

Managing Comorbid Eating Disorders and Autism Spectrum Conditions: An Eden Unit Quality Improvement Project

Introduction

Currently there are no clear guidelines or recommendations for people who have autism spectrum conditions (ASC) and a comorbid eating disorder (ED). The Maudsley ED team is pioneering a tailored approach for ASC and ED comorbidity called the PEACE pathway to improve and adapt evidenced-based ED treatments and improve the experience for patients, families and clinicians involved in their care.

Our aim is to try and replicate this approach for the inpatient services (Eden Unit) in NHS Grampian and come up with a guideline or a pathway for the patients with comorbid ASC and ED.

Method

We handed out tailored questionnaires to two stakeholders: patients and staff in the inpatient eating disorder service (Eden Unit).

The patient questionnaires had 18 multiple choice questions. The answers ranged from strongly agree to strongly disagree, with optional space for explanation and comments or suggestions.

The questions aimed to identify whether the inpatient care was adequate in terms of care, routine, environment, mealtimes and staff for general inpatients with an ED diagnosis.

Additionally, we also had specific questions related to ASC e.g. whether sensory needs are met e.g. dining room environment and whether communication needs are met e.g. using pictorials or story-telling.

The staff questionnaires were tailored to gauge the staff attitude towards managing someone with comorbid ED and ASC. The questionnaire had 10 questions with "yes or no" answers with space for comments.

Results

Out of 7 patient questionnaires handed out we got back 6. We had a total of 7 inpatients in the unit. Three of them have established ASC and one with suspected diagnosis of ASC during the time of the audit.

Most said they found the ward environment and structure suitable for their needs.

One patient wrote:

"Due to my ASC I find the ward environment very overwhelming."

Patients found transitioning from outpatient to inpatient services anxiety provoking or distressing as they did not know what to expect however when facing subsequent admissions, they felt less anxious as they are familiar with the ward routine and staff.

On transitioning back to outpatients or community they struggled with different routine and pace also some of the patients being out of area (Tayside or Highland) posed a different challenge.

Overall, the patients were happy with the staff members, particularly healthcare support workers and staff nurses and felt it was easy to talk to them. They were generally well supported at times of distress and they knew what to do. However, they felt that clinicians and dietitians were not always available.

On occasion there would be discrepancy in the meal in terms of what was ordered and what was received. The names on the menu were sometimes too vague like "fish" or "curry". Sometimes the food would be inedible due to being too spicy or too hard and the food had to be sent back prolonging the mealtime which was distressing. All patients except for one said that they would not find a picture of food on the menu helpful as it would be triggering. They were well supported by the staff during mealtimes. They found it difficult sometimes if there was a change in the setting of the furniture or seating plan.

The patients were allowed to have stress toys, ear defenders, soft toys etc. to meet their sensory needs however they were not allowed to have weighted blankets or hot water bottles.

Out of 20 staff questionnaires we got back 13. Comments and suggestions were completed by 3 out of 13.

Overall, the results showed that the experience of the staff varied widely ranging from years of experience, knowledge and confidence in working with comorbid ED and ASC to someone who had just started working on Eden Unit in recent weeks.

Eleven out of 13 had received no formal training in managing someone with comorbid ED and ASC however all 13 said they would be keen on some sort of training.

The level of confidence, knowledge and skills was related to the level of experience the participants had held in the services, and not through formal training.

Discussion

A significant portion of inpatients have comorbid ASC and ED. Therefore awareness of potentially greater needs around communication, environment and sensory hyper or hyposensitivity is important. Using resources from the PEACE pathway website, both staff and patients can learn more about this comorbidity. It should be further noted that some ED patients without ASC can have similar symptoms due to prolonged starvation so they too could benefit from the sensory and communication adaptations used for patients with ASC.

Conclusion

- Re-audit and complete the cycle in 1 year
- Quality improvement project for outpatient services
- Include family members and carers in future projects
- Staff training (for example weekly huddles, monthly meetings, psychoeducation groups) to manage and care for comorbid ED and ASC
- Raising more awareness about the link between ASC and ED e.g. posters, badges, pens

References

Tchanturia, K. et al. (2020) 'Towards an improved understanding of the anorexia nervosa and autism spectrum comorbidity: Peace pathway implementation', *Frontiers in Psychiatry*, 11. doi:10.3389/fpsy.2020.00640.

Peace pathway Available at: <https://www.peacepathway.org/> (Accessed: 22 November 2023)

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