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**RESEARCH** **Open Access**

# Improving adult inpatient eating disorder treatment: perspectives of a sample of individuals in Canada with lived experience

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## Abstract

**Background** Eating disorders (EDs) are increasingly common, affecting over one million individuals in Canada. Canadian adults (i.e., age 18+) requiring medical stabilization for their eating disorder (ED) may be referred to adult inpatient (IP) ED treatment for care. Recent Canadian publications have brought attention to the need for improved approaches to Canadian ED treatment; urging researchers to seek perspectives of people with lived experience to determine how to best do so. This study explored the perspectives of a sample of individuals in Canada with lived experience to identify recommendations for improvement of adult IP ED treatment programs and processes.

**Methods** Employing a transformative philosophical view and feminist standpoint theory, this study utilizes a qualitative hermeneutic phenomenological approach to fulfill the objectives. Eleven participants with lived adult IP ED treatment experiences from across Canada were interviewed individually, to discuss their experiences and recommendations regarding referral, transitions into and out of care, and treatment itself using an online video conference platform. Data were analyzed using interpretative phenomenological analysis. A comprehensive list of recommendations was drafted and brought back to participants for feedback. The feedback was implemented to create the final list of recommendations.

**Results** Several limitations of referral, transitions, and treatment, facilitated and exacerbated by stigma at individual and societal levels, were identified by participants. These included guilt and shame upon referral, lack of respect and trust from healthcare providers during transitions, and lack of consideration of social determinants of health during treatment. Participant-informed recommendations, which can be categorized as *interim support*, *individualized care*, *dignified treatment*, *resources*, and *stigma*, were identified to ameliorate the experiences of those in Canada with EDs while also combatting stigma.

**Conclusions** Adult IP ED treatment in Canada is in urgent need of significant change to meet the needs of those requiring care and to address harmful stigma. Implementing participant-informed recommendations may aid in achieving this goal. The meaningful inclusion of those with lived experience, particularly marginalized populations, will be paramount to the development of an approach to adult IP ED treatment that properly serves individuals in Canada who need it.

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**Plain English Summary**
Eating disorders (EDs) are common and can be deadly, yet treatment approaches are not currently meeting the needs of individuals in Canada requiring care. As noted in the existing literature, ED treatment is largely inaccessible in Canada and can be ineffective in facilitating long-term recovery. Recent research has suggested that improvement to publicly funded, hospital-based ED treatment for adults is necessary and that those in Canada with lived experience should be involved in the process of doing so. This paper is based on a study that set out to explore ED treatment and gather potential recommendations from eleven individuals in Canada with lived experience. Several recommendations were identified to improve ED treatment in Canada, while simultaneously addressing harmful stigma about people with lived experience with EDs. These recommendations included providing interim support, ensuring individualized care, offering dignified treatment, increasing resources, and directly targeting stigma. From this study, it is suggested that current ED treatment methods must change to improve health outcomes and reduce stigma, and exploring the perspectives of those with lived experience is a promising method for doing so.

**Keywords** Eating disorders, Inpatient treatment, Adults, Lived experience, Recommendations, Stigma

## Background

Eating disorders (EDs) are a group of psychological illnesses that negatively affect eating behaviours and attitudes towards food, exercise, and the body, resulting in significant harm to overall health and well-being [1, 2]. Over one million individuals in Canada experience EDs and an estimated one in ten people will die because of their eating disorder (ED) [3, 4]. Despite these statistics, the current approach to publicly funded treatment in the Canadian context fails to meet the needs of many of those experiencing EDs.

Because healthcare is a provincial responsibility, publicly funded ED treatment differs in availability and modality across the country, creating a fragmented system of inequitable access and care [5]. Those in Canada requiring adult inpatient (IP) ED treatment (i.e., hospital-based, publicly funded care for those 18+needing medical stabilization) are particularly affected by this disconnection due to issues of structure, access, and efficacy. To our knowledge, no treatment standards for adult IP ED treatment have been developed and recognized on a national scale. Furthermore, access to adult IP ED treatment is scarce and unequal across the country, with several provinces having no adult IP ED programs at all [5]. This scarcity and geographic disparity inevitably contribute to growing wait times across the country, with some individuals in Canada waiting up to two years for life-saving ED treatment [6, 7]. Finally, the general efficacy of IP ED treatment remains contested, with studies suggesting high instances of patient drop-out and low rates of long-term ED symptom reduction [8–14].

One way to combat these issues is to work with individuals in Canada who have lived IP ED treatment experience to determine how they feel treatment programs and processes can be improved to better serve those in need of care [5, 11, 15]. While the research has begun to shift in the last 20 years, the valuable perspectives of those with lived ED experience have historically been excluded from research dedicated to improving treatment outcomes due, in part, to stigma and ethical concerns [16]. Stigma at all levels has long been proven to impact how EDs are perceived, understood, experienced, and treated [17]. For example, social and professional stigma within the healthcare system suggests that ED patients are vain, manipulative, difficult to work with, and complex to treat, impacting the power dynamics between patient and caregiver and contributing to existing self-stigma that often accompanies an ED diagnosis [18–21]. Such stigma, combined with how quantitative data has often been privileged over qualitative research in clinical settings, likely contributes to the historic exclusion of the perspectives of those with lived ED experience in research [22].

In addition to stigma, there exists ethical concern about exposing those with lived ED experience to ED-related topics for fear of facilitating relapse [16]. To mitigate potential risks and create an opportunity to explore the valuable perspectives of those with lived experience, protective methods can be put in place. This might include providing participants with recovery-oriented resources, facilitating open dialogue between researcher and participant, integrating supportive methods of data collection, and ensuring ongoing, informed consent [16]. In consideration of the potential risks and methods for risk mitigation, there has been an increase in qualitative, patient-centred ED research conducted over the past two decades. For example, two studies from the early 2000s explored adolescent experiences of IP ED treatment in the United Kingdom, bringing attention to peer relationships in treatment and the importance of a sense of identity and individuality [23, 24]. Another patient-centric study based in the United Kingdom was conducted in 2014 to explore patient perspectives of therapeutic alliance in IP ED treatment [25]. In 2019, two researchers sought to understand the general experiences of adolescents in IP ED treatment in China; a context in which the topic had previously been significantly under-researched [26]. More recently, a study based in the United States explored participants' experiences of ED treatment in the midst of the COVID-19 pandemic [27]. This form of inclusion, combined with input from healthcare professionals, has the potential to uncover novel findings that may aid in improving patient experiences and health outcomes, while also simultaneously addressing widespread stigma regarding EDs.

Though research centred around lived ED experience has increased in general, greater data must be collected across the globe in order to have meaningful and applicable impact in individual countries. Accordingly, such research specific to the Canadian context has historically been limited and in recognition of this, recent Canadian publications have urged researchers to seek further the perspectives of those with lived experience to aid in identifying areas for improvement of ED treatment [5, 11, 15]. This endorsement has resulted in several recent studies on the subject, though most research has been specific to youth and pediatric care. For example, Couturier et al. (2020) assembled a panel of stakeholders, including those with lived experience, to establish Canadian practice guidelines for the treatment of children and adolescents with eating disorders [28]. Also in 2020, a team of researchers in British Columbia, Canada sought to understand the treatment outcomes of youth (aged 16–24) in residential ED treatment via chart review in addition to participant interviews [29]. Finally, Coelho et al. (2022) conducted interviews with Canadian youth to explore their experiences with treatment, particularly noting the challenges they faced in accessing care [30]. While these studies are critical to improving care among a Canadian population that is significantly impacted by EDs, particularly since the beginning of the COVID-19 pandemic, input from Canadian adults is needed to develop a better system of care that meets the adult population's unique and diverse needs.

The purpose of this study, then, was to explore the perspectives of a sample of Canadian adults with lived experience of referral to and/or participation in adult IP ED treatment and identify participant-informed recommendations for the improvement of the processes associated with such treatment programs. This study not only responds to the call of recent Canadian publications to include those with lived experience in ED research, but it produces in addition a concrete list of detailed recommendations for the improvement of adult IP ED treatment in Canada that is entirely informed by those with lived experience [5, 11, 15].

### Researcher positionality and reflexivity

I, Catherine Armour, undertook this work in partial fulfillment of my M.A. degree in Health Promotion from Dalhousie University and have lived experience with Canadian adult IP ED treatment. The methodology for this study was chosen intentionally to allow for this lived experience to be integrated into the research conduction rather than eliminated. My connection to the research topic aided in establishing mutual trust and respect between myself and the participants, allowing for a rich exploration of the research topic as perceived by participants. Seeking participants' feedback in developing the final list of recommendations ensured that they were reflective of the participants' experiences and not my own.

## Methods

### Philosophical worldview

A transformative philosophical worldview, defined by Mertens (2009) as an approach that aims to catalyze political and social change for the benefit of marginalized populations, guided this study [31]. Research that employs this worldview provides target populations, in this case, those in Canada with lived adult IP ED treatment experiences, the opportunity to have their voices heard and valued, meeting the purpose and rationale of this study [31, 32]. In alignment with this philosophy, those with lived ED experience were sought out to inform recommendations for change. This rejects existing discourse, upheld by existing literature that does not include lived experience, that healthcare professionals alone should inform treatment processes [32]. A transformative philosophical worldview is congruent with the methodology of this project in that it aims to bring attention to the experiences of marginalized populations and bring about change [31].

### Theoretical framework

Feminist standpoint theory (FST) was employed for this research because of how patriarchy has shaped societal perceptions of EDs, who experiences them, and how they are treated [33, 34]. FST acknowledges that those who hold power over others in certain settings can shape and promote societal views on how these populations are perceived and therefore treated within society [35]. These perceptions (e.g., EDs are a women's issue, EDs are a result of vanity) are often inaccurate and perpetuated by stigma at the societal level [17, 36, 37]. FST theorizes that such ideologies can be shifted by seeking and valuing lived experience in research [35]. This theoretical framework informed the data collection process, ensuring participants a safe space to share their experiences, and the data analysis process (see *Discussion*), referring to feminist theories regarding gender, lived experience, and power in the context of IP ED treatment.

### Research design

Given the sensitive nature of this study, a qualitative approach to data collection was regarded as the most appropriate study design to fulfill the purpose of the research. Conducting inductive qualitative research as an individual with lived experience ensured that data were collected respectfully and were reflective of the participants' experiences. The study followed hermeneutic phenomenology; a research design aimed at exploring lived experience to gain new understanding and knowledge on a phenomenon [38]. Hermeneutic phenomenology was most congruent with the transformative philosophical worldview, FST, and the overarching objective of the research [31, 35, 38]. Further, this approach appreciates, rather than prohibits, the connection between researcher and participant, acknowledging its value in the data collection and analysis processes [38, 39]. Building rapport with participants through our common experience was necessary to foster meaningful conversations and facilitate rich data collection. By employing hermeneutic phenomenology, explicitly stating my positionality, and engaging in peer review throughout the research process, I was able to conduct research that was reflective of the participants' experiences and perspectives without omitting my interpretations as a researcher with lived experience. Given my identity as someone with lived ED treatment experience, it is important to acknowledge my experience and its connection to this research.

### Participants

Participants were recruited by sharing physical and electronic copies of a poster with ED support organizations across Canada; ten of which shared the poster with their networks. Potential participants were screened via email for their eligibility (see Table 1). They were also asked to share general information regarding their experience with adult IP ED treatment in Canada (i.e., age(s), location(s), year(s)) per maximum variation purposeful sampling which, in the context of this study, aimed to develop a participant sample that was diverse in their experience of the phenomenon of interest [40]. Participants were compensated $15 for their participation in a virtual one-on-one interview and an additional $5 for their participation in a virtual one-on-one follow-up meeting.

**Table 1** Participant inclusion criteria

| Inclusion Criteria |
|---|
| Lives in Canada |
| English fluency |
| Referred to an IP ED treatment program in Canada between the years 2012 and 2022 while aged 18 years or older |
| Not currently in IP ED treatment |

### Data collection

Qualitative data was collected via virtual, semi-structured, one-on-one, open-ended interviews and virtual, one-on-one follow-up meetings between the participant and me. Interviews and follow-up meetings were conducted virtually due to my geographic location at the time and the increased reach that virtual data collection allowed. Interviews lasted between 60 and 90 min, while follow-up meetings lasted between 20 and 45 min.

An interview guide was followed, however; the semi-structured nature of the interviews allowed for flexibility to encourage exploration of each participant's perspective. The interviews generally followed three categories of questions: referral, transitions, and treatment. 'Referral' being the process associated with seeking and receiving a referral to an adult IP ED treatment program in Canada, 'transitions' meaning the processes associated with transition into and out of adult IP ED treatment program(s) in Canada, and 'treatment' referring to the processes associated with participating in adult IP ED treatment program(s) in Canada. Participants discussed elements within each category that they felt impacted their experience before identifying recommendations for how these elements might be improved to better support individuals in Canada.

### Data analysis

Data were analyzed using interpretative phenomenological analysis (IPA) [41]. Interview transcripts were developed with assistance from a transcription software [42]. The transcripts were reviewed in-depth, and data were categorized. Recurring topics and recommendations were identified and were connected to related topics and recommendations that transpired in other participants' accounts. Common topics/recommendations identified in this process formed the draft list of recommendations. Eight of the eleven participants engaged in follow-up meetings where they shared their feedback on the draft list and prioritized the recommendations. This method of peer review was to ensure that my interpretations accurately reflected the participants' experiences and perspectives. The feedback informed the development of the final list of recommendations for the improvement of adult IP ED treatment in Canada. Ten categories of recommendations were identified; five of which are presented and discussed in this article due to their relevance to stigma and EDs.

## Results

The following section will present the demographics of the participants and then define the participant-informed recommendations for the improvement of adult IP ED treatment in Canada. Recommendations are supported by the experiences of participants and excerpts from their virtual one-on-one interviews and follow-up meetings.

### Demographics

The study sample was made up of eleven participants who met the inclusion criteria and represented the geographic diversity of lived Canadian adult IP ED treatment experience. Note that the demographic results only reflect what participants felt comfortable sharing. Participants were aged 22–37 years and represented ED diagnoses of anorexia nervosa (AN) ($n=7$), bulimia nervosa (BN) ($n=1$), and other specified feeding or eating disorder (OSFED) ($n=1$). Participants self-identified as non-binary ($n=1$), [cis-gender] female ($n=9$), and trans masculine non-binary ($n=1$). The study sample described their race/ethnicity as either Caucasian ($n=10$) or Moroccan Jewish ($n=1$) and their sexual orientation as queer ($n=3$), heterosexual ($n=5$), bisexual ($n=2$), or asexual ($n=1$). Study participants had lived adult IP ED treatment experience in Nova Scotia ($n=1$), Ontario ($n=9$), Alberta ($n=2$), and British Columbia ($n=1$). Several participants had been admitted to programs in several of the listed provinces. Demographic results have not been matched with individual participants to protect their identity.

### Recommendation 1: interim support

As made evident through participant experiences, the lack of accessible interim support (i.e., treatment during the waiting period between referral and admission to adult IP ED treatment) combined with rigid eligibility criteria surrounding publicly funded treatment had significant consequences on the health of study participants. In recognition of this, our first recommendation is that support must be available in the interim to prevent patient health deterioration and improve overall well-being. Interim support programs and services, (e.g., meal support, psychotherapy, dietetics, medical monitoring) must be available to all incoming patients and must be made accessible. Patients' geographical location and non-ED commitments (i.e., family, education, employment) must be accommodated when designing accessible interim support programs.

Upon referral to treatment, participants recalled feeling guilty and shameful about their impending admission to adult IP ED treatment. These feelings were perceived to be influenced by internalized stigma due to a lack of resources in adult IP ED treatment in Canada. Participant Two described these feelings saying:

> *That I had to go into a hospital - that made absolutely no sense to me ... I had this overwhelming sense of guilt about taking up a bed ... I believed ... I didn't need that level of care and that by taking that level of care, I would be doing something really, really wrong by taking it away from someone who might need it more.*

In addition to feelings of guilt and shame, the 'not sick enough' mindset (i.e., feeling unworthy of care) was common among participants. Participant One eluded to this mindset, saying: *"[I felt] a lot of self-judgment [upon referral] ...the whole 'I'm not sick enough' mindset, and 'I'm undeserving of care' and 'people need it more than I do'"*, describing the self-judgment that accompanied referral to adult IP ED treatment.

Long wait times were also of concern among the study sample. Participants waited up to 15 months between referral and admission. During this waiting period, every participant reported a decline in their physical and mental health. This decline resulted in medical emergencies in some participants, including Participant Three, who said: *"I depleted so badly that I ended up having a heart attack and a stroke".* Participant Two had similar experiences, stating: *"[I had] to go to emergency multiple times while waiting for treatment".* The commonality of long wait times and medical emergencies in the interim was further underscored by another comment from Participant Three: *"I can honestly say I've known people personally who have died on that waitlist".* Waiting for admission to IP ED treatment was agonizing for participants, not only due to the fleetingness of motivation to recover but also because of the steep decline in health that they experienced while waiting.

Access to interim support was uncommon for study participants, with only one participant receiving specialized publicly funded outpatient treatment prior to their IP admission. Other participants sought private support in the interim, while most study participants were left with no interim support and were instead left to rely on unspecialized care via local health clinics and emergency room visits. Eligibility criteria (i.e., minimum/maximum body mass index (BMI) requirements) for adult IP ED treatment restricted many study participants from enrolling in publicly funded outpatient programs. Participant Eight described their experience of awaiting IP ED treatment admission:

> *I felt like the referral process...almost incentivized you to get worse...for so long, I was in a place where I was not quite healthy enough for outpatient services, but not quite sick enough for IP services...it felt so much easier to get worse and get care through IP than get better and get help through outpatient.*

Private treatment options allowed more flexibility in eligibility criteria, yet this form of support is costly and also proved to be unreliable in the interim. Participant Two, said, for example: *"I was seeing a therapist [and a] dietician and we were not making progress and they were saying like, we can't work with you anymore"*, describing their experience of having a private care team while awaiting admission to IP ED treatment, however; after a lack of progress, this form of support was terminated.

### Recommendation 2: dignified treatment

Participants expressed a lack of trust and a culture of disrespect in their experiences of adult IP ED treatment, which left them feeling undignified. Because of this, our second recommendation is that treatment must be respectful of patients' dignity. Maintaining all facets of a patient's life should be prioritized while in treatment. The program should collaborate with a patient's support system to determine and implement an appropriate treatment plan to allow this. All processes should be conducted with compassion, empathy, and understanding for the patient. Patients should not be stripped of their autonomy and independence. These actions require healthcare providers to implement principles of patient-centered care.

Upon admission to treatment, participants felt a power imbalance between the patients and the healthcare providers, leaving patients feeling unwelcome, powerless, and even unsafe. While certainly not the intention of all healthcare providers, this was a common experience among study participants. Participant Four reflected on their first days in treatment, recalling a 'tough love approach': *"[It was] probably what I needed at the time, but it felt very jarring, and I could see a lot of people not doing well with that"*. Participant One supported this sentiment, saying: *"I think there's room for improvement to really meet the patient's needs rather than being a drill sergeant"*. This power imbalance and culture of disrespect led some participants, including Participant Nine, to feel less than human: *"I generally just felt like an animal"*. This statement summarizes participants' common perception of treatment as being, at times, inhumane.

In addition to the culture of disrespect and power imbalance, participants noticed a lack of trust from healthcare providers. Participants felt that the patient perspective was often disregarded and not believed. Participant Seven described this phenomenon by referencing an interaction with a healthcare provider: *"They kind of looked at me like, 'Well, you're the crazy one'"*. Participant Three also recalled an instance during which they were not trusted by healthcare providers in an adult IP ED treatment program. Prior to a routine weigh-in, the participant was not allowed supervised use of the bathroom, resulting in an elevated weight on the scale. This participant was accused of intentional water-loading and was discharged from the program without an opportunity for explanation. Participant Three described the situation: *"The weight on the scale was so significantly high, because I had so much fluid in me…[that] I got discharged"*. Experiencing this distrust from healthcare providers discouraged participants in their recovery journey, making them feel as though they were alone in their hardships.

Administrative discharge (i.e., getting kicked out of a program prematurely) was a common experience among participants. Those who were administratively discharged felt there was a lack of discharge planning, as in Participant One's experience: *"I was left with zero follow-up…if you're not successful, you don't get follow-up at all"*. This meant that not only were patients being discharged prematurely, but they were also being discharged without support. Participant Seven was discharged in a concerningly dangerous physical state: *"They discharged me at like, I think I was maybe 68 pounds"*. Being discharged without discharge planning at such a low weight could have had fatal consequences.

Contrarily, participants alluded to several instances of respect and compassion from staff, and these moments were described fondly during interviews. Participant Three recalled a particular time when their doctor comforted them through a difficult time in treatment: "*[The doctor] came up to my bed that night … as he was getting ready to leave and he … pulled up the chair right beside my bed and we played cards and he says, I don't care how long this takes. When you're ready. You can talk to me.*". This moment was described as a "*breakthrough*" for this participant. Participant Five agreed that "*building rapport with staff*" was important in recovery and Participant Ten reflected on dignity in treatment, saying, "*It wasn't necessarily that they had to be specialists in eating disorders. They … just needed to be human with me…making you feel like you're on more equal ground with them can really make a big difference*". These positive reflections further underscore the value of and the need for dignified ED care.

### Recommendation 3: individualized care

Participants felt that the approach to adult IP ED treatment in Canada was too generalized and ignorant of how social determinants of health (SDOH) influence individual patients' experiences of EDs, recovery, and treatment. In response, our third recommendation is that all processes must be conducted in recognition of the fact that every person is different, and every ED experience is different. Referral processes should be more subjective and holistic; factors beyond just weight and BMI must be considered when evaluating the need for treatment. SDOH and the unique factors that impact a patient's experience of an ED, treatment, and recovery must be considered throughout all treatment processes. Future ED research in Canada should be focused particularly on improving the health outcomes of marginalized populations.

Participants noted a 'one size fits all' approach to treatment taken by programs, and how ineffective it can be. Participant Three summarized this common notion, saying: "*Maybe the … one size fits all treatment isn't actually fitting all*". The ineffectiveness of this approach was even more evident in the experiences of participants who were diverse (i.e., in comparison to other study participants) in culture, gender, or housing. As a Moroccan Jew, Participant Eight reflected on their experience seeking spiritual support while in treatment: *"They told me that they'd connect me to the spiritual care section of the hospital. Every single person who worked in the spiritual care unit was a white Christian lady … [who asked me to] teach her about Judaism."*. Not only did this lack of individualized care leave Participant Eight with insufficient support, but it also left them feeling alone in their experience: *"It just made me feel like eating disorder treatment is only for like, white cisgender Christian women"*. This marginalization left Participant Eight unsupported and with reduced hope for recovery.

Participants who identified as transgender and gender non-binary voiced additional concern for the lack of consideration given to the unique experiences and challenges of gender-diverse populations in IP ED treatment. Participant Eight reflected on their experience, saying: "*Weight gain was really hard for me, because of like gender and stuff … and they were like, you just need to accept your secondary sex characteristics …we're not a gender therapy, we're an eating disorder therapy."*. Participant Eleven expressed similar sentiments: *"Being someone who is … trans non-binary, so much of eating disorder treatment ends up catering to cis-women and I think that, like, there's a huge gap in education"*. These participants felt that gender affirmative care and attention to the roles of gender dysphoria in ED development and recovery were missing from their treatment experience. Instead, therapeutic approaches were largely built on hetero-cisnormativity, addressing topics like body image and societal expectations of femininity which held little significance in their own experiences. The perspectives of Participants Eight and Eleven provide an example of the alienation and marginalization that can arise when individualized care, particularly care that is culturally competent and reflective of one's gender identity, is not prioritized.

Because of the lack of individualization in adult IP ED treatment, housing was another SDOH not considered while in care which caused an issue for Participant Ten. This participant refrained from sharing their experience with housing instability while in treatment due to the outcome of a co-patient: *"They had kicked out someone else … because she had mentioned that she didn't have secure housing, basically … so I wasn't going to be like, 'Hi, I don't have housing either'"*. Concealing this concern created an opportunity for the participant to feel isolated and it reaffirmed the existing power imbalance between healthcare provider and patient.

Contrarily, there were several times when participants felt that their individual needs were considered and met in treatment. For example, when participants' individual medical needs were met while in treatment or when participants could collaborate with a staff member on an individualized therapy plan, daily schedule, or discharge plan, participants felt supported. Participant Two said, "*They were really thorough with the medical testing … that is the way I felt most supported*". Another participant reflected positively on a time when their admission day was moved so that they could spend a religious holiday at home with family. These experiences emphasize the benefit of, and further stress the need for, care that is tailored to the needs of each individual patient.

### Recommendation 4: resources

Many areas for improvement identified by participants can only be remedied with increased resources allotted to Canadian adult IP ED treatment. In consideration of this, our fourth recommendation is to allot sufficient resources (i.e., funding, staff, training, beds, programming) to this form of care to increase accessibility of treatment and improve population health outcomes. Participants' experiences with the lack of interim support, long wait times, disrespectful and untrusting healthcare providers, and generalized treatment approaches all support the need for the implementation of this recommendation.

In addition, there are several participant experiences and excerpts that relate directly to the need for increased resources. Participants recognized that many of their negative experiences with treatment were simply a product of insufficient funding and resources. Participant Eight shared: *"The psychiatric system…for me felt like they weren't there to offer support for my health, they were more there to keep it [away] from people and I know that's like [an] issue with funding"*. Participant One expressed a similar sentiment: "*I think they genuinely do what they can and what their limited funding and resources allow for, but the funding [and] resources aren't adequate*". It was common for participants to share that they felt poorly that many of their reflections on treatment were negative. Participants were sympathetic towards healthcare providers within the treatment programs as they saw first-hand just how stretched the resources were. During Participant Two's follow-up meeting, they clearly stated their feelings towards the fifth recommendation, saying: "*The bottom line is that there needs to be so much more resources for [the implementation of the identified recommendations] to happen*". Participants felt strongly that increased resources must be prioritized.

### Recommendation 5: stigma

Given the negative impact of various levels of stigma (i.e., internalized, societal, institutional) evident in the participants' experiences, our fifth recommendation, alongside implementing the aforementioned recommendations, is to apply the following methods for active stigma reduction. Educational curriculums must be established and/or updated to generate accurate and widely understood depictions of EDs, who experiences them, and how they can be treated. People with lived ED experience must be included at the forefront in the development of policies, guidelines, and practices related to EDs. Finally, referral, transitional, treatment, and hiring processes must better reflect the diversity of populations impacted by EDs.

Stigma played a direct, negative role in participants' experiences of how they felt being referred to IP ED treatment, the way they were perceived and treated by healthcare providers, and the generalized approach to IP ED treatment as discussed in previous sections. As with the fourth recommendation, several participant experiences and excerpts have been identified to further support this recommendation. Participants acknowledged the stigma associated with experiencing an ED at a normal or high weight, and how this stigma impacts one's access to referral and treatment. Participant Six said: *"If I, today, just stayed in this body [as someone who lives] in a relatively thin body…I would be dealing with people going, 'Oh, but you're healthy, what do you mean you're sick?'…That would add a whole other layer to seeking support and also being taken seriously [in treatment]".* Participant Three experienced this stigma first-hand as someone who was admitted to treatment several times at varying weights: "*My weight was fluctuating every admission…[and] how I got treated and their approach to me completely changed".* Many participants already felt guilty about being referred to treatment or 'not sick enough' to deserve treatment, and experiences like that of Participant Three contribute to the stigma that perpetuates these feelings. Stigma also affected the relationships between participants and healthcare providers. Participant One eluded to this stigma, saying: "*I think even eating disorder professionals carry somewhat of a stigma with them [toward patients]".* This stigma likely contributed to the culture of disrespect and distrust that was commonly experienced by participants in treatment.

## Discussion

This study explored perspectives on improving adult IP ED treatment of individuals in Canada with lived experience, identifying recommendations categorized as interim support, dignified treatment, individualized care, resources, and stigma. The discussion will place the study sample, their lived experiences, and the identified recommendations within the context of the existing literature before acknowledging the strengths and limitations of the study, and suggestions for future research.

The demographics of the study sample reflect trends in relevant literature regarding who can typically access ED diagnosis, referral, and treatment. Many adult IP ED treatment programs in Canada only treat AN and BN, and the average onset for these diagnoses is between the ages of 18 and 21 [5, 43, 44]. These data can explain the lack of diversity in diagnoses in this study's sample, as well as the ages of participants being relatively young. Further, people of colour and Indigenous populations experience unique and disproportionate barriers to ED diagnosis, referral, and treatment, hence the lack of racial/ethnic diversity in the study sample [37, 45]. Finally, adult IP ED treatment exists in only seven provinces, therefore; lived experience from programs in Manitoba, Quebec, and Newfoundland was missing from this study.

According to current data, individuals in Canada are waiting up to 2 years to be admitted to treatment which is dangerous considering the high mortality rate of EDs [3, 6, 7]. The inaccessibility of this sort of treatment is largely due to the scarcity of adult IP ED treatment programs in Canada and spots within those programs [5]. These data mirror the experiences of the study sample who waited, on average, six months for admission following referral, during which time, feelings of guilt, shame, and not being 'sick enough' were common. Existing literature suggests that shame is commonly associated with diagnoses of AN and BN, and skewed self-perception of the illness' severity contributes to the challenges associated with seeking and accepting ED treatment [46–48]. More recently, researchers have explored the role that diagnostic criteria for OSFED, particularly for Atypical AN, have in contributing to stigma and the 'not sick enough' mindset described above. Atypical AN is diagnostically the same as AN, however; the weight of individuals with Atypical AN falls within a 'normal' range. Research has suggested that this distinction can facilitate self-stigma among those of all ED experiences and diagnoses and even translates to under-recognition from clinicians [49, 50]. This research challenges the long-standing use of weight and BMI as indicators of ED severity and could aid in alleviating the widespread stigma that impacts the health of individuals with EDs as it did in this particular study.

Lack of interim support contributed most significantly to participants' health decline while awaiting admission to IP ED treatment. According to MacNeil et al. (2016), publicly funded adult outpatient ED treatment programs across Canada typically require patients to have a BMI of 16 kg/m$^2$ [51]. Patients with a lower BMI are referred to IP ED treatment as they require medical stabilization. This leaves patients awaiting admission to IP

ED treatment without interim support, as was the case for the majority of this study's participants. MacNeil et al. (2016) studied an Ontarian woman awaiting IP ED treatment, enrolled her in an outpatient program, and reported increased body weight, increased satisfaction with life, and decreased depressive and anxiety symptoms in the woman [51]. This study suggests that outpatient treatment can benefit those awaiting admission to adult IP ED treatment, despite not meeting outpatient BMI criteria [51]. These findings in addition to the experiences of participants contributed to the establishment of *Recommendation 1: Interim Support*, with accessibility of care being paramount to its implementation.

The culture of distrust and disrespect from healthcare providers noticed by participants could be linked to the pathology of EDs and the techniques employed in IP ED treatment. EDs often develop and/or are sustained in an attempt to gain control over one's life when other elements feel out of control. Having 'control' in the form of an ED can offer a sense of security [52]. In the experiences of the study's participants, this 'control' was taken over entirely by healthcare providers, creating a clear power shift upon entry into treatment, and resulting in feelings of resentment, fear, and frustration among patients. The role of power in healthcare has long been a prominent subject within feminist literature. Take for instance an ethnographic study of an IP ED treatment facility based in the United States in the early 2000s. Employing a feminist lens, Gremillion (2003) critically analyzed the facility's approach to care, noting the impacts of power, control, and surveillance on relationships and patient outcomes. Gremillion (2003) compared healthcare providers to 'parents' within a patient's 'therapeutic family'; the psychologists (usually male) exercising more abrasive power over other staff and patients, and nurses (usually female) taking a more nurturing, though still powerful, approach with patients. The study suggested that the very socio-cultural aspects that contribute to ED development may be reinforced by the gendered and hierarchal power dynamics within the clinical setting [53].

In 2022, a group of scholars produced two papers inviting productive conversations about feminism and the spectrum of EDs. The second paper involved reflection on how feminist theories can practically inform care. In relation to power and control, LaMarre et al. (2022) emphasized the importance of collaborative care and suggested that power-sharing could aid in gaining power equilibrium between healthcare provider and patient, and ultimately contribute to improved patient outcomes [54, 55]. This suggestion is further supported by additional existing literature which suggests that ED patients respond best when healthcare providers are knowledgeable about EDs, respectful of patients' need for autonomy, and collaborative in ways that encourage autonomy, agency, and empowerment of patients [18].

Research exploring perceptions of ED patients suggests that some healthcare providers stigmatize those with EDs as vain, manipulative, non-trustworthy, and challenging to work with [19, 56]. A study from the United Kingdom suggests that patient-centred care with a focus on fostering a culture of hope and respect shows promise in treating those with EDs [57]. In consideration of the importance of collaboration, compassion, autonomy, and empowerment in positive health outcomes and the general experiences of adult IP ED treatment in Canada, *Recommendation 2: Dignified Care* was proposed with an emphasis on integrating collaborative, patient-centred care. .

The Public Health Agency of Canada (2016) considers SDOH (e.g., gender, race, housing, income, religion, culture) to be factors that affect the health of populations [58]. Despite these SDOH and their impact on patients' experiences of EDs and ED treatment, Canadian adult IP ED treatment programs, as per study participants' experiences, typically employ a 'one size fits all' approach. This approach remained unchanged regardless of patients' diverse traits, experiences, and needs. The reason for this approach may be linked to the widely understood and fiercely inaccurate SWAG stereotype, which assumes only skinny, white, affluent girls can develop an ED [37].

The experiences of participants who did not fit the SWAG stereotype further support the linkage between the SWAG stereotype and the 'one size fits all' approach to treatment. For example, Participant Eight was denied the privilege of spiritual support while in treatment due to their identity as a Moroccan Jew despite evidence that suggests spiritual health to be integral and powerful in the success of some patients' ED recovery [59]. Research has found that transgender and gender non-binary populations experience EDs and ED recovery in unique ways; changes to body size and shape facilitate gender dysphoria and increase the complexity of recovery, yet gender was excluded from treatment entirely, creating challenges for Participants Eight and Eleven [60]. Participant Ten, who experienced housing instability while in treatment, felt unsupported due to the stigma that suggests housing instability cannot coexist with maintaining recovery [61]. Feminist scholars generally criticize the medical model of EDs, which considers the illness a biological disorder, and favour instead sociocultural models which argue that EDs are inherently embedded within an individual's social surroundings and cultural environment, and therefore cannot be prevented, diagnosed, or treated effectively without acknowledging such context [62, 63]. In consideration of this, participants identified *Recommendation 3: Individualized Care* in hopes that adult IP ED treatment programs and associated processes can adapt to meet the needs of individuals in Canada requiring care rather than expecting the inverse.

The aforementioned recommendations require increased resources to come to fruition. To reiterate previous sentiments, adult IP ED treatment is not available in all provinces and territories in Canada [5]. Across Canada, hospitals are understaffed, and healthcare providers are overworked, leading to burn-out [64, 65]. Canadian medical students participate in only three to five hours, on average, of ED-specific training and a recent study estimates that health and social costs of ED treatment among youth have increased by at least 21% during the COVID-19 pandemic [66, 67]. Increased resources are required to remedy these shortfalls and implement all recommendations identified in this study, hence the development of *Recommendation 4: Resources*.

The need for increased resources spans beyond just the scope of EDs in the Canadian context; greater resources, particularly funding, are in demand across the country for mental health and substance-use health challenges of all kinds. A 2018 Statistics Canada survey found that, of the 5.3 million Canadians in need of mental health care, nearly half of them felt that their needs were partially or fully unmet due to barriers including lack of access and cost [68]. Despite the rising costs associated with ED treatment since the pandemic; an estimated increase of at least 21% for Canadian youth, funding for ED prevention, treatment, and research still trails behind that allotted to other psychiatric illnesses [67, 69]. For example, where approximately $50.17 per person affected is spent annually on schizophrenia research, only $0.70 per person affected is spent on ED research [70]. These data emphasize the need for increased resources across all psychiatric illnesses, with a particular focus on funding for EDs.

Implementing the above recommendations will aid in addressing the stigma evident in participants' experiences, but more direct action is needed as well. As recommended by Canadian ED publications, further research is required to explore the diverse lived experiences of individuals in Canada with EDs, increase awareness on EDs, and catalyze change [5, 11, 15]. An international study of 24 countries found that 73% of the 512 ED-specialized healthcare providers were white, 89.6% were women, and 84.1% were heterosexual [71]. This fact alone once again reinforces the SWAG stereotype and brings attention to the need for ED treatment and the staff who administer it to reflect the diversity of those requiring care. It is due to the immense impact that stigma has on those with EDs in Canada and their experiences accessing and navigating recovery that *Recommendation 5: Stigma* was identified in this study.

### Strengths, limitations, and suggestions for future research

This study is qualitative in design, specific to adults in Canada, and explores lived experiences from within the last decade, addressing gaps in the existing Canadian literature where studies are often quantitative, youth-focused, or outdated. Additionally, it achieves suggestions put forth by several Canadian publications to include lived experience at the forefront when developing methods for the improvement of Canada's approach to EDs. This research is significant in that it provides detailed recommendations, informed by lived ED treatment experience and supported by existing literature, that have the power to positively impact future generations.

This study is only reflective of the lived experiences of eleven participants who expressed interest in the study, met inclusion criteria, and were selected to participate according to the sampling technique. Countless perspectives are missing from the development of these recommendations and these perspectives must be sought, included, and valued in future studies. In particular, the perspectives of people of colour, Indigenous communities, transgender and gender non-binary populations, men and especially gay men, people with disabilities, people in bigger bodies, older populations, and people with less-commonly treated ED diagnoses must be sought, included, and valued. Ideally, this research should be conducted by researchers identifying with the target population(s).

## Conclusions

This study explored lived experience as a catalyst for improvement to current adult IP ED treatment programs and processes in Canada; an exploration necessitated by the need for increased first-voice perspectives in the existing Canadian literature. Participants reflected on their experiences of referral, transitions, and treatment itself and identified recommendations for the improvement of adult IP ED programs and processes. It was found through working collaboratively with people with lived ED experience that interim support, individualized care, dignified treatment, increased resources, and stigma-reducing strategies must be prioritized and implemented with haste to improve the health outcomes of those in Canada and the overall experience of IP ED patients while also addressing individual and societal levels of stigma contributing to the negative experiences of people with EDs. It is evident that people with lived ED experience have considerable insight into how treatment approaches can be improved, and how stigma can be reduced; therefore, their perspectives and opinions must be esteemed in future research and program/policy development. In particular, the lived ED experience of people not fitting within the SWAG stereotype must be explored to develop an approach to care and stigma reduction that reflects the diversity of those impacted by EDs.

### Abbreviations

| | |
|---|---|
| EDs | Eating disorders |
| ED | Eating disorder |
| IP | Inpatient |
| SWAG | Skinny, white, affluent girls |
| SDOH | Social determinants of health |
| BMI | Body mass index |
| FST | Feminist standpoint theory |
| IPA | Interpretative phenomenological analysis |
| AN | Anorexia nervosa |
| BN | Bulimia nervosa |
| OSFED | Other specified feeding and eating disorder |

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### Author contributions

Miss Armour conceived the study, conducted the data collection and analysis, and wrote the manuscript draft. Dr. Gahagan served as the co-supervisor for Miss Armour's MA Health Promotion thesis, and Dr. Feicht served as a committee member; they provided mentorship, guidance, and supervision for the study, thesis development and defense, and manuscript preparation and revision.

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### Data availability

To maintain confidentiality of participants, the data collected and analyzed for this study are not publicly available.

## Declarations

### Ethics approval and consent to participate

This study was approved by Dalhousie University's Research Ethics Board. The participants were provided written information on the study and all signed informed consent documents prior to their participation. Participants were informed of their ability to terminate their participation at any time. Identifiable information was removed to protect participants.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

### Additional information

Not applicable.

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## Publisher's note