



What Canadians with Lived Experience are Saying About Adult Inpatient Eating Disorder Treatment

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INTRODUCTION

At least one million Canadians¹ are affected by eating disorders (EDs), which are serious mental illnesses that can become life-threatening, especially in the absence of timely intervention. Adult inpatient ED treatment is scarce in Canada, however, with only a small number of programs and very few beds per program. East of Quebec, there are only seven inpatient beds. Furthermore, adult inpatient ED treatment in Canada lacks the structure (i.e., nationally recognized ED treatment standards), accessibility, and adequacy (i.e., treatment methods that are effective for diverse patient populations) that is necessary to care for those who need it. With no nationally recognized treatment standards, this type of publicly funded, hospital-based care is inconsistent across the country. Specifically, ED programs differ in their treatment approaches, meaning some forms of treatment are not available to all Canadians. When folks do access treatment, they often leave or are discharged early and still experience symptoms years post-admission. Research suggests that upwards of 51% of inpatient participants² leave treatment prematurely and approximately 70% experience ED symptoms³ a decade following their admission.

Existing documents have identified areas for improvement in the Canadian context (e.g., Eating Disorders Among Girls and Women in Canada⁴; Canadian Eating Disorders Strategy⁵; and Canadian Practice Guidelines for the Treatment of Children and Adolescents With Eating Disorders⁶) but the perspectives of adults with lived

inpatient treatment experience are often missing at the forefront. This may be a result of stigma and ethical concerns⁷. With my graduate thesis research⁸, I sought to explore these invaluable viewpoints and answer the question: *how can adult inpatient ED treatment be improved from the perspectives of Canadians with lived experience?*

Besides the evident need for improvement of adult inpatient ED treatment in the Canadian context that is fuelled by those with lived experience, my own relationship to the subject matter catalyzed this study. During my undergraduate studies, I developed anorexia nervosa (AN) and was eventually admitted to adult inpatient ED treatment at age 19. The process of seeking a diagnosis, receiving a referral, accessing treatment, and engaging in an inpatient program was in many ways challenging, discouraging, and traumatic for me – and I perfectly matched the stereotype of what someone with an ED “should” look like. As a Health Promotion student, my privilege was apparent to me, as was the fact that the current approach to ED treatment in Canada needed to change in to effectively support the diversity of those who are affected by EDs. Since finishing treatment, I have dedicated my time to being an ED advocate. This study was for all Canadians affected by EDs, but also for myself.

MY STUDY

Eleven adults with inpatient ED treatment experiences between the years 2012 and 2022 across the country were interviewed to explore their perspectives on three aspects of treatment: referral, transitions into/out of care, and the treatment itself. The study participants brought experience from inpatient programs in four Canadian provinces and represented ED diagnoses of anorexia nervosa (AN), bulimia nervosa (BN), and other specified feeding and eating disorder (OSFED). The sample was diverse in gender identities and sexual orientations, but was primarily made up of white individuals, and all were between 22 and 37 years of age.

I asked my participants questions concerning each of these aspects, focusing on what they felt was done well in each aspect, what they felt could be improved upon, and how these improvements could be achieved. My study found that, while there are aspects of treatment programs and processes that are being done well, they are not being done everywhere and they are not being done well all the time. For example, one participant had the opportunity to practice portioning their own meals with guidance from a registered dietitian and found this to be supportive of their recovery, but other participants who had attended different programs did not have the same type of opportunity. One participant engaged in a transitional program offered by the hospital while awaiting inpatient admission, which they felt was positive in their overall treatment experience, but this sort of program was not offered to other study participants who were referred to treatment in other provinces. Based on the data, my participants and I co-created a list of recommendations for improving adult inpatient ED treatment in Canada; the most critical of recommendations will be discussed in this article.

RECOMMENDATIONS

In total, ten categories of recommendations were identified: *Stigma*, *Early Intervention*, *Interim Support*, *Patient Support*, *Individualization of Care*, *Treatment Methods*, *Dignified Treatment*, *Stagnation* (lack of innovation in treatment programs and processes), *Transition out of Treatment*, and *Resources*. Each recommendation within these categories is a reflection of how my participants feel that Canadian adult inpatient ED treatment can be improved to better

support them and others who experience EDs. While all recommendations are important, and even necessary, to improving Canadian adult inpatient ED treatment programs and processes, several recommendations should be implemented with urgency due to their necessity as identified by my study's participants.

Interim Support

Interim support, in the context of my study, refers to specialized programs for those who have been referred to inpatient ED treatment and are awaiting admission. Participants in my study generally waited a long time between referral and admission, some as long as one and a half years, but very few had access to support while they waited. This caused a significant decline in health for every one of my participants.

“I depleted so badly that I ended up having a heart attack and a stroke.”

– Study Participant

Eligibility criteria for hospital-based treatment are often such that they prevent people from accessing any specialized care. For example, the [Nova Scotia Health's ED Program](#)⁹ requires patients to maintain a body mass index (BMI) of 17.5 in order to participate in its outpatient program. Even private ED care providers will often turn away people awaiting inpatient treatment as it is thought that those meeting inpatient eligibility criteria, such as a low BMI, do not have sufficient cognitive capacity to engage effectively in psychotherapy at the outpatient level. Sadly, this leaves people who are in desperate need of care with nowhere to go but the emergency room (ER). While visits to the ER may be useful in treating acute physical complications, the ER is not equipped with the comprehensive resources necessary to effectively treat EDs to facilitate lasting recovery. Interim support, in the form of outpatient services led by specialized healthcare providers, should be implemented nationwide so that those awaiting admission have a chance at maintaining what health they have left.

Transition out of Treatment

Many Canadian adult inpatient ED treatment programs use a step-down approach for patients who have completed their program, meaning they are then admitted to a day hospital or intensive outpatient program, and finally to outpatient treatment. However, this is not always the case for program graduates, and seldom the case for patients who are administratively discharged (i.e., kicked out) or leave the program early by choice.

I was left with zero follow-up ... if you're not successful, you don't get follow-up at all.

– Study Participant

Discharge planning is a process in which a patient meets with their healthcare provider(s) and sometimes their support network (e.g., friends, family) to determine an individualized plan to help the patient maintain their recovery and avoid relapse. It involves the identification of available resources and supports. Without this step, many individuals are left with little to no support for the post-inpatient period; they relapse and begin the cycle once again. In my participants' experiences, lack of discharge planning was a result of self-discharging (choosing to leave treatment prematurely), administrative discharge (being kicked out of treatment prematurely), staff availability, and general lack of resources. Several of my participants self-identified as "revolving-door patients", meaning they would enter treatment, leave, and return within a matter of months. The lack of discharge planning contributes significantly to this cycle. Discharge planning must be done collaboratively with each patient and their support network, even when they have not graduated from the inpatient program, to give patients the best possible chance at recovery post-inpatient admission.

Individualization of Care

When asked to recall their experiences with inpatient ED treatment staff, participants recalled their best memories of staff members who treated them with empathy, respect, and humility. Establishing mutual trust, respect, and open communication between patient and care provider is a necessary step in delivering patient-centred care.

It wasn't necessarily that they needed to be like, specialists in eating disorders. They kind of just needed to be human with me.

– Study Participant

Aside from practicing compassion, providing care that is patient-centred involves willingness to engage in collaboration and information-sharing, and enabling patients to participate in decision-making and to maintain their dignity. Many participants felt that this was missing from their experience in inpatient treatment and that, to be effective, treatment plans should be individualized to each patient's unique needs, values, and goals. In the experiences of my participants, inpatient treatment programs took a "one-size-fits-all" approach to care, ignoring the impacts of patients' gender, religion, race, culture, age, or ED diagnosis. In some cases, patients' experiences of trauma were not considered during the treatment processes, perhaps as a result of understaffing or a lack of trauma-centred education and resources. Inpatient ED treatment for adults should take a compassionate approach, facilitate patient autonomy whenever possible, and reflect the unique needs of each patient to improve their experience and outcomes.

Resources

Most evident is the need for increased resources when it comes to adult inpatient ED treatment in Canada. Increased government funding would allow programs to add beds, expand their capacity, treat more patients, and reduce wait times. Increased opportunity for healthcare providers to be trained in cultural competency and humility, patient-centred care, and treating eating disorders, with the input of those with lived experience, would allow for more specialized, compassionate, and de-stigmatized care. Increased research into the ED experiences of people of colour, Indigenous people, men, transgender and gender non-binary people, people living in bigger bodies, and people affected by co-occurring health challenges would allow for a better understanding of how treatment programs and processes (e.g., diagnosis, referral, intake, admission, discharge) can be tailored to address the unique needs of these populations that have long been ignored in the context of ED treatment. By increasing the resources allotted to adult inpatient ED treatment, the recommendations set by my participants and I can be achieved and Canadians with EDs can finally receive the care that they deserve.

CONCLUSION

The key findings from my study contribute to existing evidence that adult inpatient ED treatment in Canada needs to change to best serve its target population, and these changes must be made with national unity (i.e., nationally-recognized standards for the treatment of EDs), but these findings also highlight the value in the perspectives of those with lived experience. It is critical that these perspectives are sought, understood, and heard when working to improve adult inpatient ED treatment programs and processes. And if you have lived experience, know that it is valuable and seize the opportunity to share your story and use your voice – it may just hold the power to change someone else's experience for the better.

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