

The Other Side of Care: An Ethnographic Exploration of Recovery and Care Experiences Among People

Experiencing Eating Disorders and Disordered Eating

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Background

- There are many myths and stereotypes surrounding people experiencing eating disorders (ED's) on both a broader cultural level and among healthcare providers.
- Among treatment providers, some of these stereotypes include the belief that people with eating disorders are manipulative, resistant to treatment, and intentionally choose to not recover (Lester 2018).
- Since people suffering from eating disorders can use the disorder as a way to cope, they often experience a high degree of ambivalence about recovering, and this further complicates their care (Sciolli 2016)
- There is no formal agreement in the ED field on how to define recovery from an ED (LaMarre and Rice 2021).
- In the ED field, there have been growing calls for a recovery-oriented practice (ROP) which asserts that the patient is the expert of their own experience (Churruca at al. 2020).
- ROP also calls for professionals to move away from defining recovery as simply the absence of symptoms and instead focus on the person as a whole (Churruca at al.
- There may be a difference between how professionals and individuals experiencing eating disorders define recovery and good care

Relevance

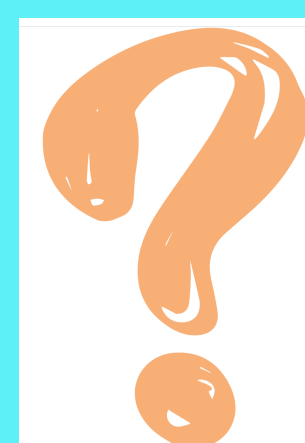
Definitions of recovery influence the type of care people receive, and improving care for EDs helps people recover and have a better long-term outcome

Research Question

1. What does good care look like for people experiencing eating disorders?
2. How do people experiencing eating disorders define and understand recovery?

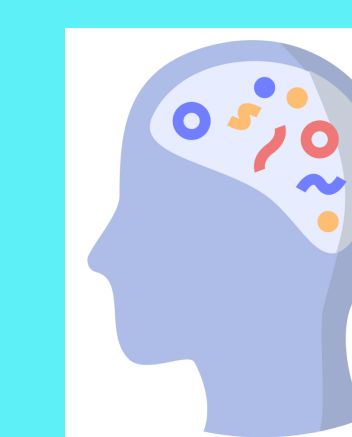
Methods

- This project is a digital ethnography of an online peer support forum for EDs
- I conducted participant observation of posts on the forums. I also engaged by posting responses to some posts.
- Qualitative interviews are ongoing
- Survey data collection is ongoing



Theme#1

Defining Recovery



- The findings on how people define recovery are *inconclusive*.
- People's experience with recovery seems to always be shifting. They describe going back and forth between doing well (sometimes for years) but also sometimes returning to experiencing eating disorder symptoms.
- Further research is needed on whether people experience recovery as something that is always a work in progress or if there is any final goal/destination.



Theme#2

Reading Symptoms, Self-diagnosis, and Professional Diagnosis

- Diagnosis is not straightforward! It is a dynamic process that often starts with self-diagnosis. On the forums, people repeatedly expressed being unsure if what they are experiencing are signs of an eating disorder.
- Sufferers often turn to others on the forums who can be seen as "lived experience experts" who can evaluate their symptoms and subjective experiences and share if they think this is an ED or not. A healthcare professional may or may not be contacted for diagnosis during this stage or even for some time after.
- The professional's diagnosis can be helpful for some and shameful for others.
- Further research: Self-diagnosis info seems important to engage with in caring for patients. Future work could look at useful ways to incorporate patient perspectives into the diagnosis and subsequent care.

Theme#3

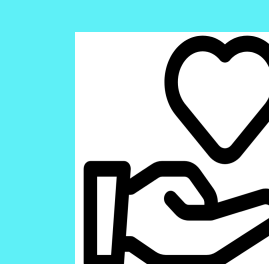
Mixed Experiences with Healthcare professionals

- Lengthy waitlists and feeling discouraged while on them was unfortunately a common experience.
- Another theme was disagreement or difference of opinion. Sometimes what professionals thought would be helpful, were things that patients worried would not help. Or patients had different opinions about what would be helpful in their care.
- Overall people had mixed experiences with professionals, some of the help they received was instrumental in their getting better, while other experiences did not help.
- Further research is needed to clarify what differentiates good care experiences from poor ones.



Looking to The Future of ED and Care Research In Anthropology

- Next steps: Continuing this research with ongoing ethnographic interviews and a survey
- Flipping the coin and asking: "What are health providers' views on what successful recovery looks like? How do they view good care?"
- Previous Anthropological research (Lester, 2018; Sciolli 2016) has found that care providers struggle with finding a healthy level of attachment and detachment to their ED patients and may therefore suffer from burnout.
- Future research should examine the impact of provider burnout in the ED field, and how we can better support our care providers.



References

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