diagnosis. 90% of the carers wanted increased awareness and education about autism in females.[6] Kinnaird et al found that clinicians reported a lack of confidence in treating individuals with AN and comorbid ASD.[15] The AQ-10 (Autism Spectrum Quotient) used to assess autistic traits (mainly used in primary care) has not been found to be reliable in patients with eating disorders.[16]

All carers interviewed by Adamson et al believed that services could be improved to address patients' difficulties associated with their autism.[6] Clinical audit data from King's College London has

found that patients, carers and staff share this view and feel frustrated that current approaches do not work for patients with both ASD and AN.[17]

The Adamson et al study showed that patients with ASD and AN did not respond to group psychological interventions but did show significant improvement with the same interventions on an individual basis. Clinicians with a good awareness of autism were able to build rapport and a therapeutic relationship more easily with their patients. ASD traits such as liking to follow rules were found to act as a protective factor since patients are more likely to adhere to treatment.[6]

The PEACE pathway (Pathway for Eating disorders and Autism developed from Clinical Experience) has been developed by a team from Kings College London using the Institute for Healthcare's Model of Improvement quality improvement methodology.[18] A regular training programme has been developed for the multidisciplinary team (MDT) at South London and Maudsley NHS foundation specialist eating disorder service. Experts in the field of ASD deliver training on autism friendly adaptations that can be made to assist in the care of patients on the eating disorder wards with comorbid ASD. Further to clinician training, regular support and meetings for all staff is being trialled as part of the pathway.[19]

As part of the PEACE pathway an updated algorithm is being used on top of the ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition) to help increase the sensitivity for identifying ASD in females with AN. Using autism assessment tools enabled the teams looking after the patient to identify areas in which they could provide extra support; e.g., For CREST (Cognitive Remediation and Social Skills Training) for those who struggle with their emotional recognition and expression. Additionally the sensory sensitivity scale can be used, as the ADOS-2 was created before sensory difficulties were identified as autistic traits.[19]

Often treatment environments, especially in-patient settings, were deemed to be not autism friendly. Improvements suggested varied from relatively simple measures such as noise reduction in clinical settings by having soft-close doors, to educational measures to increase awareness amongst clinicians in the service. Other potential adaptations suggested for treatment of AN in those with comorbid ASD were more intensive care, longer treatment durations, considering sensory needs when refeeding and establishing clear pathways for autism diagnosis particularly in women.[6] Some changes implemented by the PEACE pathway included painting walls of the ward neutral colours, providing “sensory boxes” containing weighted blankets, essential oils and ear defenders. Occupational therapists have developed a sensory group and a one-off sensory workshop is being provided by psychologists involved in the PEACE pathway. An autism-friendly welcome pack has been implemented including what a typical bedroom and weekly schedule looks like.[19]

90% of carers interviewed in the Adamson et al study felt that sensory difficulties made it more difficult for patients to follow their meal plans. They described these sensory difficulties around food as being longstanding from an early age and pre-dating anorexia symptoms.[6] Almost all the women interviewed in the Brene et al study reported experiencing food-related sensory sensitivities surrounding texture, temperature, taste, smell and mixing of foods meaning that they became limited on the range of foods they would eat.[9] A specialist PEACE menu has been developed with the input of dieticians and patients, aiming to address complex sensory and nutritional needs. The meals were typically soft and bland and the menu aimed to be as simple and predictable as possible. To reduce patients’ anxiety, pictures of the meals were provided with the menus.[19]

More support for carers has been identified as an area requiring further research and development. A monthly workshop for carers has been implemented as part of the PEACE pathway. During the pandemic this continued virtually.[19]

The PEACE pathway has recently been commended at the HSJ (Health Service Journal) value awards 2021 in the Acute Service Redesign Initiative category. PEACE provide resources on their website for patients, carers and clinicians. The PEACE pathway aims to assist clinicians with knowledge and confidence in supporting those with AN and ASD.[7]

A large cohort of patients with AN are likely to have comorbid ASD. It is clear that, whilst patients with AN and ASD are challenging to manage, with specialist tailored management taking into account the difficulties associated with their ASD these patients can be managed more effectively. The PEACE pathway is a promising example of how a service can change its practices to better accommodate eating disorders patients with ASD. Through educating clinicians, promoting team-working and specialist advice from other services and making environmental changes, the service has been able to improve outcomes for those with AN and ASD, as well as their carers. Their website provides lots of resources for patients, carers and clinicians and every eating disorders service should be made aware of it.[7] The changes I would like to make to the field would be to implement the PEACE pathway into all eating disorders services and incorporate it into national guidance for the management of eating disorders. I would like both acute physicians and mental health professionals to be more aware of how to manage these often complex patients with ASD and AN.

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