Eating Disorders and Autism Spectrum Conditions: practical issues and solutions

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Plan for the afternoon

• Discussions around the coexistence of Eating Disorders and Autism Spectrum Conditions
• Thoughts on how ASC features might be manifest in ED presentations
• Ideas to help improve outcomes: in individual sessions and in inpatient/day settings
Introduction and some basic principles

- My background
- Every person is unique
- Don’t make assumptions
- Autism is classed as a disability therefore is subject to Equality Act (2010)
- Reasonable Adjustments are a legal requirement
- ASC often associated with more than one comorbidity in addition to ED. This can be the explanation for the ED itself
Why do Eating Disorders co-exist with ASC?

OCD / rituals

Something to excel in

Something to control

Sensory issues

Comorbidities

MIRRORING / form of camouflaging?
Facts about Autism and comorbidities

- 20% Co-morbidity with Eating Disorders
- Mean number of comorbidities 3 +/- 2.3 (Joshi et al 2012)
  - Including adult ADHD 42%
  - Major depression 31%
  - Multiple anxiety disorders 59%
- This means that for a number of patients with ED and ASC they are likely to have another comorbidity.
- It is extremely important to understand the full picture and the interaction between the comorbidities to treat the person holistically.
Anorexia nervosa

- An irrational fear of gaining weight which leads to food restriction and other weight loss strategies

- Obsession relates to having a thin figure and the fear of weight gain is overwhelming

- Often associated with body image distortion

- Other behaviors include mirror gazing, repetitive weighing, measuring, body checking
Anorexia nervosa

Dawn is a 19 years old. She has had a diagnosis of AN for 7 years.
She found going to Secondary School a real strain and struggled to fit in.
She has a life long passion for all things Disney and whereas at Primary School she could talk about her favourite films and characters and no one seemed to mind, her peers started to make fun of her once they moved to Secondary School. They became more interested in makeup and boys. Dawn became aware of her peers talking about dieting. She thought this was something she could do as well, to join in. She discovered she was good at it: it was really quite easy. She got lots of positive feedback and enjoyed the attention. She feels she has to keep going with her diet as she is now ‘the thin girl’.
Bulimia nervosa

- Characterized by a cycle of bingeing and compensatory behaviours such as self-induced vomiting, laxative misuse, restriction
- A feeling of being out of control during the binge-eating episodes
- Self-esteem overly related to body image
- Body weight often in the ‘healthy’ range means that this is often a hidden condition
Bulimia nervosa

Jackie has a secret. She has always used food to make herself feel better if things have not gone well at school or if she has felt stressed or overwhelmed. Recently she has discovered that if she overeats she can also make herself sick and this means that she overeats more often. Jackie knows that her parents would be cross if they found out; her mother has noticed food going missing and has been cross with everyone at home about it especially if she has bought something that she planned to cook with. She doesn’t know its because Jackie has been eating it.
Binge Eating Disorder

- A compulsion to overeat on a regular basis
- Very large quantities of food are consumed over a short period of time
- Binges are often planned and can involve "special" binge foods
- Binge eating can alternate with periods of dietary restriction
- Usually takes place in private, with a feeling of loss of control
- Often associated with feelings of guilt or disgust
Binge Eating Disorder

Toni’s family are worried about her: she has always been a good eater and has always carried too much weight. The GP has said that she is at risk of diabetes and arthritis even though she is only 42 years old. Toni really doesn’t seem to be able to stop eating. She eats really fast as well. The other day she choked while she was eating in her bedroom. Luckily her father heard her coughing and was able to give her a potentially life saving slap on the back.
Other Specified Feeding or Eating Disorder (OSFED)

- Used to be called ‘EDNOS’
- A feeding or eating disorder that causes significant distress or impairment, but does not meet the criteria for another feeding or eating disorder
- Atypical anorexia nervosa
- Purging disorder
- Does **not** include ARFID
Examples of OSFED

Obsessive compulsive disorder
- Compulsions can revolve around food and eating

Complex post traumatic stress disorder
- Starvation/ binging / purging can suppress memories and flashbacks
Examples of OSFED

John spends 2 hours preparing every meal: he is meticulous about measuring everything and has specific utensils, plates and bowls for each type of food. He gets extremely annoyed if anyone interrupts his food prep. John has never been in a restaurant and his family are resigned to the fact that he will never be able to join them for a family meal.

Julie finds it really hard to speak to people, often she is completely mute. She was abused as a child and has never been able to tell anyone. She discovered that starving was an effective way of suppressing the flashbacks and nightmares she experienced. The only problem is she keeps being admitted to hospital when her weight drops too much.
More examples of disordered eating

Anxiety Disorders
e.g. GAD, panic disorder, social anxiety, phobias

Gender Dysphoria
Starvation suppresses sex hormones and mean the body looks androgynous
More examples of disordered eating

Anxiety Disorders

Sue feels misunderstood. Her eating disorder practitioner talks to her about body image distortion, but she cannot relate to this. She has always felt different from other people, so she assumes this is just another example of not fitting in. She has been seeing her eating disorder practitioner for 10 years and her BMI has always been in the underweight category. She has developed osteoporosis. She has had eating difficulties as far back as she can remember (Mum said she was a picky eater) and she is now in her 40s. Sue is petrified of eating: she has an intense fear of vomiting. She sticks to “safe” foods which she eats in small quantities: ‘just in case’. She eats the same things for each of her meals. Sue used to work as a teaching assistant, but had to give this up due to her ill-health. She was sad about this, but was also relieved as she found dealing with the people very stressful.
More examples OSFED

Gender Dysphoria

Jane is in a mess. She feels completely stuck. She keeps being admitted to inpatient ED units because her weight drops to dangerously low levels which means that everyone around her gets worried. Every time it’s the same problem: she is given too much food and eventually her periods come back and her body starts to change: this is absolutely unacceptable to Jane. Although she has never spoken about the fact that she finds her female body so alien. As far back as she can remember Jane has believed she was a boy. She has never spoken about it because she has struggled enough in her day to day life and doesn’t really know who to talk to about it anyway. Often Jane feels desperate and feels that life cannot go on.
Areas for consideration

1. Communication
2. Routines and rituals
3. Social aspects
4. Sensory aspects
5. Creativity and ASD
6. Special interests
7. Strengths
8. Overlap between ASC and Eds
9. Modifications in IP settings
10. Modifications in OP settings
Communication

Processing speeds, not keeping up, not being able to put thoughts into words, getting left behind

“often it does not occur to me to tell someone something, I assume because I know they know”

➤ Ask what would help?
➤ Slow down speed of your speech
➤ Use shorter sentences
➤ Have shorter sessions (to begin with)
➤ Check the patient is following and if not ask what would help
➤ Be very sensitive to body language
➤ Use of spider diagrams (before or during session)
➤ Allow patient to bring anything in the session that might help e.g. pet dog, other comforting object or aid
➤ Write down a summary of what has been said / record a summary
communication and autism

Hi, how are you?

Interpret hand gestures

Interpret facial expressions

Interpret body language

Hi!
The Maglev Train in
Shanghai is the fastest
train in the world.

I don't understand
what you're saying.

I don't know what to say
next.

I need more time to
process this information.

Their voice is too loud, it
really hurts my ears.

I don't know that script,
but I have to respond.

I don't know the appropriate
script to respond with.

What are they trying to
tell me?

Do I know the appropriate
response?

Is this a good or bad
thing? Are they happy?

Am I giving too much
information or not enough?

I like trains, I am comfortable
talking about trains.

What are the appropriate
physical gestures?

I am not comfortable
moving my body like that.

I'm nervous, the little noises
make me feel calm.

That breaks on their
nose looks like a train.

I feel uncomfortable when
people look at me.

Keep body calm, use
appropriate gestures

Are they going to touch me?
I don't like to be touched.

Are they going to touch me?
I don't like to be touched.

Maintain eye contact

the little black duck

www.thelittleblackduck.com.au

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Communication

Selective mutism and mutism.
How to communicate with some one who cannot speak?


➢ Ask what would help?
➢ What strategies do they use at home?
➢ Use of technology (including text to speech / BSL)
➢ Use of sign language / Makaton?
➢ Use of a translator?
Communication

Misunderstandings,
Black and white thinking,
Taking things literally,
In (any) groups: difficulty following conversations

➢ Check things out
➢ Make sure you both understand
➢ Remember neither are mind readers
➢ For meetings e.g. CPA reviews, MDTs:
  Set ground rules and boundaries e.g.
➢ Speak one at a time
➢ Take your time
➢ Rehearse
➢ Allow the person to choose the order of events / place names / check out the room / rearrange if possible

All made worse by ↑ anxiety
Communication: metaphors

A word about metaphor, some people with ASC like them (often as long as they are their own) others don’t at all: make sure you both know what you mean!
Routines and Rituals

The need for sameness and predictability
What happens if something unexpected happens?
How does the person cope with change?

- Ask what helps and what doesn't help?
- Use of time-tabling
- Give plenty of notice
- (reasonable adjustment)
- Give warning about environmental changes
- Take in to account change in the therapist (hairstyle!/ shoes etc)
- Use of ‘rules’ / ‘new rules’: very clear expectations, written down
Social aspects

- Social interactions: eye contact, facial expressions, non-verbal communication.
- Explaining what you are thinking and feeling with examples: ‘Andrea’s unfortunate face’.
- Learning about emotions: may need to go to basics
- Reminding people that you (as the therapist or anyone else) cannot read their mind.
Sensory Issues

• Many individuals experience over- and/or under-sensitivity in some or all of the sensory domains
• Some individuals describe sensory ‘overload’ which can be distressing and overwhelming
• Others describe more positive experiences, for example, sensory ‘fascinations’, ‘soothing functions’ and ‘strengths’

https://www.youtube.com/watch?v=K2P4Ed6G3gw
Sensory Sensitivities

Vision
• Fascination with patterns, lights and colours
• Some lights intolerable e.g. strip lights / very bright lights

Hearing
• Inability to screen out between background and foreground noise
• Extremely good hearing / painful sensitivity

Touch
• Sensitivity to textures can be pleasant <> unpleasant

Smell
• Sensitivity to smell can be pleasant <> unpleasant
Sensory Sensitivities

**Taste**
- Hyper-sensitivity to taste
- Shutting down other senses – sensory overload

**Proprioception**
- Placing body in strange positions Turning whole body to look at something

**Vestibular**
- Excessive physical movements
- Repetitive movements
- Spinning, rocking back and forth
Sensory Aspects

How might ASC affects someone's relationship with food and eating?

Think about each sense in turn…
Sensory assessment
Sensory Sensitivities

Vision

• Eating in a brightly lit / busy place
• The colour of some foods
• The way food looks on the plate
• The way food behaves ie running into each other
• The predictability of food and packaging (brand loyalty new and improved?)

Hearing

• Noisy places
• Dishwasher / hoover/ other people talking
• Sounds of other people eating
Sensory Sensitivities

Touch
• Sensitivity to textures can be pleasant <> unpleasant
• Some textures completely unpalatable and disgusting (often spongy or slimy)

Smell
• Sensitivity to smell can be pleasant <> unpleasant
• Strong smells / cooking smells
Sensory Sensitivities

Taste
• Hyper-sensitivity to taste
• Shutting down other senses – sensory overload
• Often prefer bland food or raw food e.g. vegetables

Proprioception
• Placing body in strange positions. Turning whole body to look at something (inspecting food from the table level)

Vestibular
• Excessive physical movements
• Repetitive movements
• Spinning, rocking back and forth particularly when distressed and need to self soothe
Sensory Overload

https://www.youtube.com/watch?v=yoCn3q6Yyo
Sensory Sensitivity / overload: what helps?

1) Being understanding: the world can be exhausting
2) Having a plan (note similar to school / college / work place)
3) Time out: what does this look like: own room / den within room / Snoezeln / a quiet space
4) Other sensory calming strategies
Sensory Sensitivity / overload: what helps?

https://www.youtube.com/watch?v=hw5RHFTIq24
Snoezelen = from Dutch "snuffelen" (to snuggle, also: to sniff) and "doezelen" (to doze, to snooze)

Snoezelen or controlled multisensory environment (MSE) is a therapy for people with autism and other Developmental disabilities, dementia or brain injury. It consists of placing the person in a soothing and stimulating environment, called the "Snoezelen room". These rooms are specially designed to deliver stimuli to various senses, using lighting effects, colour, sounds, music, scents, etc. The person is usually accompanied by an aide or therapist. Developed in the Netherlands in the 1970s, Snoezelen rooms have been established in institutions all over the world and are especially common in Germany, where more than 1,200 exist.
Sensory Sensitivity / overload: what helps?
Creativity and ASC

Lack of imagination is said to be characteristic of ASC?

What does this really mean?
Problems with social imagination
Creativity per se can be extremely developed
Can be usefully used to create solutions in therapy
Special interests

“a really good way to start a therapy session”
The worse question in therapy is:
“how are you?”

- Ice breaker
- To get to know the persons strengths
- To use in therapy e.g. Harry Potter characters
- To give the person a break in therapy: ‘lets talk about xxx for a bit.'
Strengths

- Often exceptionally honest
- Have deep passions and intense interests
- Capable of intense absorption
- Can be very detailed orientated
- May have a very good memory
- Rarely have ‘hidden agendas’
- Are typically punctual and follow a schedule
- Often rule bound and will not break rules
- Can be especially gifted in one or more subjects / topics
- May be very good at visual thinking
Overlap between ASC and ED: a venn diagram

https://youtu.be/Vs4U7doXdAQ
Modifications in inpatient settings
Modifications in inpatient settings

“one size does not fit all”

- Identify the personnel needs
- Care plan them
- Identify the reasonable adjustments that can be made and
- Educate the team
- Discuss feelings among team in supervision
- Re-visit reasonable adjustments regularly
Modifications in outpatient settings

Environment
Waiting room / busy-ness / noise levels
Therapy room / noise levels

Individual sessions:
Assessment – likely to take 2-3 x as long.
Ongoing sessions
- what time of day best?
- any communication issues? what is best?
- Do you what to bring anything into session?
Modifications to therapy

- Structure: agenda/session plan
- ↓ social demands of the session
- Written summaries
- Taylor duration of session

- Assess emotional literacy
- Recognising emotions/feelings thermometers
- Normalising experiences
- Very helpful resource
To finish

Write down 5 things that you have learnt today that you will change in your practice when working with someone with ASC and ED

![Frank Zappa Quote]

One size does not fit all.

— Frank Zappa —
Thank you for listening!
Any questions?