Anorexia nervosa in autistic females

Caitlin had always been a fussy eater. When she was 15, she started narrowing her food intake even more and developed a strict routine around her food consumption, eating pretty much the same things every day. She liked this routine, as it meant there were no surprises and this kept her anxiety at bay. Soon she started losing weight and her parents became worried, insisting that she go to her GP. There, she was diagnosed with anorexia nervosa.

Anorexia is a severe eating disorder, characterised by low body weight due to restricted calorie intake. It is assumed to be caused by a disturbance of the way people experience their body weight or shape, or a persistent denial of how serious their low body weight is.

Caitlin was offered a group therapy session once a week where other teenagers with anorexia nervosa would meet and learn ways to tackle their eating disorder. Caitlin found the bright strip lighting in the group therapy room overwhelming and disturbing. Also, the sessions often focused on the teenagers’ concerns about body image. This felt irrelevant to Caitlin who had no desire to look thin or fear of being overweight. So, she would close her eyes and say nothing for the whole hour. She was discharged for “failure to engage in treatment”. It wasn’t until she was in her 20’s that Caitlin was diagnosed as autistic.

Caitlin’s story is fictional, but it is based on fact – it is a composite, encompassing some of the experiences of numerous autistic women we have met over the last few years in our clinical practice and research into eating disorders. Research studies consistently show that around a fifth of women being treated for anorexia are autistic but this has gone unrecognised (Huke et al., 2013) (Westwood, Mandy & Tchanturia, 2017). As a result, clinicians are unable to adapt treatment to make it appropriate and effective.

Funded by the charity Autistica, a team of researchers at University College London and Cardiff University have set out to investigate the experience of anorexia in autistic women and how this might differ from those who are not autistic. We want to use this knowledge to improve services for autistic people with severe restrictive eating difficulties.

We are investigating the idea that autistic women with severe restrictive eating often do not fit the pattern of classic anorexia, because their eating difficulties are not primarily driven by a
desire to be thin. Instead, autism-related factors often contribute to the development and maintenance of their restrictive eating. For some women, sensory sensitivities and aversion to food taste or texture seem to play a role. Others say that they do not sense when they are hungry and so cannot judge how much they should eat. Some struggle to break their eating habits because they have a tendency to follow strict rules. Autistic girls and women might also use dieting as a strategy to fit in with their peers.

Learning more about the potential links between autism and anorexia will be crucial in order to raise awareness among health care professionals and provide better support for girls and women like Caitlin. Research studies suggest that, currently, autistic women diagnosed with anorexia benefit less from treatment than do non-autistic patients (Stewart et al, 2017) (Wentz et al, 2009). We hope that by understanding autism-specific mechanisms underlying restrictive eating problems, we can promote better treatments, and therefore happier lives, for autistic women with eating disorders.

Further information

You can follow the SEDAF research team on Twitter or read our blog to stay up to date with the research.

References


Further reading

Autism and controlled eating

Eating disorder or disordered eating? Eating patterns in autism

Copyright: When reproducing this document, you must fully acknowledge the author of the document as shown at the top of the page. Please see Network Autism Terms and Conditions for details.