WHAT COULD CO-DESIGN LOOK LIKE IN EATING DISORDERS TREATMENT?

Andrea LaMarre, PhD, Leora Pinhas, MD, FRCPC, Raluca A Morariu, BSc, Patients and Staff of the Ontario Shores Centre for Mental Health Sciences Adolescent Eating Disorders Unit 2016-2017

A (Brief) History of Eating Disorders Treatment

- William Gull (1860s) – “hysteria”
- AN generally observed in young, white, thin, cis women
- Eating disorders described in ways that blamed a) parents & b) people themselves for developing them

- Treatment entailed separating the child from their parents
- Psychoanalytic treatment also common
- Emphasis on individual therapy

A (Brief) History of Eating Disorders Treatment

- 1970s, 80s: Maudsley Hospital in London, UK began work on a family-integrated form of treatment
- Family framed as important in recovery process (as opposed to pathological)
- Eating disorders continued to be primarily diagnosed in young, white, thin cis-women
- These are also those on whom measures of pathology were developed

A (Brief) History of Eating Disorders Treatment

- 1990s: feminist researchers (from cultural studies, anthropology, psychology) wrote about the problems with how eating disorders were described, treated
- 2000s: continued development of this work – attention called to EDs in BIPOC folks, LGBTQ+ folks, those in larger bodies
- Increasing recognition that "treatment as usual" does not work for all

However…

"Expertise" in the eating disorders field continues to signify "professional" expertise

Hesitancy to embrace co-design

There is a notable hesitancy to integrate people with lived experience in a significant way into treatment models.

Perspectives of those who have had negative treatment experiences exist in the literature (e.g. Boughtwood & Halse, 2010) and in advocacy work.

Still, people with eating disorders described as being dominated by the eating disorder voice (Saukko, 2008) & assumed to resist treatment – which can paradoxically promote resistance (Musolino et al., 2016)

Co-design, or even a recovery model orientation, is rare in the eating disorder space

Notable exceptions are generally from the "severe and enduring anorexia nervosa" literature (e.g. Ålgars, Anttonen & Suokas, 2018; Hay, Touyz & Sud, 2012; Molin, von Hausswolff-Juhlin, Norring, Hagberg & Gustafsson, 2016 Munro et al., 2014; Schmidt, Wade & Treasure, 2014; Touyz & Hay, 2015)

RECOVERY MODEL

The recovery model itself is only recently being embrace in some ED spaces (e.g., Churruca, Ussher, Perz & Rapport, 2019; Dawson et al., 2014; Musolino et al., 2016)

Dawson et al. (2014) note that there *is* possible alignment between AN treatment in particular and the recovery model & suggest that collaboration, contextualization, and innovation do have a place in ED treatment.

Churruca et al. (2019) point to the need for individualized ways of being in BN recovery, grounded in a recovery model orientation.

Musolino et al. (2016) specify that due to the centrality of therapeutic alliance in promoting recovery, taking a recovery model orientation can help build healing-conducive care.

Still…

- Patients are not often engaged in their own treatment decision-making, particularly when they are adolescents
- This may be due at least in part to (legitimate) fears around people not acting in their best interest, which can and sometimes does lead to death.

Possibilities on the horizon

Example of an adolescent ED treatment program grounded in the recovery model, co-design

- Qualitative program evaluation, September 2016-February 2017
- Multidisciplinary staff, recovery-model oriented public hospital*

* Please note that the program no longer runs as a co-designed recovery model unit after 2018, and a 100% staff turnover has taken place since the research was conducted

Methods

- **Experience-based co-design** (EBCD; Larkin, Boden & Newton, 2015) – adapted
- Aims to make re-design of programs possible in a way that engages patients **beyond simplistic/tokenistic** engagement
- Observation, interviews, data collated into themes, feedback shared with stakeholders
- 11 staff members, 8 patients, 2 caregivers interviewed

Results

- Patients enjoyed participating in research as a way to have their **voices heard** & to **make a difference** for others with eating disorders
- They noted feeling **free to refuse** participation in unit-wide studies
- Staff longed for more **specialized ED research**
- Staff wanted to know about strategies to **meaningfully engage** patients in research efforts & about how to acknowledge their contributions

- On the unit, patients were involved in **clinical rounds, community meetings, goal setting** and more
- This was often quite different from previous treatment experiences
- Patients were not used to having their voices heard; this was both **helpful** and at times **challenging**
- Additional “culture shock” adjustment assistance might be warranted

Results

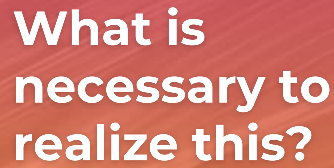
- Staff noted some challenges and benefits of working in a co-designed unit, including:
  - Communication (clarity, **transparency**)
  - Collaborative **problem solving** (different orientations, multidisciplinarity)
  - **Support,** teamwork
  - Shared **goals**

Co-design in practice

- Despite alignment of co-design with **personal** and **professional** commitments, it is not without its challenges to enact
- The ED field is rife with statements about "evidence-based practice" that exclude lived experience (and even clinical experience, at times)
- There is a lack of training in **how to enact co-design**
- Patients **may not be used to co-design** given the "treatment as usual" they've been exposed to

So, what CAN co-design look like in practice in
the eating disorders context?

- Consulting with patients about their care, not just once at the beginning of care
- Taking a “nothing about us without us” approach to clinical rounds & other decisions about plans of care
- Avoiding the sweeping rules & inflexibility common in ED treatment
- Providing a multi-disciplinary support team who can help determine individually-appropriate responses to moments in which people are *not* acting in their own best interests



What is necessary to realize this?

- Recognition in the ED field of the various forms of expertise that **matter**
- Openness to **doing things differently**
- **Funding** for programs that integrate co-design
- Willingness to communicate transparently about the **outcomes** of existing ED programs and the possibilities for improvement therein

- Allows for an understanding of the **individual and contextual/relational definitions of recovery** people hold
- Re-orients to the question of "**expertise**"
- Promotes the importance of constantly trying to provide **better treatment**

Thank you to 2016-2017 EDU staff and patients & to Dr. Leora Pinhas and Raluca A Morariu

- Presentation template by SlidesCarnival
- Photographs by Unsplash

References

Ålgars, M., Anttonen, M. & Suokas, J. (2018). Developing an outpatient unit for patients with severe and enduring anorexia nervosa.

Boughtwood, D., & Halse, C. (2010). Other than obedient: Girls' constructions of doctors and treatment regimes for anorexia nervosa. Journal of Community and Applied Social Psychology, 20, 83–94.

Churruca, K., Ussher, J.M., Perz, J. & Rapport, F. (2019). 'It's always about the eating disorder': Finding the person through recovery-oriented practice for bulimia. *Cultural Medicine and Psychiatry,* e-pub ahead of print.

Dawson L., Rhodes, P. & Touyz, S. (2014). The recovery model and anorexia nervosa. *Australian and New Zealand Journal of Psychiatry, 48*(11), 1009–16.

Hay, P.J., Touyz, S. & Sud, R. (2012). Treatment for severe and enduring anorexia nervosa: A review. Australia and New Zealand Journal of Psychiatry, 46(12), 1136-44.

Larkin, M., Boden, Z.V.R. & Newton, E. (2015). On the brink of genuinely collaborative care: Experience-based co-design in mental health. Qualitative Health Research, 25(11), 1463-1476.

Malson, H., Bailey, L., Clarke, S., Treasure, J., Anderson, G., & Kohn, M. (2011). Un/imaginable future selves: A discourse analysis of in-patients' talk about recovery from an "eating disorder". *European Eating Disorders Review, 19,* 25–36.

Musolino, C., Warin, M., Wade, T. & Gilchrist, P. (2016). Developing shared understandings of recovery and care: a qualitative study of women with eating disorders who resist therapeutic care. *Journal of Eating Disorders, 4*(36).

Saukko, P. (2008). *The anorexic self:* New *political analysis of a diagnostic discourse.* New York: SUNY Press.

Schmidt, U., Wade, T. & Treasure, J. (2014). The Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA): Development, Key Features, and Preliminary Evidence. *Journal of Cognitive Psychotherapy, 28*(1), 48-71.

Touyz, S. & Hay, P. (2015). Severe and enduring anorexia nervosa (SE-AN): in search of a new paradigm. *Journal of Eating Disorders, 3*(26).