CHIEF PSYCHIATRIST
of Western Australia

26 October 2022

Chief Psychiatrist's Community of Practice

Part 2 - Eating Disorders: Understanding risk in co-occurring needs and complexity

Acknowledgement of Country

I acknowledge the Traditional Custodians of the lands on which each of us meet today, throughout Western Australia, and here in Perth, the Whadjuk Nyoongar people, I pay my respects to their Elders past and present.

Introduction

Today we'll talk about what to look out for when working with someone with eating disorders, co-occurring needs and a transdiagnostic presentation, with Lived Experience giving an insight into that experience.

Fintan O'Looney, Clinical Nurse Specialist WA Eating Disorders Outreach Consultation Service (WAEDOCS) &

Shannon Calvert, Lived Experience Advocate and Educator

Key Messages

Recognise the spectrum of eating disorders happens across a continuum. It is dynamic and it changes over time. For example, someone initially diagnosed with anorexia nervosa may later present as someone with bulimia nervosa, and then with binge eating disorder as well. People's journey may not fit into neat diagnostic boxes.

Acknowledge the function of the eating disorder(s) first. This enables the clinician to explore collaboratively more helpful alternatives to coping. All eating disorders have different sides of the same dice and similar driving factors. The need to control what is happening around them is extreme. Anorexia nervosa correlates to the fear of not being in control, whereas binge eating disorder can derive from losing or lacking control and difficulty managing impulses.

Validate and understand the impact of that person's experiences to better understand their illness. Consider life transitions, past trauma, epigenetics, genetics and metabolic issues. A holistic broad view of how the person's illness began and how it has developed through their illness is needed.

Trauma; a contributing factor. Practice-based experience at WAEDOCS and growing evidence suggests that most people who experience eating disorder will have had at least one episode of significant trauma. It is vital that trauma history is identified early and informs a supportive and safe approach to treatment. Systems must understand that difficulties with behaviour are due to damaged attachments as it is under-addressed in the system's response.

Overlapping and interplay of co-morbidities contributes to different presentations of eating disorders across the spectrum of under-control (e.g., impulsivity) and over-control spectrum (e.g., restriction) of behaviours.

Treat both the trauma and build emotional regulation skills alongside the eating disorder and the re-feeding.

The extent of internal distress leads the person to turn to restriction/bingeing/purging to numb painful emotions. The behaviours may be as protection from shame, guilt and fear and are often due to prolonged hypervigilance related to trauma. For example -

"I lose weight to disappear, not be noticed, to avoid being hurt." This stems from a trauma history.

"Sometimes it's better to feel nothing than to feel awful."

A safe containing environment for re-feeding must be provided with development of emotional regulation and meal support. Treating the eating disorder should not mean the co-occurring mental illness is not addressed. Both sides must be a focus of treatment especially if it's complex and transdiagnostic. It's not a dichotomy- it is a dialectic.

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The presentation are available on our website/ subscribe for future dates and topics

Thank you to everyone who attended this session

Neurodevelopmental disorders and co-occurring complexity. What does it look like?

Neurodevelopmental disorders co-occur with eating disorders, so assessment is pivotal in addressing needs accurately. Eating disorders are much more frequent in people with autism spectrum disorder, attention-deficit/hyperactivity disorder (ADHD). Females with ADHD are 5.6 times more likely to develop bulimia nervosa.

Co-occurring eating disorders are also common. For example, avoidant/restrictive food intake disorder (ARFID) is the most common initial presentation with anorexia nervosa (AN), followed by binge eating purging subtype (AN-BP) and then binge eating disorder (BED).

Diagnosis and history: Take the family history of neurodevelopmental conditions and of eating disorders as causes are multifactorial and not purely situational. Accurate diagnosis of neurodevelopmental conditions in eating disorders relies on re-feeding prior to assessment as starvation impacts on brain function.

Neurodevelopmental disorders when coupled with an eating disorder and starvation may be mistaken for emotionally unstable personality disorder (EUPD).

- For co-occurring needs and complexity, **care planning must be individualised** to the unique presentation, personality and situation of the person (and family/carer) and reflect where they are in their recovery journey.

Emotional dysregulation and the fear of abandonment (from trauma) can maintain the cycle – the eating disorder provides a sense of certainty and safety for the individual.

There are multiple reasons for emotional dysregulation related to past trauma:

- The **threat response** that comes from trauma combined with coping mechanisms that people utilise as part of their eating disorder makes for an entangled cycle of self-perpetuating coping strategies.
- **Difficulty making sense of internal bodily sensations** heightens the need to control them.
- **Poor vagal tone** severely compromises ability to regulate emotions. For example, the function of engaging in binging and purging behaviour may be to assist affect regulation. Some evidence suggests this may be due to poor vagal tone.

"People will look for anything to try and reduce that level of distress - internal distress and external distress. This leads a lot of people to engaging in restriction which leads to malnutrition and emotional blunting, distinct from the effect of the trauma." *Fintan O'Looney, CNS*

Part of the issue with refeeding, particularly with a trauma background, is the narrow window where someone gets re-fed and where they have a re-emergence of trauma memories and strong emotions, but they don't quite have the skills or the resources to be able to manage them.

Collaborative, comprehensive care planning is essential. Formulating an effective and comprehensive plan with the multidisciplinary team and the person and family is so important due to the ambivalence about recovery related to recovery being unpredictable. Community treatment orders can be useful for some but very unhelpful for others.

"It does not make sense why someone would enter into this relationship with the eating disorder –but the reality is you won't be abandoned by your eating disorder. So, there was no ability to see the purpose of me letting go of my eating disorder which wanted me to be part of it.

Often in an inpatient setting, even if I say I want to do the right thing, the inner torment and uncertainty is too great because I can't navigate the reasons why I was behaving like that. Practically the eating disorder helped me regulate both positive and negative emotions."
Shannon Calvert, Lived Experience

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Establishing the therapeutic relationship:

Get to know the person. Experienced clinicians *(& lived experience)* agree it takes a very nuanced and compassionate approach. Patience and time doing an assessment can make all the difference in the world.

A safe space to co-regulate emotions: Allow the person to create a space to feel vulnerable and experience strong emotions. Teaching co-regulation is essential, especially with the younger cohort who may never have had experiences or the environment to learn emotional regulation. As a clinician, provide that comfort and safety to teach emotional regulation skills, build trust, and share responsibility.

A nuanced and compassionate approach is needed– meet the person where they are at. The person should not have to justify where they are at in their treatment as this may drive them to escalate their needs. Some may request admission and a nasogastric tube because it is validating their experience even if, in that instance, it is counterproductive therapeutically.

Question: Are there any other any statistics on a correlation between LGBTQA+ people and eating disorders?

Presenters raised that research is available in this area, below is the experience of presenters:

"As a community peer support worker, my clients with eating disorders were unique depending on their relationship with their body and identity. They often felt the need to control their fear of being stigmatized and shamed. Sometimes an eating disorder makes sense when the cause or drive is a person's desire to change or control their shape and size. For example, a young gay man may fear being stigmatized by his loved ones. They may resort to eating disorder behaviours to numb their lack of self-acceptance and feelings of sexual attraction" Shannon Calvert

Physiological needs of trans people needs consideration. Physiological needs are different depending on the body they have been born into and type of transition they are going through. Someone transitioning from male to female might have quite different physiological needs to someone transitioning from female to male. If using hormones, nutrition may be a significant consideration. But above all we are trying not to cause harm or any iatrogenic treatment – adopting a trauma-informed perspective is the safest approach.

"When people are deeply embedded in their eating disorder, you poke the bare of the eating disorder when intervening with treatment - eating doesn't make someone feel better straight away. It's incredibly confusing for the individual: "Am I genuinely hungry or am I trying to meet another need?".

"Regardless of a person's trauma, consistency, transparency and communication regarding the care plan must include everyone involved, the individual, family & treating team; it means being trauma-informed. There is a subconscious need to push everyone's boundaries in a self-sabotaging way, with the expectation that everyone will abandon you - you're adamant the eating disorder has the upper hand. When a team puts boundaries in place firmly and compassionately, eventually, you build trust. It's like a parental role". Shannon Calvert, Lived Experience

Recognition of Lived Experience

We recognise the contributions of people with lived experience of eating disorders and their families. So much learning and growth happens in the space between lived experience leadership and clinical expertise.

Further information:

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WAEDOCS website page (NMHS), including the Management of Youth and Adults Quick Reference Guide