

Lessons learned from PEACE case studies: practical challenges in meeting the needs of adults with anorexia nervosa and autism

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Li, Z., Hutchings-Hay, C., Byford, S., & Tchanturia, K. (2022). How to support adults with Anorexia Nervosa and Autism. *(submitted for publication)*

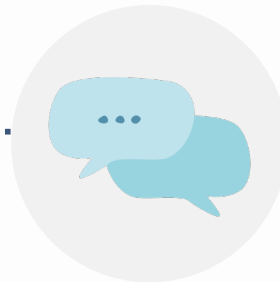
BACKGROUND

PEACE 

Pathway for Eating disorders and Autism
developed from Clinical Experience

PEACE Pathway: Instigation

A gradual implementation at
SLaM ED service



Case discussions

As part of the
implementation of the PEACE
pathway from 2019 to 2022,
team meetings ('huddles')
were held regularly to discuss
cases with the comorbidity



20+ case notes and minutes

Discussing patient
presentation, challenges in
treatment, suggestions for
treatment adaptations and
feedback on what
adaptations were helpful

Smith, K. A., & Tchanturia, K. (2020). Are Huddles the Missing PEACE of the Puzzle in Implementing Clinical Innovation for the Eating Disorder and Autism Comorbidity?. *Frontiers in psychiatry*, 11, 593720. <https://doi.org/10.3389/fpsy.2020.593720>

Synthesis of clinical challenges

- Clinical challenges associated with autism and anorexia nervosa (AN), based on review of the case notes and minutes from these discussions
- Outline the team's approach to the subsequent adaptation of treatment.



Sample

De-identified clinical notes on patient cases analysed. Minutes from the team meetings were also analysed alongside the clinical notes. All cases were adult patients admitted to the SLaM ED Service from 2019 to 2022, who either had a previous diagnosis of autism or presented with autistic characteristics

Screening

All patients' autistic characteristics were explored on their admission with autism screening tools (AQ-10, SRS & ADOS)

Analysis

Thematic analysis (Braun & Clarke, 2006; 2018) was used to analyse clinicians' notes and minutes from discussions to identify clinical challenges and adaptations.



Demographic characteristics

Most cases were white British female (n=16, 80%) mean age 26 years (SD=10.7, range 19–68).



Autism

Half of the cases had a formal diagnosis of autism prior to contact with the ED service, the other half were flagged up by the AQ-10 or ADOS-2



Other co-morbidities

Further co-morbidities were reported, the most common of which was generalised anxiety disorder (GAD; n=10, 50%), followed by OCD (n=8, 40%), depression (n=8, 40%), emotionally unstable personality disorder (EUPD; n=2, 10%) and ADHD (n=2, 10%).

RESULTS

Managing boundaries

Dilemma:
Accommodate & adapt?
Or facilitate change for
recovery?

Communication difficulties

Reduced therapeutic
engagement;
Difficulty with groups

Emotional difficulties

Identifying and articulating
emotions;
Therapeutic engagement



Sensory difficulties

Sensory environment;
Texture/taste/smell of food

Atypical eating behaviours

Restricted food preferences;
Need for consistency and
predictability

Cognitive rigidity

Difficulty coping with
changes and unpredictability

Challenge 1: Socio-communication difficulties

"Engagement in [online] groups was minimal and would not look at the screen as a way of avoiding eye contact"

"Communication has been a struggle. Some meetings may have some verbal input but this is rare."

"Can be difficult knowing if the patient understands, there is lots of nodding and it can seem fairly superficial at times."



1. Communication Passport

Written information?
Visual aids?



2. Clarify understanding

After the session, review what has been discussed and check shared understanding, clarifying points when required.



3. Modify communication style

Multiple choice is easier than 'what do you need/how can I help' or open ended questions



4. Groups: Voice-only sessions

Audio-only sessions allow more space for patients to process what others are saying.

Challenge 2: Emotional difficulties

"Emotions were not described well:

'Don't know how to answer, not sure I can', 'Don't know how I feel'."

"Perhaps he would agree to goals because I'd suggested them so sometimes it was tricky to work out what was meaningful to him, especially as he didn't report having emotional responses to many things."

Alexithymia

Around a half of autistic people have difficulties understanding and describing their own emotions.



1. Emotions list

For patients to indicate current emotions from

2. Traffic Light Communication System

Red = I am really struggling, approach me with the emotions list and ask me to mark what I am feeling;
Amber = Today is difficult, check in on me and ask me how I am doing; Green = I am ok

3. Cognitive Remediation and Emotion Skills Training (CREST)

Emotion sorting task, processing cycle, and exploration

More information on CREST:

<https://www.katetchanturia.com/publications>

Emotion Skills Manual:

https://www.katetchanturia.com/files/ugd/2e1018_99431835fc0047529c286b775a2a6ff9.pdf

Challenge 3: Cognitive rigidity

"[The patient] keeps a precise idea of what each thing should look like and cannot seem to settle until they can see exactly how the staff have measured their food out."

"Change is a huge source of anxiety. [The patient] depends on routines, sameness and predictability."

"[Patient] attributes this to autism and says 'she is never going to change'."



• Changes: Early notice

Early notice of any plans or changes to minimize uncertainty;
Most changes are collaborative



2. Cognitive Remediation Therapy (CRT)

Cognitive flexibility training



3. Reflect: flexible approach

Are we becoming "rigid & detail-focused" as well?

CRT manual in different languages:

<https://www.katetchanturia.com/publications>

CRT self-help guide for carers:

https://www.katetchanturia.com/files/ugd/2e1018_a4ff797340204be7909ecd62808fe4ce.pdf

Challenge 4: Atypical eating behaviours

"Atypical presentation: Enjoys calorie dense foods. ... i.e., oat milk, mash potato, peaches, rice pudding and rice, chocolate and ice cream."

"Food: small range at any time and then tires and stops eating them, resulting in the range of acceptable meals ever shrinking (This seems to be common within autistic patients)."

"At home, [the patient] eats just a small range of foods, eating the same foods repeatedly until [the patient] tires of them."



1. PEACE Menu

The 'beige' menu
Bland tasting, smooth texture, pre-packaged for consistency



2. Food exposure

Experiment!



3. Sensory sensitivities?

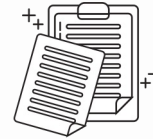
Taste of food?
Texture of cutleries?
Dining room environment? Noise?
Key is to ask and listen.

Challenge 5: Sensory difficulties

"Hypersensitive to human sounds especially chewing food."

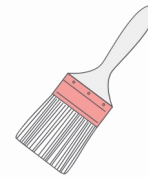
"Dislikes flashing lights, loud noises, sudden noises such as clapping."

"Very sensitive to noise and lights. Describes herself as having increased interoceptive awareness (fullness) and she experiences lots of physical pain associated with this."



• Sensory screener

Hyper- vs. hypo-sensitivity in different senses



2. Environmental adaptations

Redecorations and de-cluttering;
Sensory toys and low stimulus room



3. Adapting individual sessions

Room a little too warm? Close the window or keep it open? Need a cushion?
Again - ask and listen.



4. Sensory workshop and resources

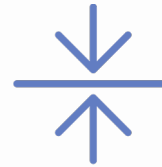
One-off sensory workshops and sensory booklet for psychoeducation

Challenge 6: Managing boundaries

"Patient's sensory needs sometimes are in conflict with the ward protocol and other patients' needs. Team can struggle with when to accommodate and when to encourage for change."

A learned helplessness mindset (e.g. I have autism, I'm never going to be able to ..)

"Difficult to manage boundaries with [the patient]; Need to limit the number of adaptations which can be agreed."



• Meet in the middle

Is it ED? Is it autism? Is it something else?
What compromises can be made?



2. Challenge mindset

Positive mindset to work on the challenges autism brings, instead of a learned helplessness mindset



3. Goal-oriented conversations

Identify long term goal. The fully adapted environment on the ward is a perfect opportunity to practise essential skills



4. No perfect solution

Inevitable dilemma when adapting treatment?

Comorbidities

Co-morbid symptoms were often intertwined, sometimes fuelling one another

"Comorbidities predate ED and are intertwined with it."

ED symptom that should be addressed

Cause of the problem

Autism-related difficulty that can be managed

Autism-driven need that could be accommodated

Kinnaird, E., & Tchanturia, K. (2021). Looking beneath the surface: Distinguishing between common features in autism and anorexia nervosa. *Journal of Behavioral and Cognitive Therapy*, 31(1), 3-13.

RESEARCH PAPER

Looking beneath the surface: Distinguishing between common features in autism and anorexia nervosa



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KEYWORDS

Anorexia nervosa;
Autism;

Abstract Anorexia nervosa (AN) and autism share a number of common features, including restrictive eating, cognitive rigidity, and social difficulties. However, these similarities make distinguishing between co-occurring autism and AN, and AN only, complicated. Diagnostic tools

OTHER CHALLENGES

Autism screening

Autism not picked up by screener;
Sex differences in autism presentation (Lai et al. 2011)

Combine use of the AQ-10 with other self-report screening measures for increased validity, such as sensory sensitivity screening (Kinnaird et al., 2020) or more detailed measures like the Social Responsiveness Scale (Kerr-Gaffney et al., 2020)

Adamson, J., Brede, J., Babb, C., Serpell, L., Jones, C. R. G., Fox, J., & Mandy, W. (2022). Towards identifying a method of screening for autism amongst women with restrictive eating disorders. *European Eating Disorders Review*, 30(5), 592– 603. <https://doi.org/10.1002/erv.2918>

The AQ-10

How to fill out the questionnaire

Below is a list of statements. Please read each statement very carefully and rate strongly you agree or disagree with it by circling your answer.

DO NOT MISS ANY STATEMENT OUT.

1. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I usually concentrate more on the whole picture, rather than the small details	definitely agree	slightly agree	slightly disagree	definitely disagree
3. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
6. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree

Sensory Summary

Mark where you think you are on the below scales. Hypersensitivity means you are highly sensitive to sensations and may try and avoid them where possible; hyposensitivity means you have lower sensitivity and may try to seek out these sensations. There are examples below each scale. If you think you are neither hyper/hyposensitive and have no sensory differences, mark yourself in the middle as a 5.

Taste

0	1	2	3	4	5	6	7	8	9	10
(Hyposensitive)					(No sensory differences)					(Hypersensitive)

If I am hyposensitive, I might add lots of salt to my food to make it taste stronger. If I am hypersensitive, I might prefer to eat bland foods as I find them too strong.

Smell

0	1	2	3	4	5	6	7	8	9	10
(Hyposensitive)					(No sensory differences)					(Hypersensitive)

If I am hyposensitive, I might not notice strong smells and enjoy smelling essential oils. If I am hypersensitive, I might dislike smelly places like a canteen and find smells overpowering.

Vision

0	1	2	3	4	5	6	7	8	9	10
(Hyposensitive)					(No sensory differences)					(Hypersensitive)

If I am hyposensitive, I might really like watching bright light displays. If I am hypersensitive, I might prefer to have lights dimmed or turned off.

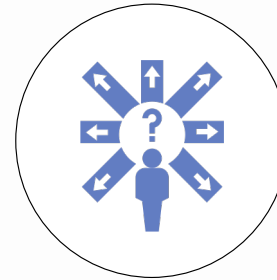
OTHER CHALLENGES

Going Forward...



Pragmatic Screening Tool

Screening of autistic characteristics in ED population



Extensive guiding framework

For differentiating between difficulties caused by ED, autism, and other common comorbidities such as OCD and EUPD.



Food experiment

Test and validate the use of food exposure experiment in cases with autism comorbidity.

Thank you!

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