BARRIERS TO TREATMENT & RECOVERY
THE PATIENT’S PERSPECTIVE
WHO ARE WE?

Vancouver Island Voices for Eating Disorders (VIVED) is a collection of voices (patients, family members, & professionals) interested in eating disorder awareness and advocacy in our community.

Incorporated as a non-profit society in B.C. in the fall of 2018.
VIVED (Vancouver Island Voices for Eating Disorders)

Victoria Eating Disorder Peer Support Group
- In-person, weekly peer support (since 2015)

Online support

Therapeutic/recreation component (starting winter 2018/2019)

Advocacy, Education, & Awareness Projects

OUR ORGANIZATION
Why We Chose This Topic

(Barriers to Treatment & Recovery – The Patient’s Perspective)

- Feedback from those we help support (in our peer support group and in our online spaces – Facebook, Twitter, Instagram, etc.)
- Out of hope to increase understanding and communication between patients and professional groups
- Our own personal experiences in our recovery journeys.
- Answering the question what can we (as patients) offer professionals in this field?
- Answering the question of how we can give back to our community and help it move forward in the care of those (individuals and their families) struggling with eating disorders.
Disclaimer

• While some of our members work (or have worked) in the healthcare field (including with eating disorders), we are here today as an advocacy group. We are not experts and we offer experiential (versus professional) knowledge.
• Information from professional sources is included in this presentation, but the information we are focusing on has been gathered through VIVED members and members of our peer support group (online and in-person). This information is anecdotal and themes that have been drawn out have not been subjected to proper qualitative study procedure.
• Some of what is expressed in this presentation reflects frustration from patients. VIVED as an organization understands the complexity of healthcare, funding, and limited resources. Our focus is on feedback and collaboration with healthcare professionals.
• VIVED’s focus is on Vancouver Island, but much what is relevant to our area is applicable to the rest of the province (largely outside of the lower mainland).
• We have no financial conflicts of interest to disclose at this time.
• Some members may have been through treatment programs associated with Providence Health Care or other health authorities in the province of B.C.
• Photographs included in this presentation are from members.
Overview

Internal Barriers:
• Ambivalence & Motivation
• Competition in Group Settings
• The “Not Sick Enough” Phenomenon

External Barriers:
• Perceptions & Beliefs
• Service-related Barriers
• Additional Barriers for Marginalized Groups

Recommendations
References
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BARRIERS TO TREATMENT & RECOVERY
INTERNAL BARRIERS

Ambivalence & Motivation

Competition in Group Settings

The “Not Sick Enough” Phenomenon
Ambivalence & Motivation

- Ambivalence → “simultaneous and contradictory attitudes or feelings … toward an object, person, or action” - in this case recovery, treatment, and/or the idea of change (Merriam-Webster, n.d.).

- Well documented phenomenon in the context of eating disorders.
  - Numerous studies looking at application of the transtheoretical model/stages of change for the treatment of eating disorders (Blake, Turnbull, & Treasure, 1997).
  - Motivational interviewing (MI) has also been effectively applied to the treatment of eating disorders (Ritchey, 2015*; Treasure & Ward, 1997).

- Highlights several important features of eating disorders:
  1. Intellectual knowledge about the negative consequences of eating disorders and the potential positive outcomes of recovery does not necessarily translate to change.
  2. Even following these necessary steps, full recovery for the individual...
Competition in Group Settings

- Documented (Vandereycken, 2011) and anecdotal recognition of competitive aspect to eating disorders.
- Competition can arise when there is a perceived threat to identity.
- Validity of suffering is often related to visible illness (inaccurate stereotypes are internalized by patients, professionals, and the broader public).
  - Creates a sense of needing to “prove” illness → patient does not feel “sick enough.”
- Patients frequently experience competition in the form of triggering comments & behaviours in treatment settings.
  - These can challenge a patient’s motivation to engage in treatment.
  - Competition can create further division between patients and clinicians when patient’s disordered behaviours escalate one another.
  - Fear of being triggered can lead to fear of seeking treatment.
The “Not Sick Enough” Phenomenon

- Relates to competitive aspect of eating disorders → threat to identity (the way in which a patient may primarily value themselves.)

- Stereotypes contribute to false idea of what eating disorders are or “should” be in the patient’s mind (e.g. thin, young, white, female).
  - Most media representations of eating disorders showcase anorexia nervosa (AN) and perpetuate harmful stereotypes in their portrayal. While it is the most widely represented, AN is the least common eating disorder diagnosis. (http://nedic.ca/know-facts/statistics).

- “Sick enough” is unattainable, but in theory it is the point at which one has suffered enough, one’s struggles are valid, and thus the point at which one deserves recovery.
  - There is no sick enough, there is only having enough of being sick.

- “Sickness” is often thought of in terms of physically measurable or demonstrable features of illness.
EXTERNAL BARRIERS

- Perceptions & Beliefs
- Service-related Barriers
- Additional Barriers for Marginalized Groups
Perceptions & Beliefs

- Lack of awareness and limited education (both public and professional)
  - Numerous healthcare professions receive little to no coverage of eating disorders in their educational curriculum.
  - Poor & limited representation of eating disorders in media → contributes to harmful stereotypes

- Stigma towards eating disorders (and mental health in general)
  - “Stigma” → “a mark of shame…” (Merriam-webster, n.d.)
  - Unhelpful language (in society and healthcare).
  - Focus on physical and measurable components of health.

- Weight stigma and diet culture in society
  - The result is a society where a disordered relationship with food, exercise, and one's body is the norm.
  - Limited understanding of “health” and weight and the complexity of these interactions (e.g. thin is seen as equating to healthy, weight loss is almost always seen as unquestionably good).
  - Moralization of food, the body, and health.
**Service-Related Barriers**

- Limited treatment options & limited funding

- Current structure of treatment programs in B.C.
  - Lack of continuity of care increases the risk for relapse and treatment cycling.
  - Limited variations in approaches to treatment (one-size-fits-all).

- Lack of integrated services for co-morbid mental and physical health conditions
  - e.g. managing the care of individuals who struggle with diabetes mellitus and an eating disorder (in outpatient settings)
  - e.g. “silo”-ing of services (the issue with specialists)

- Structure of our healthcare system
  - Focus on objective/measurable indicators of disease and “health.”

- Ethical issues in the treatment of eating disorders
  - Autonomy vs. beneficence.
  - Decision-making capacity → Stanford Encyclopedia of Philosophy

- Weight stigma and diet culture in healthcare
Additional Barriers for Lower Profile Groups

- Older adults
  - Limited effective treatment options for SEED
  - Unhelpful labels – noncompliant, treatment refractory, failure to engage with treatment, etc.

- Men with eating disorders
  - Lack of male clinicians to build working therapeutic relationships
  - Body image concerns specific to males

- LGBTQ+
  - May also experience different body image concerns – “gender dysphoria”

- People in larger bodies
  - Weight stigma
Moving Forward in the Care of Eating Disorders in B.C.

- More research & statistics on eating disorders with a focus on special populations (males, older adults, etc.)
- Campaigning to raise awareness and challenge stereotypes in public and professional spheres
  - Concerning eating disorders, but also concepts like “diet culture” and looking after our mental health in general.
  - Eating disorder specific training and education for multiple disciplines in the healthcare field.
- Creation of more in-between levels of service (based largely on the 2012 B.C. Eating Disorder Clinical Practice Guidelines & the 2011 report upon which those guidelines are based.)
  - Improving community and outpatient supports.
  - Implementing ACT teams with a focus on eating disorders (SEED in particular).
  - Expanding day treatment options through existing facilities.
  - Expanding residential treatment options for adults.
References (A-H)

References (K-V)


- Preamble to the Constitution of WHO as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of WHO, no. 2, p. 100) and entered into force on 7 April 1948.


QUESTIONS?

“ALL BELLIES ARE GOOD BELLIES”

“WORK”

“ALL BELLIES ARE GOOD BELLIES”

“FUCK FATPHOB”

“LOVE YOURSELF”

“RECOVERY ISN'T ONE SIZE FITS ALL”

“RIOTS NOT DIETS”

“DEPRESSION”
THANK YOU

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