IMPROVING ADULT INPATIENT EATING DISORDER TREATMENT: PERSPECTIVES OF CANADIANS WITH LIVED EXPERIENCE

by

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DEDICATION PAGE

There are more than a few handfuls of people that made this thesis possible (see *Acknowledgements*); all of whom I'd like to dedicate at least a part of this project. Beyond those fantastic people, I'd like to dedicate this thesis to every Canadian living with an eating disorder (shout-out participants!) and every Canadian supporting someone with an eating disorder. I am determined for this study to make positive change in the way eating disorders are understood, prevented, and treated in Canada.

Lastly, I want to dedicate this thesis to the young woman who couldn't imagine a life beyond anorexia. The woman who felt alone in her suffering, betrayed by the healthcare system, and hopeless about her future. In other words, I'd like to dedicate this thesis to myself from four years ago. I guess that doesn't help the stereotype that eating disorders are all about vanity, does it?

I invite you to read my thesis, truly consider the words of my participants, and seek to better understand what eating disorders are all about. Eating disorders are not a choice, they are not a result of vanity, and changes must be made to better support Canadians experiencing these illnesses.

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ABSTRACT

Eating disorders (EDs) are experienced by approximately one million Canadians and represent the greatest mortality rate of all mental illnesses. Despite this, adult inpatient eating disorder (ED) treatment remains unstructured, inaccessible, and inadequate in supporting many Canadians who require care. The purpose of this l study was to determine how the processes associated with adult inpatient ED treatment could be improved to better serve Canadians who require care from the perspectives of those with lived referral and/or participation experience. Eleven participants were interviewed regarding their perspectives, beliefs, and opinions towards referral processes, transitions into and out of treatment, and treatment itself. This study identified several participant-informed recommendations for the improvement of adult inpatient ED treatment in Canada, and the processes associated with it. It is evident, from this research, that current treatment processes must change and people with lived experience have meaningful insight on how this should be done.

LIST OF ABBREVIATIONS USED

AN = Anorexia Nervosa

ARFID = Avoidant Restrictive Food Intake Disorder

BED = Binge Eating Disorder

BMI = Body Mass Index

BN = Bulimia Nervosa

CBT = Cognitive Behavioural Therapy

CGS-M = Canadian Graduate Scholarships – Master's

CHEO = Children's Hospital of Eastern Ontario

CIHR = Canadian Institutes of Health Research

DBT = Dialectical Behavioural Therapy

ED = Eating Disorder

EDs = Eating Disorders

EDNOS = Eating Disorder Otherwise Not Specified

FBT = Family-Based Therapy

IPA = Interpretative Phenomenological Analysis

MCHA = Mental Health Care Act

NIED = National Initiative for Eating Disorders

NPS = Ninety Percent Society

REB = Research Ethics Board

SDOH = Social Determinants of Health

GLOSSARY

In this study, **eating disorders (EDs)** referred to a multitude of psychological illnesses characterized by unhealthy, compulsive eating and/or exercise behaviours which can be harmful both physically and mentally. These disorders include, but are not limited to, anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED), and orthorexia (American Psychiatric Association, 2013; National Eating Disorder Information Centre, 2021). **Inpatient eating disorder (ED) treatment** referred to 24/7 publicly funded, hospital-based psychiatric programming in Canada for adults (i.e., aged 18+) struggling with an ED. **Lived experience**, or people with lived experience, referred to people who have been referred to and/or participated in, a Canadian adult inpatient ED treatment program. **Processes** associated with inpatient ED treatment referred to aspects such as referral procedures, treatment programs, and transition into/out of treatment that may impact one's perception of their lived experience.

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I'd like to acknowledge every single person who shared my recruitment poster, who showed interest in my study, and who voiced their support. I want to recognize the immense gratitude and admiration I hold for my eleven participants. It takes great courage to be vulnerable, to reflect on the worst times of your life, and to use your voice when it has so often been silenced. Thank you for sharing with me, and I promise that your experiences will help to make a positive impact.

I'd like to acknowledge my family and my friends – especially my brother, William, and my parents, Margaret and Jim. You have each taught me how to approach challenges with strength, confidence, and humour. Most importantly, you've taught me to never be ashamed of seeking support. Lastly, I'd like to acknowledge my boyfriend, Logan. The unconditional love you continue to show me disproves everything my ED wants me to believe about myself and your support has made the completion of this project possible.

CHAPTER 1: INTRODUCTION

One of Canada's most deadly groups of mental illnesses does not have nationally recognized inpatient treatment standards (Arcelus et al., 2011; LeBlanc, 2014; Fassino, et al., 2009; Milos et al., 2004; Masson et al., 2007; van Hoeken & Hoek 2020; Walker et al., 2009). EDs, which are psychological illnesses characterized by extremely unhealthy eating behaviours, kill upwards of 10% of people who struggle long-term according to a meta-analysis of 36 studies from various countries (Arcelus et al, 2011). Approximately 3% of Canadians will struggle with an ED during their lifetime, but only an estimated 10% of people will ever receive formal treatment (Galmiche et al., 2019; Langlois et al., 2011; LeBlanc, 2014; Noordenbos et al., 2002). Inpatient treatment for EDs has an attrition rate of up to 51%, meaning that a significant number of patients drop-out of the program before achieving sufficient levels of physical and psychological improvement (Fassino et al., 2009; Masson et al., 2007; Walker et al., 2009). Furthermore, research suggests that EDs have increased significantly in prevalence and severity across the country because of the COVID-19 pandemic (Spettigue et al., 2021). A Canadian study of six paediatric care hospitals found that monthly diagnoses of anorexia nervosa (AN) among youth (ages 9-18) had increased from 24.5 to 40 cases and monthly ED hospitalizations had increased from 7.5 to 20 admissions since the beginning of the pandemic (Agostino et al., 2021). Though EDs can negatively affect Canadians of all ages, treatment is considered to be unstructured, inaccessible, and insufficient for many of those who need it (Canadian Eating Disorders Alliance, 2019; LeBlanc, 2014; Obeid et al., 2020).

1.1 Rationale

The gaps in existing ED-related literature, including lack of qualitative data in the Canadian context, lack of research specific to adult treatment, and disproportionate focus on AN and bulimia nervosa (BN), contributed to the rationale for this specific study. Additionally, the rationale for this study came from several Canadian studies, strategies, and priority-setting documents regarding EDs. Explored further in the literature review, three key recent publications have urged researchers to incorporate lived experience in their studies as a means of improving existing inpatient ED treatment in Canada. These publications include a report presented by the Standing Committee on the Status of Women entitled 'Eating Disorders Among Girls and Women in Canada', the Canadian Eating Disorders Strategy produced by the Canadian Eating Disorders Alliance, and research priorities identified by the Canadian Eating Disorder Priority-Setting Partnership (Canadian Eating Disorders Alliance, 2019; LeBlanc, 2014; Obeid et al., 2020). These documents and their associated recommendations solidified the need for improvement to inpatient ED treatment programs and processes in the Canadian context and further support the importance of exploring the experiences of those who have been referred to such programs. Though these experiences are said to be needed in ED research, very few existing studies have sought to explore these critical perspectives in any capacity (Canadian Eating Disorders Alliance, 2019; LeBlanc, 2014; Obeid et al., 2020).

1.2 Purpose

The purpose of this qualitative thesis study was to explore the experiences and perspectives of people who have been referred to an adult Canadian inpatient ED treatment program to identify participant-informed recommendations for the improvement of the processes associated with such programs.

1.3 Research Questions

This thesis research sought to answer the question: 'From the perspective of those with lived experience, how can referral, transitional, and participation processes for adult inpatient eating disorder treatment programs be improved to better serve Canadians who require care?'. Sub-questions nested under the main research question included:

a. What are the experiences with, and perspectives toward, the processes associated with adult inpatient ED treatment programs of Canadians with lived experience?
b. From the perspectives of Canadians with lived experience, what aspects of the processes associated with adult inpatient ED treatment programs were beneficial in supporting their recovery?
c. From the perspectives of Canadians with lived experience, what aspects of the processes associated with adult inpatient ED treatment programs were not supportive of their recovery?
d. What recommendations do Canadians with lived experience have for the improvement of the processes associated with adult inpatient ED treatment programs?

1.4 Document Format

The layout of this document includes seven chapters (i.e., Introduction, Literature Review, Methodology, Demographics, Results, Recommendations, Conclusion) as opposed to six chapters (i.e., Introduction, Literature Review, Methods, Results, Discussion, Conclusion). *Chapter 4: Demographics* provides the demographic results of the study sample and provides context for the contents of the results chapter. *Chapter 5: Results* presents and discusses the findings of the participant interviews and categorizes the findings as they relate to either referral, transitional, or treatment processes. *Chapter 6: Recommendations* provides the final recommendations for the improvement of Canadian adult inpatient ED treatment programs and processes as informed by participants, researcher interpretations, and current literature.

1.5 Researcher Interest

As a health promotion student of six years (i.e., four years as a Bachelor of Science in Health Promotion student and two years as a Master of Arts in Health Promotion student), I feel strongly about the importance of improving population health outcomes, striving towards health equity, amplifying the voices of marginalized populations, and advocating for change that those affected by an issue wish to see. Since 1986, five core actions have been associated with the discipline of health promotion: build healthy public policy, create supportive environments, strengthen community action, develop personal skills, and reorient health services (World Health Organization, 1986). These actions shape the focus and work of health promotion specialists across Canada, and beyond. Personally, I feel most drawn to strengthening community action, reorienting health services, and building healthy public policy as a health promotion student. With these health promotion values in mind, paired with my passion for ED advocacy, I knew that this research topic was most appropriate for me to explore for my MA thesis.

Beyond my experience as a health promotion student, my interest in this research topic comes from my personal experience with adult inpatient ED treatment in Canada. In 2018, I developed AN while in the second year of my undergraduate degree. Even as a thin, white, young woman with significant privilege, accessing the treatment I needed was a challenging, discouraging, and long process. As a health promotion student, I recognized that barriers to treatment would be even greater for people who did not hold the same privilege as I do. When I entered treatment, after months of waiting for admission, I experienced the positives and negatives associated with treatment itself and identified areas in which I personally felt the experience could be improved to better serve Canadians requiring care. My recovery experience is ongoing and as I have continued this journey, I've gained a passion for supporting others impacted by EDs. This passion has seeped into the jobs I work, the groups I spend time with, and now, the research I conduct. When I decided to embark on achieving a MA Health Promotion degree, I knew that it had to revolve around my passion for supporting people impacted by EDs. Conducting this study is my passion project, and it is only the beginning in my future of ED advocacy as a health promoter.

1.6 Significance of Study

This study is significant in that it bridges key gaps in existing literature, while following recommendations put forth by numerous recent ED-related Canadian publications. Most notably, existing ED-related literature is lacking qualitative data specific to inpatient treatment experiences and perspectives of Canadian adults. This thesis research produces adult-focused, Canadian data regarding the improvement of inpatient ED treatment programs and processes, from the perspective of people with lived experience. This thesis document and its results provide guidelines, priorities, and perspectives for clinicians and policymakers to consider when working towards the active improvement of adult inpatient ED treatment programs and processes across the country. Finally, this study furthers the field of health promotion in that it seeks to reorient health services, build healthy public policy, and strength community action (World Health Organization, 1986).

Chapter 1: Introduction briefly introduced the research topic and discussed the rationale and purpose of the study. The research questions and sub-questions were outlined as well as the document format. I stated my interest as a researcher and discussed the significance of the study. *Chapter 2: Literature Review* provides further detail on the research topic and will summarize the findings of the initial review of the literature.

CHAPTER 2: LITERATURE REVIEW

Chapter 2: Literature Review includes existing research to further describe the research topic and research problem in detail before discussing the three main Canadian documents that rationalize this research. This chapter also analyzes previous research in relation to the research topic and problem, making note of the gaps within the existing literature. Finally, the contributions of the current research are discussed.

2.1 Literature Review Methods

The following literature review was first conducted as part of the thesis proposal in Spring 2022 and has been updated in Winter 2023 to include new literature. Other relevant findings from the literature have been addressed in *Chapter 4: Demographics* and *Chapter 5: Results.* The databases that were used to conduct this literature review were PubMed, CINAHL, and Scopus, each resource available through Dalhousie University's libraries. The keywords employed in the search process included, but were not limited to, eating disorders, anorexia nervosa, bulimia nervosa, binge eating disorder, Canada, prevalence, treatment, cause, guidelines, standards, qualitative, lived experience, and inpatient. The literature was filtered to include only Canadian studies for certain sections of the literature review. In other instances, age filters were applied to streamline literature relevant to child, adolescent, adult populations. A reference database software, Zotero, was used to organize and manage the reviewed literature.

2.2 Research Topic

This thesis research considered the topic of inpatient ED treatment programs in Canada. The topic is defined and described in terms of prevalence, mortality, morbidity, etiology, and treatment in this section to provide basic knowledge before introducing the research problem.

2.2.1 Eating Disorders Defined

The term 'eating disorder' represents a growing number of psychological illnesses involving disturbed eating, feeding, and/or exercise behaviours which negatively affect health (American Psychiatric Association, 2013). Both AN and BN are the most recognized and researched EDs, however; there are several other EDs that are equally as common and harmful (Keski-Rahkonen, 2021). Some of the lesser-known EDs include, but are not limited to, binge-eating disorder (BED), avoidant and restrictive food intake disorder (ARFID), other specified feeding or eating disorder (OSFED), orthorexia, pica, rumination disorder, and unspecified feeding or eating disorder (National Eating Disorder Information Centre, 2021).

2.2.2 Prevalence of Eating Disorders

Eating disorders affect over 7% of the global population and an estimated one million Canadians experience EDs (Galmiche et al., 2019; LeBlanc, 2014). It is important to note that AN is estimated to impact 1% of Canadians, while BN affects more than 3% (Langlois et al., 2011). These numbers are likely underestimates given the stigma regarding mental illness and a lack of timely surveillance data (Santomauro et al., 2021; Smink et al., 2012; Qian et al., 2021). Point prevalence of EDs has increased drastically over the past few decades, with global cases increasing from 3.5% (2000-2006) to 7.8% (2013-2018) over an 18-year period (Galmiche et al., 2019). EDs affect people of all genders, races, and ages, however; they are particularly common among those who identify as a woman, young adults, and athletes (Joy et al., 2016; Langlois et al., 2011; LeBlanc, 2014; McAndrew & Menna, 2018). Women and girls represent about 80% of ED cases in Canada (LeBlanc, 2014). Though EDs are most identified and treated among girls and women, this overrepresentation is highly associated with the societal stigma and existing social and medical systems which consider EDs to be primarily 'women's issues' (Holmes, 2016). Thus, it is likely that estimates for people who do not identify as women are also under-reported and underdiagnosed. The mean age of onset for AN and BN is 18 years of age, therefore; young adults represent a considerable percentage of the population affected by EDs (Volpe et al., 2016). A study conducted in the United States identified ED behaviours and symptoms among 21.2% (male) and 14.5% (female) of a sample of collegiate athletes (Sanford-Martens et al., 2005).

2.2.3 Mortality and Morbidity of Eating Disorders

Having an ED negatively affects an individual's health in many ways and can have significant physical consequences. People who experience EDs often develop comorbidities affecting digestion, cardiac function, and bone density. Osteoporosis and/or low bone density is common among people with EDs (Mehler, 2019; Robinson et al., 2016). Additionally, gastrointestinal symptoms and disorders, such as functional dyspepsia, irritable bowel syndrome, heartburn, nausea, and constipation, are typical among those who experience EDs (Hanel et al., 2021; Santonicola et al., 2019). Furthermore, bradycardia, arrhythmia, and hypotension affect many people with EDs which can increase their risk of congestive heart failure (McCallum et al., 2006; Meczekalski et al., 2013).

Alongside the physical comorbidities of EDs, those who experience an ED are at a high risk of developing additional mental disorders including substance use disorders, anxiety disorders, and suicidal tendencies (Steinhausen et al., 2021). Suicide accounts for almost one quarter of deaths among people with an ED (Fichter & Quadflieg, 2016). Overall, 1 in 10 people die because of their ED (Arcelus et al., 2011; LeBlanc, 2014). Further, EDs represent some of the deadliest of all mental disorders, second only to opioid overdose. Data from 2014 found that AN and BN caused upwards of 1,500 yearly deaths in Canada, though that number is likely higher because EDs are not always identified on death certificates. Failure to include EDs as a cause of death is likely a result of the vast physical co-morbidities associated with EDs (LeBlanc, 2014).

2.2.4 Etiology of Eating Disorders

There is no single cause of an ED; they often result from an accumulation of several contributing factors. Numerous studies have explored the various factors which may impact the development of an ED (Monteleone et al., 2020; Palmisano et al., 2018; Rossi et al., 2021; Watson et al., 2021; Wilksch et al., 2020). Some research suggests that genetics play a role in determining the likelihood of developing an ED (Watson et al., 2021). Other studies have suggested that traumatic experiences can cause people to develop an ED (Palmisano et al., 2018; Rossi et al., 2021).

According to the CIHR Institute of Gender and Health (2018), both sex and gender impact on health outcomes and yet funded research often treat these concepts as interchangeable (Gahagan et al., 2015; Gahagan & Bryson, 2021). It is not surprising, then, that sex and gender are also influential on risk of experiencing an ED, with women and girls in Canada being especially at risk for disordered eating (LeBlanc, 2014). Culbert et al. (2021) explored how biological differences between sexes impacted ED pathology and determined that women were at a greater risk than men for experiencing an

ED. While EDs can occur to anyone, regardless of biological sex, it is essential to recognize the heightened risk present among women and girls (Culbert et al., 2021). Apart from sex-based risk factors, social expectations and norms related to gender also contribute to the development of an ED, including the influence of family expectations, friends and peer group norms, and social media have been researched extensively as contributors to ED development (Monteleone et al., 2020; Wilksch et al., 2020). Although women and girls disproportionately experience disordered eating and EDs, it is necessary to acknowledge the unique challenges that men, boys, transgender people, and people of colours experience when seeking diagnosis and treatment for EDs (Mikhail & Klump, 2020; Sonneville & Lipson, 2018; Thapliyal et al., 2018).

2.2.5 Treatment of Eating Disorders

The treatment of EDs is critical to restoring the mental and physical well-being of those who struggle. In Canada, there are several options for treatment and they each differ in cost and availability across the provinces/territories. Therapeutic approaches to the treatment of EDs include family-based therapy (FBT), enhanced cognitive behavioural therapy, and pharmacology (Canadian Eating Disorders Alliance, 2019). Specialized ED services in Canada are offered through residential facilities, inpatient units, day treatment programs, outpatient programs, intensive outpatient programs, step-down outpatient services, and transitional/supportive housing (Canadian Eating Disorders Alliance, 2019). This thesis focuses specifically on inpatient treatment occurring through inpatient units; publicly funded hospital-based programs that offer 24-hour medical care with a focus on physical stabilization (Canadian Eating Disorders Alliance, 2019).

2.2.6 Health Promotion and Eating Disorders

Several studies have explored the connection between health promotion and EDs. Such studies often consider how health promotion principles may aid in the prevention of EDs. For example, Bullivant et al. (2019) explored the knowledge and beliefs of key stakeholders regarding obesity and EDs, and found that, relative to obesity, EDs were not well understood by stakeholders (e.g., health professionals, teachers, personal trainers). Their findings suggested health promotion programs focusing on sharing protective and risk factors for EDs be implemented to increase knowledge of EDs among these stakeholders (Bullivant et al., 2019). An Australian study explored how assessing the knowledge and beliefs of people who will access a support program for ED support may improve the actual efficacy of such a program (Mond et al., 2010). The study findings suggested that assessing people' mental health literacy and attitudes towards care may be beneficial in tailoring programs that directly target their needs. A recent study, also based in Australia, took a different approach to assessing the connection between health promotion and EDs.

Bristow et al. (2022) conducted an online survey to analyze the impact that anti-obesity campaigns have on people' weight/shape satisfaction, desire to control weight/shape, and desire to engage in unhealthy weight control behaviours. The study found that anti-obesity campaigns could encourage the use of unhealthy weight control behaviours among consumers, and ultimately increase risk of ED development (Bristow et al., 2022). Medvedyuk et al. (2018) explored how such anti-obesity campaigns further stigmatize obesity and place blame on individuals, rather than addressing social determinants of health (SDOH) that may contribute to populations' experiences of obesity. Approaching such campaigns from a health promotion perspective, considerate of SDOH and the importance of population health outcomes, could be more beneficial for those experiencing obesity, those experiencing EDs, and those experiencing both.

Though health promotion research does exist in relation to EDs, it is often focused on primary prevention of EDs and/or increasing mental health literacy as a method for prevention. This study took a novel approach to improving health outcomes for Canadians impacted by EDs by assessing the perspectives people with lived experience have towards adult inpatient ED treatment programs and processes, and considering how these programs and processes can be altered to improve population health experiences and outcomes.

2.3 Research Problem

Inpatient ED treatment in Canada differs substantially across the country in relation to accessibility and type of care provided (Canadian Eating Disorders Alliance, 2019). This section briefly describes how the lack of structure, inaccessibility, and inadequacy of inpatient ED treatment affects its ability to appropriately serve Canadians who require care.

2.3.1 Lack of Structure

Across the country, there is no single, nationally recognized standard for the treatment of EDs (Fassino, et al., 2009; Milos et al., 2004; Masson et al., 2007; van Hoeken & Hoek 2020; Walker et al., 2009). Suggested guidelines for treatment have been created in the recent past, however; they have not been acknowledged with national unity (Couturier et al., 2020). Furthermore, existing recommendations and guidelines that have been published focus on children/adolescents, AN and BN, and were published over a decade ago (Yager et al., 2006). The structure and availability of Canadian inpatient ED treatment care tends to be inconsistent across the country. This inconsistency is discussed further in the *Inaccessibility* section. Some care may be more appropriate for certain cases of EDs but may only be available in certain provinces (Canadian Eating Disorders Alliance, 2019). National standards for practice and treatment of EDs are crucial to ensuring that Canadians are being cared for adequately and appropriately, regardless of where in the country they reside (Canadian Eating Disorders Alliance, 2019; LeBlanc, 2014; Obeid et al., 2020).

2.3.2 Inadequacy

It is important to note that ED treatment has historically, and continually, not been accessed by those experiencing EDs, with few people seeking treatment (Noordenbos et al., 2002). Resistance to treatment is often rooted in the psychopathology of EDs and can be exacerbated by inaccessibility of resources (Halmi, 2013). Additionally, of those who do participate in treatment, around half drop out of inpatient ED treatment, meaning that they voluntarily end treatment prior to reaching expected levels of physical and psychological improvement relevant to their experience of an ED (Fassino et al., 2009; Masson et al., 2007; Walker et al., 2009;). These data suggest a discrepancy between the treatment that people with EDs are being offered, and the treatment that they require. Several North American studies have also found that populations who participated in inpatient ED treatment are likely to continue to meet some or all criteria for an ED decades after their experience in treatment. Nearly 70% of people who have participated in ED treatment still meet diagnostic criteria for an ED after at least ten years (Fichter et al., 2008; Fichter et al., 2017; Quadflieg & Fichter, 2019). With high rates of drop-out from treatment and lasting symptoms of ED following treatment, inpatient ED treatment is often inadequate in supporting the recovery of those with EDs (Fassino et al., 2016; Quadflieg & Fichter, 2019; Roux et al., 2016).

2.3.3 Inaccessibility

Generally, approximately 23% of North Americans with an ED seek treatment (Hart et al., 2011). Unfortunately, only 10% of all people experiencing an ED receive any specialized treatment for their illness, particularly because of stigma and inaccessibility of care (Noordenbos et al., 2002). This inaccessibility is exacerbated in Canada by the lack of available care facilities and treatment programs. Private care (i.e., treatment that is funded solely by the person receiving care) is available in some provinces, however; these services are expensive. Private treatment can incur out-of-pocket costs of thousands of dollars (De Oliveira et al., 2017).

The Northwest Territories, Nunavut, and Yukon possess few treatment options for EDs (Canadian Eating Disorders Alliance, 2019). Treatment in the provinces is concentrated in highly populated urban areas; disadvantaging those who reside in rural areas of Canada (Canadian Eating Disorders Alliance, 2019). Halifax, Nova Scotia (Queen Elizabeth II Inpatient ED Treatment Program) and St. John’s, Newfoundland (Health Sciences Centre ED Inpatient Program) possess the only adult inpatient ED treatment programs in Atlantic Canada, with just seven total spaces for patients. Cost and location of inpatient ED treatment in Canada, among other factors, affect the ability for Canadians to access care, putting those affected by EDs at risk mentally and physically. It is estimated that only 89 inpatient ED treatment beds exist in Canada; inclusive of both adult and youth programs (CBC/Radio Canada, 2022). Considering the number of Canadians requiring care, this number is vastly insufficient.

Adult inpatient ED treatment is inaccessible for many Canadians, however; certain populations are particularly impacted. People in Canada identifying as women and girls are most likely to experience EDs and are also most likely to access treatment (LeBlanc, 2014). Men and boys also experience EDs but are significantly less likely to access treatment (Kinnaird et al., 2019). Trans and non-binary people also face significant challenges in accessing treatment, particularly due to a lack of provider knowledge (Riddle & Safer, 2022). People of colour and Indigenous populations of Canada experience many significant barriers to mental health support due, in part, to institutional and systemic racism (Gajaria et al., 2021). Weight stigma is also present in society and in ED treatment, meaning people in bigger bodies often have difficulty accessing care (Ralph et al., 2022). Systematic barriers to accessing adult inpatient ED treatment programs in Canada (e.g., lack of treatment programs and funding) combined with systemic barriers (e.g., challenges accompanying gender identity and race) exacerbate the need for improved adult inpatient ED treatment in Canada.

2.4 Rationale of Study: Canadian Publications

Considering the noted gaps in existing inpatient ED treatment in Canada, improvements must be made to address the structure, accessibility, and adequacy of care for EDs across the country. This study sought to explore the experiences, perspectives, and opinions that people with lived experience have regarding Canadian adult inpatient ED treatment programs and processes (i.e., referral, transitions into/out of care, treatment itself) and their improvement. This section reviews existing literature and documents that suggest and support the need for increased inclusion of the voices of Canadians with EDs in ED research.

2.4.1 Eating Disorders Among Girls and Women in Canada

In 2014, a report titled 'Eating Disorders Among Girls and Women in Canada' was published by the House of Commons' Standing Committee on the Status of Women. The report provided ED statistics, discussed EDs' contributing factors, considered obstacles to providing and accessing treatment, and identified promising treatment methods. A list of recommendations was also provided in the report. The report was created through collaboration with several Canadian ED organizations, included reference to Canadian data, and included input from several key stakeholders including ED practitioners and caregivers. In total, the report resulted in 25 recommendations for the Canadian Government to act upon. Some recommendations included the need for reduced wait times for inpatient ED treatment, the development of nationally recognized standards of care, and an increased transparency of data on EDs. The report also encouraged the collaboration and inclusion of Canadians living with EDs in the conversation when considering mental health and improvements to mental health care (LeBlanc, 2014).

2.4.2 Canadian Eating Disorder Strategy: 2019-2029

In 2019, the Canadian Eating Disorders Alliance released Canada's first Eating Disorder Strategy, offering information, data, and recommendations in five distinct yet interconnected pillars. These five pillars include Prevention, Public Awareness and Education, Treatment, Caregiver Support, Training, and Research. The strategy was created because of the 2014 report: 'Eating Disorders Among Girls and Women in Canada' and involved collaboration between the Eating Disorders Association of Canada

- Association de Troubles Alimentaires du Canada, the National Eating Disorder Information Centre, the National Initiative for Eating Disorders (NIED), and the Eating Disorders Foundation of Canada. The purpose of the strategy was to improve outcomes for Canadians with EDs by providing stakeholders with guidelines for improvement. Recommendations included increased communication and unity of ED practitioners across the country, enhanced training for service providers, and improved access to treatment programs. Most relevant to this thesis, the strategy recommended the inclusion of people with lived ED experience in the research process to ensure that their priorities regarding treatment are understood and addressed (Canadian Eating Disorders Alliance, 2019).

2.4.3 Canadian Eating Disorder Priority Setting Partnership

In 2020, the Canadian Eating Disorder Priority-Setting Partnership set out to identify the top 10 priorities for ED research from the perspectives of key stakeholders, including women aged 15 years or older who were experiencing AN. Other stakeholders included family members of people with lived ED experience and healthcare providers in the field of EDs. The top research priorities identified by the three stakeholder groups involve addressing the treatment gaps and the lack of surveillance data on EDs in Canada. Research priorities of the participants were identified in a question-based format. The top two research priorities identified by Obeid et al. (2020), both of which are relevant to this proposed research, were:

> What is the short- and long-term efficacy of treatment methods for anorexia nervosa at different ages and which ones are the best?' and 'What are the most helpful and

> least helpful treatment elements as identified by recovered individuals, and what long-term outcomes do they perceive them to help with? (p. 668)

These research priorities suggest that ED stakeholders value the exploration of treatment gaps as perceived by people with lived experience (Obeid et al., 2020).

2.5 Research Problem: Existing Literature

While literature exists in relation to the research topic of EDs, there are few published studies specifically exploring individual Canadian treatment programs, what constitutes success as perceived by participants, and how programs might be improved. Approaching this research topic from a health promotion perspective could be valuable, considering the field's focus on health program development and evaluation (Lederer et al., 2023). This section reviews the existing literature relevant to the research problem of improving ED treatment to better serve Canadians who require care.

In 2020, a retrospective chart review was conducted to determine the outcomes of a British Columbian residential ED treatment program among patients aged 16-24 years (Williams et al., 2020). Most participants had a diagnosis of either AN or BN and spent an average of 81.7 days in residential treatment. The study identified structured eating, therapy, and a multidisciplinary care team to be supportive of positive treatment outcomes through the chart review as well as an interview process (Williams et al., 2020).

A case study from Ontario in 2016 considered an innovative outpatient treatment approach aimed at supporting an individual with severe AN who awaited inpatient treatment. The approach involved engaging a multidisciplinary team in supporting the individual through acceptance and commitment therapy, cognitive remediation therapy, medical monitoring, nutritional counselling, and psychiatric assistance. The approach was found to be successful in restoring weight, improving life satisfaction, and decreasing anxiety and depression (MacNeil et al., 2016).

Recently, a systematic review and meta-analysis was conducted to determine the efficacy of eHealth interventions in treating people with BED (Moghimi et al., 2021). The study found that internet-based cognitive behavioural therapy (CBT) can substantially reduce the number of objective binge episodes an individual with BED experiences. Furthermore, eHealth interventions were found to improve general body satisfaction. These interventions, however; had no effect on the body weight or body mass index (BMI) of participants (Moghimi et al., 2021).

A systematic review was also completed in Quebec to identify promising practices for the treatment of AN. The study considered the efficacy of medication, hospitalization, outpatient programs, and family therapy in treating AN. This review determined that a multidisciplinary team is crucial to positive treatment outcomes and psychological support alongside medical monitoring render best results. The research also identified the need for care to be personalized to the individual, given the uniqueness of each separate experience of an ED. Finally, the study found FBT to have significant success (Thibault et al., 2017).

In 2020, Couturier et al. published a set of suggested Canadian practice guidelines for treating EDs among children and adolescents. These evidence-based guidelines were identified using a systematic review of literature, an analysis of the quality of information in the literature, and consultation with stakeholders including clinicians, parents, and children/adolescents with EDs. Recommendations from the study supported the use FBT, less intensive levels of care, and peer support. Meanwhile, approaches of CBT, adolescent-focused psychotherapy, and adjunctive yoga were not supported by the study's recommendations (Couturier et al., 2020).

2.5.1 Gaps in Literature

Apart from the overarching lack of available research focused on improving existing ED treatment to better serve Canadians who require care, there are several key gaps in the existing relevant literature. Primarily, there exists a persistent focus on AN and BN, though there are various other common EDs that are under-researched (MacNeil et al., 2016; Thibault et al., 2017; Williams et al., 2020). In fact, other EDs, like BED, ARFID and OSFED, warrant particular focus due to the lack of treatment that exists specific to them (National Eating Disorder Information Centre, 2021). In addition, existing literature tends to focus solely on ED treatment for children and adolescents (Couturier et al., 2020; Thibault et al., 2017; Williams et al., 2020). Considering cases of EDs among children/adolescents have risen substantially during the COVID-19 pandemic, focus on these younger populations is necessary (Vyver & Katzman, 2021). However, this focused research excludes a considerable population of adults in Canada who experience EDs.

As well, the existing research regarding the improvement of Canadian ED treatment is largely created using a quantitative approach (MacNeil et al., 2016; Moghimi et al., 2021; Thibault et al., 2017). Though quantitative data can provide statistical evidence to support a hypothesis or answer a question, it excludes the valuable insight that comes from lived experience. The reviewed Canadian recommendations and strategies for ED research encouraged the inclusion of lived experience in studies to guide the improvement of treatment, and qualitative research should be employed to best do so (Canadian Eating Disorders Alliance, 2019; LeBlanc, 2014; Obeid et al., 2020). On a national level, patient-oriented research (POR) has been encouraged in all types of health-related studies by the Canadian Institutes of Health Research (CIHR) (Government of Canada, C. I. of H. R., 2022). Not only does POR have the potential to improve patient and healthcare outcomes, but it also ensures that research being done is important from the perspective of those who are most affected by the topic (i.e., patients and caregivers) (Manafo et al., 2018; Patrick et al., 2018).

Generally, research in relation to the topic of EDs is substantial, but more exploration is required. There is a focus on determining prevalence, mortality, morbidity, etiology, or treatment of disorders, and little insight on improving inpatient treatment processes from the perspective of those who experience EDs. Furthermore, ED research in the Canadian context is not common. When searching the CINAHL database, the geographical breakdown for the search phrase ‘eating disorders or anorexia or bulimia or disordered eating or binge eating disorder’ is: 13,722 articles in the United States, 9,031 articles in Europe, 6,167 articles in the United Kingdom and Ireland, 2,864 articles in Continental Europe and only 382 articles in Canada. Finally, data relevant to EDs are often outdated and no longer accurate or appropriate considering global and national changes to diagnoses, prevalence, and treatment of these disorders.

Chapter 2: Literature Review provided greater detail on the research topic, research problem, and the study’s rationale. Existing literature was discussed and analyzed, with key gaps being identified. Finally, ED research in the context of health promotion was explored. *Chapter 3: Methodology* outlines the study design, methods, procedures, and processes employed to complete this research.

CHAPTER 3: METHODOLOGY

Chapter 3: Methodology describes the philosophical worldview, theoretical framework, and research type and design of the study, as well as outlining the processes employed to collect and analyze data for this study. The ethical considerations of the study are also considered in this chapter.

3.1 Study Design, Methods, and Procedures

3.1.1 Philosophical Worldview

This thesis research employed a transformative philosophical worldview. According to Martens (2009), transformative research aims to facilitate political and social action addressing inequities among marginalized populations. Marginalized populations refer to groups of individuals who are disadvantaged “based on their identities, associations, experiences, and environment” (Hall et al., 1994, p. 25). Further, transformative research involves providing these populations a platform to share their experiences (Martens, 2009). Though uncommonly used in ED research, Janse van Rensburg (2021) advocates for increased use of transformative qualitative research that is driven by the experiences of those who live with an ED. Employing a transformative philosophical worldview in these circumstances can remove the individualized ideology often associated with EDs and lead to improved societal outcomes (Janse van Rensburg, 2021). In the context of this study, a transformative philosophical worldview guided the research in exploring the experiences of participants and seeking to understand how these experiences can be reflected in recommendations. Furthermore, participants were consulted via virtual one-on-one follow-up meetings for feedback on the recommendations that were drafted upon preliminary data analysis. Because this study’s findings reflect the experiences, opinions, and perspectives of Canadians who have lived ED experience and resulted in recommendations to inform structural change, a transformative approach was the most appropriate paradigm to be employed.

This research is transformative in that it rejects the existing ideology that health professionals alone know best when it comes to the treatment of those with EDs and instead, proposes that Canadians with lived experience have valuable insight as to how programs and processes related to inpatient ED treatment should be improved. Including both the expertise of health professionals and the lived experience of those who have been referred to and/or participated in ED treatment may yield the most promising results when it comes to improving current processes associated with treatment. To follow principles of a transformative philosophical worldview in the context of this study, I relied heavily on the perspectives of the participants when interpreting the data and creating the final recommendations. Where possible, existing literature was used to support the participants' perspectives, however; unique perspectives that were not identified in the literature were also included. In doing so, this project identified novel recommendations for the improvement of Canadian adult inpatient ED treatment, using methods that should become standard for future ED research.

3.1.2 Theoretical Framework

Alongside a transformative philosophical worldview, this research used feminist standpoint theory. Feminism as a theoretical framework involves bringing gender to the forefront when conducting research that considers situations, institutions, and systems (Henwood & Pidgeon, 1995). Though historically focussed only on the diverse experiences of women, feminist theory can be applied to all situations existing within our overarching patriarchal society (Beetham & Demetriades, 2007). Patriarchy, defined by Nash (2020) as "a system of relationships, beliefs and values embedded in political, social, and economic systems that structure gender inequality" (p. 43), has had a considerable impact on the ways in which EDs are societally understood in relation to gender. Patriarchal ideologies mould gender-based societal expectations, which can have harmful impacts on societal expectations of who experiences EDs and who deserves treatment (Nash, 2020; Thapliyal et al., 2018). For example, feminine ideals, upheld by patriarchal norms and expectations, are known to contribute to ED prevalence among women (McBride & Kwee, 2020). Women disproportionately experience and receive treatment for EDs, meanwhile people identifying as men, transgender, or non-binary may also develop EDs and experience unique challenges accessing and receiving ED treatment (LeBlanc, 2014; Thapliyal et al., 2018). These inequalities are a result of societal expectations constructed by patriarchy, which affect all gender identities, and they validate the importance of utilizing feminist theoretical frameworks when researching EDs.

Feminist theory addresses inequity, promotes social justice, and considers phenomena that often go unnoticed because of patriarchy (Creswell & Poth, 2018; Henwood & Pidgeon, 1995). Feminist standpoint theory suggests that existing knowledge comes from the perspectives of society's powerful, which is most often patriarchal knowledge used to inform gender-based social expectations. To challenge these perspectives and gain knowledge, we must consult those with lived experience who come from a diversity of backgrounds regardless of gender (Henwood & Pidgeon, 1995). Feminist standpoint theory aligns with this research in that this study sought to understand the experiences of those impacted by EDs; illnesses historically considered a ‘women’s issue’ (Holmes, 2016). Guided by feminist standpoint theory, this research involved a sample diverse in gender who have ED experience to explore ED treatment and consider the impacts of patriarchy while seeking recommendations on how to dismantle such systems. Feminist standpoint theory informed the decision to employ hermeneutic phenomenology as the research design, one-on-one interviews as the method for data collection, and interpretative phenomenological analysis (IPA) as the method for data analysis. The following sections describe these approaches in further detail. Each method (i.e., hermeneutic phenomenology, one-on-one interviews, IPA) involves uncovering the lived experiences that populations have with a phenomenon, and presenting the data in a way that is respectful and truly representative of these perspectives. Combined, these approaches to research resulted in findings that are novel, and that bring forward perspectives on experiences often overshadowed by perspective of those who traditionally hold power (i.e., healthcare professionals, policymakers).

3.1.3 Research Type

This qualitative study used open-ended questions to collect data to understand the lived experiences of Canadians who have been referred to an inpatient ED treatment program. Defined simply by Punch (2013), qualitative research explores phenomena using words as opposed to numbers. In the realm of mental health research, qualitative data collection and analysis can be particularly useful in “involving service users in developing interventions for mental health problems ensuring that the questions asked are meaningful to individuals” (Peters, 2010, p. 35). Qualitative research into mental health issues involves subjective enquiry and can amplify the experiences of participants, while providing evidence to inform significant interventions and approaches to mental health policies, programming, and service provision (Peters, 2010). As identified in the literature review, there exists a considerable gap in qualitative research related to ED treatment in the Canadian context. Considerable quantitative research exists to determine the suggested success of ED treatment programs, but the valuable input from people with lived experience is missing. Collecting qualitative data through this study adds necessary and novel interpretations to the existing body of research on ED treatment. As discussed further in the *Collection Instruments and Site* section, the qualitative method of interviews was used to collect data for this study.

3.1.4 Research Design

Phenomenology is a research design centered in the exploration of lived experience of a phenomenon. Furthermore, phenomenology seeks to understand the meaning that people associate with their experience of a given phenomenon (Teherani et al., 2015). Hermeneutic phenomenology is both an empirical and reflective branch of phenomenology which aims not to completely understand a phenomenon as described by participants, but rather to gain new knowledge and understanding of the phenomenon through exploration of lived experience (McManus Holroyd, 2007). Further, McManus Holroyd acknowledges the relationship between participant and researcher in hermeneutic phenomenology and suggests this connection to be beneficial in a rich interpretation and analysis of data collected using this approach. Unlike transcendental phenomenology, hermeneutic phenomenology does not seek to eliminate the researcher's identity, but instead embraces the researcher's interpretations through rigorous reflection (McManus Holroyd, 2007; Neubauer et al., 2019). Because I have personal experience with referral to a Canadian inpatient ED treatment program (see *Researcher Reflexivity*), hermeneutic phenomenology was appropriate in the context of this study. Rather than abandoning my identity as someone with lived treatment experience, I was able to state my positionality in relation to the research and use it to gain rapport with the participants. This common ground helped to facilitate open, comfortable conversation with participants during interviews. During data analysis, hermeneutic phenomenology allowed for the identification of recommendations that were intended to represent participants' perspectives and experiences rather than recommendations that were primarily reflective of existing literature.

3.2 Participants

3.2.1 Inclusion and Exclusion Criteria

Table 1
Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
• Residing in Canada • Fluent in English • Referred to an inpatient ED treatment program in Canada a) between the years 2012 and 2022, and b) while aged 18 years or older • Not currently participating in an inpatient ED treatment program	• Not residing in Canada • Not fluent in the English language • Never been referred to an inpatient ED treatment program in Canada • Never been referred to an inpatient ED treatment program in Canada while aged 18 years or older • Never been referred to an inpatient ED treatment program in Canada between the years 2012 and 2022 • Participating in an inpatient eating disorder treatment program (at the time of data collection)

Participants were required to reside in Canada because the study sought to explore the perspectives of Canadians specifically. Additionally, participants were required to be fluent in the English language to facilitate adequate communication between myself and participants. This study included participants who were referred to an inpatient ED treatment program in Canada while aged 18 years or older, and between the years 2012 and 2022. Participants were 18 years or older when referred to a Canadian inpatient ED treatment program because this study focused only on adult care and not that of children and youth. Participants were referred to Canadian inpatient ED treatment between the years of 2012 and 2022 to ensure the data collected for the purpose of this study was relatively current. Finally, participants could not be participating in an inpatient eating disorder treatment program at the time of data collection as not to interfere with their treatment.

Several inpatient ED treatment programs in Canada were explored in this study given the diverse geographic location of participants. Inclusion for this study required referral as opposed to participation in a Canadian inpatient ED treatment program due to the inaccessibility (i.e., wait times, lack of programs) and inadequacy (i.e., high dropout rates, prolonged symptoms) of treatment that were discussed in the *Chapter 2: Literature Review*.

3.2.2 Recruitment

Recruitment for the study involved sharing the recruitment poster with various organizations and groups. Only one physical copy was shared, at the Halifax location of Seven Bays Bouldering: a small coffee shop and bouldering gym in the North End of Halifax, Nova Scotia. Staff agreed to post the poster on their bulletin board, and it was removed once recruitment was complete. This location was specifically selected as it is known as a space that welcomed people of diverse gender, sexuality, race, and culture.

Next, I approached the Ninety Percent Society (NPS), a ratified Dalhousie student society that I founded in 2020 which is dedicated to supporting students with EDs. The NPS President at the time of the study agreed to share the recruitment poster with the society's social media community. Additionally, I contacted several eating disorder support non-profit organizations across the country via email requesting that they share my poster. The response was extremely positive, and ten organizations agreed to share the poster. These organizations shared the poster in several ways, including through their websites, newsletters, and emails to clients. I did recognize that my membership/connection with some of these groups could have caused a potential conflict of interest in recruitment for the study. This matter was disclosed and addressed when applying to Dalhousie's Research Ethics Board (REB).

Recruitment occurred through in-person conversations with the staff at Seven Bays Bouldering and the former President of the NPS. Most of the recruitment involved email correspondence with the ED support non-profit organizations listed above.
The recruitment instrument that was shared via social media (i.e., Instagram, Twitter, and Facebook) and in physical poster form can be seen in Appendix A. Participants were compensated up to $20 (i.e., $15 for initial interview, additional $5 for follow-up meeting) in cash for their time commitment to the study. Funding for this compensation came from the CIHR Canadian Graduate Scholarships – Master's (CGS-M) grant that I was awarded for this study.

3.2.3 Selection Methods

This study purposefully sampled participants by employing the maximum variation strategy. Maximum variation or heterogeneous purposeful sampling involves selecting participants with varying backgrounds to produce a sample that is high in diversity of experience (Harsh, 2011; Patton, 2002). In the context of this research, ‘varying backgrounds’ referred to a diverse representation of adult inpatient ED treatment programs across Canada. Employing a maximum variation purposeful sampling technique helped to form a participant sample that was representative of a portion of the myriad of diversity that exists within those who require inpatient ED treatment while increasing the findings’ transferability across Canada. Selecting the study sample in this way cultivated results that were all-encompassing and less focused than results that may have arisen from a homogenous sample. The maximum variation purposeful sampling technique, in this context, drew attention to the differences that exist in experience of a singular phenomenon as a result of one’s geographical location. Finally, this technique aided in making this research transformative, as it resulted in findings that can be applied to adult inpatient ED treatment programs across the country, as opposed to one singular program.

Screening procedures were put in place to employ the maximum variation of recruited individuals. Those interested in participating in the study contacted the primary researcher by email, which was available on the recruitment poster. Through email correspondence, recruited individuals were asked to confirm that they met inclusion/exclusion criteria and to observe the geographical location of where they were referred to adult inpatient ED treatment (*Appendix B*). The information collected during these email correspondences were only used for initial screening purposes. Those who did not meet the inclusion criteria were not invited to be interviewed but were thanked for their interest in the study and sent a list of mental health resources (*Appendix E*).

Participants met all inclusion/exclusion criteria. Furthermore, each participant has varying demographic information and experience of referral to Canadian inpatient ED treatment in relation to the other participants in the sample. As per maximum variation purposeful sampling, some people were not invited to participate because the location of their experience with referral to and/or participation in adult inpatient ED treatment had already been represented. In other words, some were not invited to participate so that the sample was not overpopulated with experiences from one province or program. Those who were selected to participate were informed via email and consulted to determine the date and time of their one-on-one interview with the researcher. Those selected for participation provided written consent via the study's consent form (*Appendix C*). Finally, participants were only selected if they were available for interview in accordance with the study's timelines for data collection. All data (i.e., interviews and follow-up meetings) were collected between August 24th, 2022, and January 31st, 2023.

3.3 Data Collection

3.3.1 Study Setting

This research collected data from participants living in Canada who have been referred to an adult Canadian inpatient ED treatment program. Data collection (i.e., one-on-one initial interviews and follow-up meetings) took place virtually due the researcher's geographical location at the time of data collection. Furthermore, virtual data collection allowed for a sample that included experiences from several Canadian provinces.

3.3.2 Collection Methods and Site

One-on-one, in-depth interviews were conducted as a means to produce context-rich results. Interviews were semi-structured to ensure that participants were able to describe their experiences, perspectives, and beliefs in their preferred manner. Examples of questions include: ‘What was the experience of being referred [to Canadian adult inpatient ED treatment] like for you?’ and ‘If you could have designed the program(s) yourself, are there things about it that you would have changed?’. See *Appendix D* for the full interview guide. Interviews were originally projected to last approximately 60 minutes, however; most interviews lasted approximately 90 minutes. One-on-one, in-depth interviews align with the research design, theoretical framework, and technique for data analysis. Hermeneutic phenomenology requires a particular bond between researcher and participant that can be fostered through this method of data collection (McManus Holroyd, 2007; Neubauer et al., 2019). Feminist standpoint theory involves bringing power to those with lived experience, which is made possible through semi-structured interviews in which participants can help guide the discussion (Henwood & Pidgeon, 1995). Finally, IPA involves a deep exploration on the lived experience of a phenomenon, which can be done through one-on-one in-depth interviews lasting at least 60 minutes each (Reid et al., 2005; Larkin et al., 2006).

Questions within the interview guide (*Appendix D*) were modified on an interview-by-interview basis considering some questions were not relevant to all participants and some questions were answered through previous questions. Though not included in the original interview guide, participants were asked to describe their diagnosis/diagnoses in their own words for demographic purposes. Being a semi-structured interview, some questions emerged during the interviews. These questions involved asking participants to describe a situation with more clarity, to share how a certain situation made them feel, and/or to explain how they dealt with a certain situation. For example, an impromptu question sounded like: ‘I’m sorry to hear that you experienced that. Can you tell me how you felt when that happened? And can you tell me how you feel the situation could have been handled differently?’.

Interviews took place virtually on Microsoft Teams. Audio from the interviews was recorded through Microsoft Teams and using a handheld audio recording device for back-up. Physical notes were also taken to support the verbatim transcripts. Interviews were conducted one-on-one as opposed to in focus groups to avoid triggering participants through peer comparison, a common trait in those with a history of an ED (Hamel et al., 2012).

Because participants were referred to inpatient ED treatment program across Canada and there are no nationally recognized standards for inpatient treatment, interview questions were based upon Canadian recommendations for best practice in inpatient treatment. These recommendations were derived from three specific documents (see *Chapter 2: Literature Review*): The House of Commons’ Standing Committee on the Status of Women: Eating Disorders Among Girls and Women in Canada (LeBlanc, 2014), the Canadian Eating Disorder Strategy: 2019-2029 (Canadian Eating Disorders Alliance, 2019), and the Canadian practice guidelines for the treatment of children and adolescents with eating disorders (Couturier et al., 2020).

As discussed in the *Ethical Considerations* section, participants were consulted via virtual one-on-one follow-up meetings for feedback on draft recommendations that resulted from preliminary data analysis. This method for ensuring that data collection and analysis was genuine, credible, and rigorous was inspired by the member-checking technique. As defined by Creswell and Poth (2018), member-checking involves confirming with each participant that data collected during interviews, and the initial analyses of such data, accurately reflect the participants' experiences, opinions, and perspectives.

Of the eleven participants, eight participants agreed to/had the capacity to connect for a follow-up meeting to review and provide feedback on the preliminary recommendations. Prior to each follow-up meeting, participants were sent a document outlining the preliminary recommendations (*Appendix F*) and were asked to take time to review the recommendations. Follow-up meetings lasted between 20 and 45 minutes. During the meetings, each participant and I went through the recommendations in order, and I asked them how they felt about the recommendation and how they felt it could be changed to better represent their experiences and perspectives on the topic. Participants who engaged in the follow-up meetings were generally satisfied with the preliminary recommendations and they expressed feeling 'heard' and well represented. Participants did provide feedback on the preliminary recommendations which has been implemented in the final recommendations. Feedback on the preliminary recommendations has been outlined in *Chapter 6: Recommendations.* This method of conducting follow-up meetings was extremely valuable to my work in that it encouraged researcher reflexivity and it ensured that the participant perspective was present in the final recommendations. Inviting participants' input for a second time increased the strength and applicability of the findings and recommendations.

3.3.3 Sample Size

On the larger end of traditional phenomenological research sample size recommendations, which is between three and twelve participants, this study consisted of eleven people (Creswell & Creswell, 2018; Creswell & Poth, 2018). The final number of participants was determined through an iterative process. The final sample size was informed by sample sizes traditionally allotted to phenomenological research, as well as sample sizes employed by existing Canadian research on experiences of ED treatment (Creswell & Creswell, 2018; Creswell & Poth, 2018; MacNeil et al., 2016; Moghimi et al., 2021; Williams et al., 2020).

3.4 Data Analysis

3.4.1 Approach: Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA), as introduced by Reid, Flowers, and Larkin (2005), builds upon the traditional phenomenological research design, and relies heavily on the subjective experiences and meanings of participants to come to conclusions. IPA uses inductive reasoning, a bottom-up technique to shape themes upon data collection and consultation of participants (Creswell & Poth, 2018; Reid et al., 2005). This approach to data analysis goes beyond simply describing the experiences of participants as told by them, but rather seeks to grasp a meaningful 'insider's perspective' on a phenomenon (Larkin et al., 2006). Additionally, IPA aligns well with the hermeneutic phenomenological research design in that both approaches do not seek to resolve researcher positionality, but instead acknowledge how the participants' descriptions and experiences will impact the researcher's existing understanding of the phenomenon (McManus Holroyd, 2007; Neubauer et al., 2019; Reid et al., 2005).

I chose to employ IPA as opposed to a different method of data analysis because of the researcher-participant connection and the depth of results that IPA offers. Should I have used, for example, content analysis instead of IPA, I believe that my participants and I would not have benefitted from the genuine connection fostered during interviews through IPA and my results would have been more surface level due to the increased focus that content analysis allots to frequency and quantitative thinking (Bengsston, 2016). Considering my positionality as a researcher, and the purpose of the research, IPA was determined to be the most appropriate and effective method of data analysis.

There are two main aims of IPA; first, to understand and describe the phenomenon as described by the participant and second, to interpret these descriptions from the researcher's unique standpoint while still aligning with the participants' accounts (Larkin et al., 2006). Steps in this type of phenomenological analysis include creation/organization of data, reading of data, development of themes, connection of themes across participant accounts, validation of analysis, identification of final themes, and interpretation (Creswell & Poth, 2018; Reid et al., 2005).

3.4.2 Identification of Themes

In accordance with the aims and processes of IPA, the data were first collected, transcribed, and anonymized. A transcription program called Otter.ai was used to aid in the creation of transcripts for each of the interviews. Each transcript was read and re-read to become familiar with the data, ensure that the transcript matched the recording of the interview, and remove any identifying information. One by one, each transcript was analyzed. Data were categorized (i.e., coded) and recurring topics and recommendations (i.e., themes) were identified. Themes from individual transcripts were synthesized by connecting them to similar themes within the transcript and with transcripts of other participant accounts. The themes identified in this process made up the initial findings and preliminary recommendations. The preliminary recommendations were compiled into a single document (*Appendix F*) and were brought back to willing participants for feedback during virtual one-on-one follow-up meetings.

Recommendations were revisited after conducting follow-up meetings to finalize the recommendations according to feedback provided by participants. Finally, interpretation took place, which involved considering the data provided by participants, consulting the existing literature, and reflecting on my own perspectives as the researcher. Performing a rigorous IPA resulted in the identification of themes and rich descriptions that are reflective of the opinions, perspectives, and meanings that participants have toward their experiences of being referred to Canadian inpatient ED treatment.

3.5 Ethics

3.5.1 Researcher Reflexivity

I identify as a 23-year-old, white, middle-class, cis-gender, heterosexual female with a post-secondary education from Ontario. In 2019, I was admitted to the adult inpatient ED treatment program at the Queen Elizabeth II Hospital in Halifax, Nova Scotia where I received care for AN. As an individual who is an active member in the Nova Scotian ED recovery community and has participated in one of the two adult inpatient treatment programs in Atlantic Canada, it was possible that I would know study participants. Though this did not emerge as an issue during recruitment, this potential conflict of interest was addressed when applying to Dalhousie's REB. For further information regarding my positionality as a researcher, see *Chapter 1: Introduction*, sub-heading *Researcher Interest*.

3.5.2 Ethical Considerations

In June 2022, I submitted an ethics proposal for this study to Dalhousie University's Health Sciences REB, as required by Dalhousie University's School of Health and Human Performance Graduate Student Handbook. I received ethical approval for the study on July 15th, 2022. Ethical considerations regarding participants' privacy and confidentiality were identified in reference to Dalhousie's REB application (School of Health and Human Performance, 2020).

Because of my positionality as a researcher (i.e., lived experience, ED advocacy work), there was a potential that people who were eligible and interested in participating in the study would have a personal connection with me (i.e., friendship, acquaintanceship). This possibility was disclosed in the REB application and strategies were put in place to mitigate any conflict of interest that could arise in such a situation. This possibility did not come to fruition and therefore, did not cause any conflict of interest in the research.

Participants' involvement in the study was only known to me. My co-supervisor, Dr. Debbie Martin, also has access to this information for data retention purposes. We both have an obligation to keep all identifying information confidential. Participants' confidentiality was further protected through data collection, analysis, storage, and retention procedures, which are all outlined in the Consent Form (*Appendix C*). Emotional distress among participants was a potential risk associated with the research due to the sensitivity of the topic being discussed and shared. To mitigate this, participants led the pace of the interview/follow-up meeting, were encouraged to take breaks during the interview/follow-up meeting and were provided a list of mental health resources (*Appendix E*). Two limits to confidentiality were identified in the consent form, however; neither scenario occurred during the study and therefore, there were no limits to confidentiality.

3.6 Quality & Rigour

Quality and rigour were ensured in this qualitative research using several techniques suggested by Creswell and Poth (2018). Researcher positionality and reflexivity were clarified to establish dependability of results from the researcher's perspective. This involved explicitly identifying my positionality as a researcher, which was explained to each participant. Peer review was integrated throughout the entire process of the research to ensure authenticity in the work as understood by the readers. This strategy was employed during the creation of the research proposal; each section underwent peer review from course classmates and co-supervisors. Similarly, the supervisory committee has provided feedback during the creation of the final thesis. Finally, credibility of the research was ensured through virtual one-on-one follow-up meetings with participants which presented an opportunity to receive feedback on draft recommendations.

3.7 Connection to the Field of Health Promotion

This study employed a transformative worldview because of the study's overall aim to change existing processes associated with adult inpatient ED treatment in Canada. Using a transformative worldview in this context supported two objectives of health promotion, which are to reorient health services and build healthy public policy (World Health Organization, 1986). Hermeneutic phenomenology allowed for the voices of a marginalized community (i.e., those with lived ED experience) to be heard and amplified, creating opportunity for empowerment and advocacy. Employing hermeneutic phenomenology addressed another health promotion action, strengthening community action. Feminist standpoint theory as the theoretical framework brought gender and power to the forefront of this study, once again ensuring the phenomenon of adult inpatient ED treatment in Canada was being explored through the lens of people with lived experience.

Pringle et al. (2011) suggested IPA has potential to improve healthcare services by providing a deeper understanding to the patient experience. By using IPA, the results of this study create an opportunity to improve the processes associated with adult ED treatment, as informed by those with lived experience, to better serve Canadians who require care. This not only involves one of the five key health promotion actions (i.e., reorienting health services), but also works to achieving the main mission of health promotion research, which is to improve the health of populations (Crosby et al., 2006; World Health Organization, 1986).

Chapter 3: Methodology outlined the study design, methods, and procedures associated with the study before outlining the processes employed for both data collection and analysis. Finally, ethical considerations and procedures were discussed. *Chapter 4: Demographics* discusses the demographics of the study sample.

CHAPTER 4: DEMOGRAPHICS

Chapter 4: Demographics describes characteristics of the study participants to contextualize the research and results. These demographics are considered as they relate to the study's rationale and theoretical framework and their connection to existing literature.

It should be noted that although the sample consisted of eleven participants, over 60 eligible Canadians reached out with interest in participating in the study. The final sample was chosen as per the sampling and screening procedures outlined in *Chapter 3: Methodology*. Those who reached out represented several age groups and Canadian provinces, reaffirming the fact that anyone can experience an ED. While each person who reached out with interest in participating has had a unique experience and would provide meaningful insight on the improvement of adult inpatient ED treatment programs and processes in Canada, the research design did not accommodate for a sample size that large.

4.1 Results

At the end of each interview, participants were asked several demographic questions to better understand the sample population. Participants were asked to describe their age (i.e., at time of interview), ED diagnosis, gender identity, sexual identity, race/ethnicity, and location (i.e., province) of ED program(s) that they were referred to/participated in. Because this research was qualitative as opposed to quantitative or mixed methods, and to protect the identity of participants, demographic results have been described in general terms. The results of these demographic questions are described below.

Participants ranged in age from 22-37 years of age at the time of interviews. ED diagnoses represented by the sample included AN, BN, and OSFED. Participants within the sample described their gender identity as non-binary, trans masculine non-binary, and [cis-gender] female. The sample included those who described their sexual orientation as queer, heterosexual, bisexual, and asexual. Participants described their ethnicity/race as either Caucasian or Moroccan Jewish. Participants were referred to/participated in programs located in British Columbia, Alberta, Ontario, and Nova Scotia.

4.2 Discussion

Existing literature suggests that young adults are disproportionately affected by EDs, with the average age of AN and BN onset being between 18 and 21 years (Volpe et al., 2016; Ward et al., 2019). The age range of this study's participants (i.e., age 22-37) coincided with the above estimations. It should be noted, however; that societal stereotypes that only young women experience EDs may account for the generally young ages of the sample population. Ward et al. (2019) conducted a simulation modelling study that explored the average age of eating disorder onset (i.e., 18-21 years), and discovered a high prevalence of recurring EDs among older ages.

As discovered in the literature review, the majority of Canadian ED research focuses only on AN and BN (MacNeil et al., 2016; Thibault et al., 2017; Williams et al., 2020). While this study did involve the perspectives of a participant who had experienced OSFED, most participants had experience with either AN or BN. Again, considering most adult inpatient ED treatment programs in Canada only treat AN, BN, and sometimes BED, this characteristic is far from surprising (Canadian Eating Disorders Alliance, 2019).

EDs can be experienced by all genders and sexual identities, although society commonly considers EDs as female health issues (Sonneville & Lipson, 2018). Although no participants identified as cis-gender males, it should be noted that there are considerable barriers which challenge men to seek support, receive a referral, and be admitted to treatment for an ED (Bomben et al., 2022). Existing research also acknowledges the ways in which gender diverse populations (i.e., those who do not identify within the binary of male/female) experience EDs in a unique manner and often struggle to receive referral, and access, to inpatient ED treatment programs (Hartman-Munick et al., 2021). Societal stereotypes also perpetuate a stigma that only straight women experience eating disorders, however; this study sample included participants of diverse sexual and gender identities (Sonneville & Lipson, 2018). This spectrum of gender and sexual identities aided in producing rich, novel perspectives on being referred to, and/or participating in, adult inpatient ED treatment in Canada.

The sample population included little diversity of race and ethnicity, which can likely be attributed to the characteristics of the greater population of people referred to inpatient ED treatment, and the barriers to treatment that disproportionately affect people of color and Indigenous communities (Mikhail & Klump, 2020; Sonneville & Lipson, 2018). While the lived experience of all races and ethnicities being referred to and participating in adult inpatient ED treatment in Canada is necessary, the lived experience of people who are not white/Caucasian is particularly needed to better serve these populations.

Participants of the study had accessed inpatient treatment across Canada. Adult inpatient ED treatment is only offered in British Columbia, Alberta, Manitoba, Ontario, Quebec, Nova Scotia, and Newfoundland; therefore, experiences were missing from only three provinces in this sample (CBC/Radio Canada, 2022). This increases the applicability of the study's results and recommendations, though cannot be said to represent the opinions and perspectives of Canadians across the entire country.

4.3 Implications

As previously mentioned, this study employed the feminist standpoint theory which seeks to consult those with lived experience who are diverse in gender to gain perspective on a phenomenon that is influenced by patriarchy (Henwood & Pidgeon, 1995). Furthermore, the rationale for this research came from the gaps in existing ED treatment literature; lack of timely, qualitative data from Canadian adults with lived experience who represent a variety of ages, gender identities, sexual identities, diagnoses, races, ethnicities, and geographical locations. Although the sample was not as diverse across all these characteristics as was hoped, the results that came from the sample are nonetheless transformative, novel, and diverse in experience.

Chapter 4: Demographics outlined the characteristics of the sample population in terms of age, diagnosis, gender identity, sexual identity, race/ethnicity, and geographical location of treatment. Then, the demographics were discussed in consideration of the theoretical framework, rationale, and overall methodology of the research. The sample population represented a moderately diverse group of Canadians in consideration of the limitations of the study and the existing barriers to accessing treatment for minorities to produce novel results that represent some people being referred to and/or participating in adult inpatient ED treatment in Canada. *Chapter 5: Results* analyzes the data from interviews with participants in relation to their experiences with, and opinions toward, the processes associated with adult inpatient ED treatment in Canada.

CHAPTER 5: RESULTS

During the interviews, participants were asked to describe their experiences relating to the processes associated with referral, transitions, and treatment. Further, they were asked to identify aspects of said processes that they perceived as supportive and unsupportive of their ED recovery. *Chapter 5: Results* discloses the results of the interviews, organized by section, and presents them in consideration of my interpretation as a researcher and of existing related literature. Participant quotes accompany each section to help illustrate the statements made, and in order to protect their identities, participants are numbered one through eleven.

5.1 Referral

First, participants reflected on their experiences with the aspects of, and processes associated with, referral to adult inpatient ED treatment in Canada. People discussed their feelings toward referral and future admission, a common decline of physical and mental health upon referral, the importance of having a social support network, agency, and autonomy, and the detriment of wait times for admission. Participants also brought forward positive and negative approaches to intake procedures and the importance of interim support. A summary of these results can be found in *Appendix G; Table 2a*.

5.1.1 Feelings Toward Referral and Future Admission

Participants described feelings of guilt and ambivalence towards treatment when receiving a referral. Other feelings associated with being referred to inpatient treatment included shame, relief, denial, hope, abandonment, and helplessness. As participant one shared,

> “There was a lot of ambivalence towards… letting go of what I thought had kept me safe and in control for so long. Like, I just never envisioned myself letting go of certain symptoms and being able to manage my life without them and being able to feel these big emotions without numbing them out”.

These feelings are common among people with EDs, particularly shame (Anderson et al., 2022; Blythin et al., 2020). Blythin et al. (2020) conducted a systematic review which identified shame as a key feature of AN and BN. Furthermore, the study discovered a positive relationship between shame and severity of ED symptoms (Blythin et al., 2020). Feelings of shame, guilt, and ambivalence are distressing under any circumstance, but they can be particularly exacerbated because of the stigma that surrounds EDs (Brelet et al., 2021). There is a common societal belief that eating disorders are entirely appearance-based and driven by vanity (Brelet et al., 2021. Those affected by EDs, caregivers and healthcare professionals included, know this to be untrue, however, the stigma persists and fuels feelings of shame and guilt among people with EDs (Brelet et al., 2021; Geerling & Saunders, 2015). Participant two shared their feelings toward referral by 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”.

This participant’s words suggest that shame and guilt around accessing treatment may be further influenced by the lack of healthcare resources in Canada. For the millions of Canadians suffering from an ED, an estimated total of only 89 inpatient ED treatment beds exist across the country (CBC/Radio Canada, 2022). This number, determined by NEDIC in 2019 (i.e., pre-COVID-19 pandemic) does not distinguish between youth versus adult inpatient treatment beds, and does not include the number of beds available in Quebec (CBC/Radio Canada, 2022). This high need, but low availability could perpetuate a resistance to seeking and accepting care when it is needed; a resistance that may only be solved through increased allocation of resources and funding, as well as societal acceptance for diverse body types and acknowledgement of EDs as a public health issue.

5.1.2 Decline of Physical and Mental Health Upon Referral

Every participant described a severe decline in their physical and mental health following their referral and prior to their admission to inpatient treatment. Participant eight said, “I felt like the referral process almost incentivized you to get worse”. Participant three recounted their physical health decline by saying, “I depleted so badly that I ended up having a heart attack and a stroke”. No existing research was found that explores this topic. Based on data collected from participants, it can be theorized that this health decline following referral is due in part to the stigma surrounding accessing treatment, the guilt and shame associated with accepting care, and the destructive nature of EDs.

As previously discussed, EDs are unforgiving, destructive, and deadly illnesses with a high mortality rate and inpatient treatment is a last resort (Madden et al., 2015). People requiring inpatient treatment are medically unstable at the time of referral, and despite this, some participants in this study waited over a year after referral before being admitted to inpatient treatment (Canadian Eating Disorders Alliance, 2019). Participant three stated, “I can honestly say I’ve known people personally who have died on that waitlist”.

Another reason for participants’ health decline after referral and before admission may be a result of a lack in motivation to get better. Participants acknowledged that while recovery from an ED is not simply a choice, committing to the processes of treatment and recovery is necessary to thrive in such processes. As participant five expressed, “Motivation [to recover] is very fleeting”. Participant six made a similar statement, saying “Those moments [of motivation] are really fleeting”. Many participants recounted feeling significant peaks and valleys of motivation during the time between referral and admission, with valleys being especially low and destructive to their physical and mental health.

5.1.3 Agency and Autonomy

Participants appreciated the ability, agency, and power, as an adult (i.e., age 18+), to catalyze a referral to treatment. Furthermore, unless prevented by Provincial Adult Protection Acts, participants appreciated the ability, agency, and power to turn down treatment if they chose to do so. As aforementioned, a need for control or a lack of sense of control can contribute to the development and maintenance of an ED (Froreich et al., 2017).

In inpatient ED treatment, where meals, activity, and daily routine are out of the patient’s control, participants found comfort in knowing that they had some power over their entry and exit of the program. “The beauty about the adult system,” expressed participant one, “is you have that freedom to be like, ‘I have a problem, I need help’, and refer yourself. You don't have to rely on other people to do it for you". Additionally, power and control are two key aspects of empowerment in healthcare (Halvorsen et al., 2020). Research suggests that patient empowerment is correlated with health status and quality of life (Mora et al., 2022).

A Belgian study piloted an approach to inpatient ED treatment in which patients were offered greater personal choice in their participation in the program. The study determined that increasing patients' opportunity to make personal choices regarding their recovery while in inpatient treatment reduced the number of patients who dropped out early on in their inpatient admission (Vandereycken & Vansteenkiste, 2009). This research, again, suggests agency and choice to be positively impactful to patient health outcomes.

5.1.4 Social Support Network

Having strong social support has long been known to be beneficial for populations with mental illness (Chronister et al., 2015). Participants who had support from their family and friends while being referred to treatment, being admitted to treatment, and participating in treatment reflected fondly on such support. Contrary to this, those who did not feel supported by their family and friends struggled in treatment as a result.

Interestingly, many participants were particularly appreciative of their family physicians during referral and during the interim period before admission. Those who had a positive experience with their referring physician/healthcare professional during that time reflected on situations where the referring physician/healthcare professional went above and beyond, like participant seven who said, "My family doctor actually walked me [to inpatient treatment]". Participant five also recounted an instance in which their referring physician/healthcare professional acknowledged their lack of knowledge regarding EDs but vowed to educate themselves and provide adequate care: "[My family physician] came up to me and he said, look like, you're sick, like that's obvious. I don't know much about eating disorders, but I'm gonna learn and I'm going to help you". These findings suggest the importance of having healthcare professionals, particularly family physicians (i.e., practitioners who are most often referring patients to inpatient treatment), who are knowledgeable on EDs, willing to learn about these complex illnesses, and generally concerned for the health of their patients.

Participants who had existing connections with healthcare professionals within an inpatient ED treatment program, whether from personal relationships or previous admissions, tended to access treatment more quickly than those who did not have existing connections or who were accessing a program for the first time. "I got in [to the program]." shared participant six, "my family doctor… had a connection there". While this can be perceived as problematic or unfair, as it was by some participants (e.g. "I just wish it [referral/admission process] had been done in a fair way" (participant ten)), it is also relevant to consider the positive impact that patient advocacy can play in health care, particularly when considering people with EDs and other mental illnesses. The Children's Hospital of Eastern Ontario (CHEO) has implemented a Navigator Program in which patients and their caregivers can be appointed an informed, impartial individual who may help advocate for them and maneuver the healthcare system with them (CHEO, n.d.). Perhaps a similar program would be successful for adults experiencing EDs.

5.1.5 Wait Times

All participants expressed frustration with inpatient program wait lists. Most participants waited approximately six months following referral to be admitted to an inpatient program. Participant five recalled spending, on average, “five to seven months” on wait lists prior to each admission. The longest wait among this study’s sample between referral and admission was 15 months. Participant three stated, “From the time that I did my intake to determine what level of treatment that I needed to my actual admission date was over a year long”.

Wait times for inpatient ED treatment have existed and been detrimental to Canadians’ health for years, however; the COVID-19 pandemic substantially increased the amount of time people wait for admissions (CBC/Radio Canada, 2022; LeBlanc, 2014). Healthcare professionals across the country have experienced unprecedented increases in the wait list for their treatment programs, with some wait lists doubling in size since the beginning of the pandemic. In some cases, individuals may be waiting 18 to 24 months after referral to treatment before being admitted (CBC/Radio Canada, 2022). Considering the mortality rates and comorbidities associated with EDs, lengthy wait times are particularly harmful to the health of people with EDs (Arcelus, 2011; Keski-Rahkonen & Mustelin, 2016). Furthermore, the commonly occurring health decline among people awaiting admission, as noted by participants, is reason to address long wait times.

It is necessary to consider the underlying causes of such long wait times as well. Lack of resources within the healthcare system is an obvious contributor to this issue (see *Feelings Towards Referral and Future Admission*), but could EDs being seen as a women’s health issue exacerbate the wait times further? Women’s health issues have historically, and continuously, been swept under the rug, leading to devastating health outcomes for women. For example, women are often undiagnosed and un/under-treated for cardiac issues despite the fact that cardiovascular disease is the leading cause of death among women and women experience heart attacks at higher rates than men (Woodward, 2019). Endometriosis is another illness often dismissed by healthcare professionals, despite the negative impact that endometriosis can have on women’s health outcomes (Hudson, 2022). These examples, among others, show the disparities that exist when preventing, diagnosing, and treating women and women’s health issues, and suggest that a similar situation could be occurring for EDs.

5.1.6 Intake Procedures

Intake assessments for treatment that were conducted slowly with empathy and compassion positively impacted participants’ experience with referral. Participants appreciated when they had opportunity to ask questions, meet the clinical team, and communicate with them beyond the intake assessment appointment. Those who experienced a compassionate intake assessment felt better equipped to enter treatment and optimistic about their recovery. “Having that human connection definitely made a huge difference”, recounted participant three. Participant two appreciated the compassionate, informative approach that was taken during their intake assessment: “I actually met with … members of the whole multidisciplinary team”. Alternatively, participants felt unsupported in situations where their intake assessment was not conducted in a compassionate manner. Participant six, who experienced an intake that lacked compassion, shared, “I felt like there wasn’t much space for my voice”.

This topic relates to general respectfulness, empathy, and engagement of healthcare providers when interacting with patients. According to participants, collaborative discussions, good bedside manner, and empathy are all necessary to supportive intake procedures. Furthermore, this topic nods to the benefit of reducing power imbalances that often exist between patient and care provider. These traits are key aspects of patient-centred care, which results in positive health outcomes and satisfaction with overall healthcare experience (Fix et al., 2018).

Most participants identified a lack of transparency from treatment programs regarding knowing a timeline for admission/entry to the program. “She said, ‘We’ll call you back’”, remembered participant seven, “and then they never – that was a piss off – they never, ever, ever got back to me”. Participant one also reflected on the lack of communication and transparency from programs, saying, “You just have to kind of sit around and wait for a call. You don’t know how long it’s gonna be. Sometimes they check in, sometimes they don’t”. Some participants had their referral documents lost or misplaced, causing their admission to be delayed. These participants described feeling ‘stuck’ in the referral process.

Participants discussed the benefit of having, and the frustration of not having, a point of contact within the inpatient program following referral and prior to admission. EDs can be a mechanism for people to feel ‘in control’ when other aspects of their life are out of their control (Froreich et al., 2017). Participant three described having “no contact from the referral day to your admission day”, with no one to contact if needed. Participant ten felt similarly, stating “any…point of contact would have been great”. Not having a point of contact when awaiting admission to inpatient ED treatment might exacerbate this sense of lack of control and, in turn, increase severity of ED symptoms.

A few participants described a confidentiality breach caused by program staff during referral; likely a result of a clerical error that had significant repercussions for the patients. Participant seven shared their experience with a confidentiality breach stating, "I said, 'You can't talk to my mother about this because of policy reasons'. And she said, 'I'm willing to break that'. And she called my mom, and she told my mom everything. And I'm like [over 18] years old". Participant eleven had a similar experience. "[The program staff] actually called my family's home … and left a message.", said participant eleven, "And at that point in time, I hadn't had any conversations with my family about my eating disorder". Not only do these instances suggest a gap in existing intake procedures, but it also suggests a situation where patient autonomy is not being considered.

5.1.7 Interim Support

Pre-admission programming (i.e., support groups and treatment programs) was identified as supportive during the transition into inpatient care. This type of programming can also be difficult to manage, though, due to the varying levels of illness among participants pre-admission. Similarly, participants felt supported when they were able to continue receiving care from their outpatient team while awaiting admission to inpatient care. One participant was able to continue working with their private dietician between referral and admission to inpatient care. The dietician took a harm reduction approach, knowing that the patient would struggle with hitting daunting nutrition goals during that transition period. Instead, the dietician encouraged the patient to engage in small, ‘easy’, but powerful practices like drinking water and taking vitamins. Harm reduction is an approach to health promotion that involves employing strategies to reduce the risks associated with engaging in certain behaviours, without demanding abstinence from such behaviours (Hawk et al., 2017). Though often used in the context of those who use drugs, harm reduction also has promising potential among those living with EDs (Bianchi et al., 2021; Puzhko et al., 2022).

Outpatient ED treatment, whether publicly funded or private (e.g., psychiatry, psychology, dietetics), is often unavailable to people awaiting inpatient treatment due to BMI restrictions and concerns regarding cognitive ability to benefit from outpatient care (MacNeil et al., 2016). Participant eight expressed frustration with this restriction saying, “I was not quite healthy enough for outpatient services… and it felt so much easier to get worse and get care through inpatient”. MacNeil et al. (2016) conducted a case study on an individual in Canada with severe AN who was awaiting inpatient ED treatment admission and was ineligible to access outpatient services. The study involved enrolling this individual in an intensive outpatient program normally reserved for people above this person’s BMI. The results of the study were positive, suggesting that, while outpatient treatment is often not offered to people awaiting inpatient admission, it has the potential to be beneficial to this population’s recovery nonetheless (MacNeil et al., 2016). The research conducted by MacNeil et al., (2016) re-affirms the importance of interim support and suggests the potential benefit of outpatient care for people awaiting inpatient treatment in the Canadian context.

Participants who felt that their general practitioner/family physician/referring healthcare professional was not knowledgeable on eating disorders felt unsupported in the referral process. Participant nine shared their frustration by saying, “They always say, you need to be monitored by your family doctor while you’re on the waitlist, but my family doctor doesn’t necessarily know specifics”. Similarly, Participant one said, “Family physicians…aren’t necessarily educated or aware of…what an eating disorder might look like”. Furthermore, participants who did not feel supported by their friends and/or family struggled during the referral process. Some participants expressed feeling ‘abandoned’ by their outpatient care team who could no longer work with them following an inpatient referral. “I was seeing a therapist, dietician, and we were not making progress and they were saying like we can't work with you anymore”, said participant two. As previously mentioned, adults awaiting admission to inpatient ED treatment are often not able to access care on an outpatient basis due to BMI restrictions, cognitive function, or lack of progress being made (MacNeil et al., 2016).

Participant ten expressed frustration when they were not considered for treatment due to their history with substance abuse. “When I saw them, they're like, … ‘We see that you're not like 100% abstinent, so you're gonna have to [be put] back on the bottom of the waitlist and once you're 100% abstinent, we [can] reconsider’”. The program required patients to be 100% abstinent from non-prescription substance use, which the participant was not at the time; however, the participant felt that the non-prescription substance use was under control and the eating disorder was not. This participant’s experience presents another opportunity in which a harm reduction approach could have been used, and could have been beneficial in addressing the patient’s non-prescription substance use and ED simultaneously. Instead, neither were addressed, and both worsened without treatment. This participant’s experience also raises the issue of comorbidities in inpatient ED treatment. Several participants were experiencing other illnesses, mental and physical, that they felt were not acknowledged or properly attended to during referral, transition, and treatment processes. Participant three discussed the interaction between ED treatment and their experience of trauma, saying “What do you expect when you take away…what I use to suppress my trauma?”.

Participants who did not have access to pre-admission support groups felt unsupported during the referral process. Participant two shared, “[They] don’t really have anything to offer you in terms of support in the interim”. Those who were referred during the COVID-19 pandemic were particularly affected by this. Considering the importance of social support during referral processes as identified by participants, the isolation of the pandemic added another layer of difficulty to the interim period. Participants expressed their desire to know more about the program and access support from peers during the interim period.

5.2 Transitions

Next, participants reflected on their experiences with the aspects of, and processes associated with, transitioning into and out of adult inpatient ED treatment in Canada. Participants discussed the impact of experiencing multiple admissions to treatment, the unique culture that exists during the transition periods, and the importance of respect during such times. People also expressed the benefit of a solid orientation when transitioning into care, and the importance of accommodation of needs and autonomy. Finally, discharge planning and follow-up post-treatment were discussed. A summary of these results can be found in *Appendix G; Table 2b.*

5.2.1 Multiple Admissions

Several participants had been in and out of inpatient treatment many times. Some self-identified as ‘revolving door’ patients. “I was a revolving door patient and I have no shame in saying that”, shared Participant three. Those who had been in inpatient ED treatment multiple times noticed a downward trend of support received from the program and staff as time went on. Participant one said, “I found in subsequent admissions, they weren’t as nice about that kind of stuff [(i.e., admitting to ED symptoms)]”. Participant nine even compared returning to treatment with returning to an abusive relationship saying, “It just felt like…an abusive relationship. Like you…need them but they don’t actually help with anything long-term”.

This ‘revolving door’ phenomenon is not uncommon in inpatient ED treatment, in fact, an Italian study that 39.4% of their 170-participant sample had participated in more than one inpatient admission. Furthermore, 36.5% of the sample had required re-hospitalization within 12 months of their previous admission. The study considered participants amongst the 36.5% to be ‘revolving door’ patients (Marzola et al., 2021). Marzola et al. (2021) identified the drive for thinness and poor weight gain while in treatment to be predictors of ‘revolving door’ patients.

5.2.2 Culture and Respect

Participants described the transition into treatment as a ‘culture shock’. The culture of inpatient programs, as fostered by staff, processes, and practices, was described as ‘all or nothing’ by participants. Participants noted this culture as ironic, given that many people with EDs have an ‘all or nothing’ mindset and personality when it comes to disordered eating behaviours and habits.

People felt that a ‘tough love’ approach was employed by inpatient programs/staff, during the transition into inpatient treatment (i.e., during initial entry to the program). Upon reflection, some participants felt that this was what they needed at the time, while others found it to be a harmful approach during that time of transition. “That tough love approach is 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”, said Participant Four. Similarly, participant one said, “I think there’s room for improvement to really meet the patient’s needs rather than being a drill sergeant”.

People mentioned feeling disrespected and belittled during transition periods. Participant three recounted, “I almost felt like when I needed to talk to somebody, it was used against me”. Disrespect and belittlement from program staff were also discussed when participants described experiences with being kicked out of a program prematurely. The perspectives participants had on this culture of adult inpatient ED treatment in Canada suggest a more patient-centred approach could be valuable. A recent study based in the United Kingdom suggested a pathway for treating people with longstanding EDs that is patient-centred and based in a culture of hope and respect (Reay et al., 2022). Such literature reaffirms the value that this study’s participants found in having a nurturing, respectful, and collaborative culture when it comes to adult inpatient ED treatment. Participant six shared, “It [(i.e., the transition)] was quite traumatizing and I think that that fuelled a lot of subsequent admissions”.

5.2.3 Orientation

Participants felt especially supported in their transition into treatment when they were able to gain information on the program itself. This included having a point of contact within the program to ask questions to, receiving a program handbook, touring the facility, and meeting with member of the care team prior to admission. Participants described feeling secure, safe, informed, and more prepared to commit to the treatment program when they felt that they were well-acquainted when transitioning into treatment.

Many participants felt disoriented during the first few days in inpatient treatment. Participant eight said, “I felt a little bit lost”. Some were unaware if they had access to, or where to access, basic hygiene resources like shower and laundry. Participant two shared, “For the first week, I did not have a shower, because I didn't know where the showers were or again, if I was allowed to leave my room, take a shower”. The concept of dignity is discussed later on in terms of how participants found it to be missing in many processes associated with treatment. This lack of orientation mirrors such inhumanity. Participants felt that being disoriented, particularly in their transition into treatment, was belittling, inhumane, and stigmatizing. Some participants described feeling unsafe, afraid, and dirty.

5.2.4 Autonomy and Accommodation of Needs

Many participants expressed lack of agency as being a negative aspect of the transitions into and out of inpatient treatment. Participants felt they were not trusted by care providers during this time. Participants felt that when care providers lacked trust in their patients and administered their power over patients, patients lost motivation for recovery and lost trust in the program. Furthermore, participants felt that care providers, and inpatient treatment programs, lack the ability to self-reflect (i.e., admit to wrongdoing, not knowing, and considering space for improvement). This lack of self-reflection reinforced harmful power imbalances between patient and care provider, and further exacerbated feelings of shame, guilt, and ambivalence. Participant ten, who expanded on this concern, stated,

> “So, they would basically be like…you've been here before.…What are you going to do differently? And … the onus would always be on me to do something differently.… It seems sort of like counterproductive to go back and do the very same thing again, when like, I knew that I needed something different out of it…. I remember feeling frustrated that I couldn’t ask them what they were going to do differently”.

One participant was supported in their transition when the inpatient program was flexible in the patient’s admission date. According to participants’ experiences, patients are usually provided 24-48 hours’ notice when a spot in the program becomes available and should the patient not accept the spot within that timeframe, the spot is given to the next person on the waitlist. This participant was celebrating a religious holiday when they were offered a spot in the program and asked to defer their admission date by a few days to celebrate the holiday at home with family. The program was positively receptive of this request and allowed the patient to enter the program a few days later than originally suggested. Some participants reported living hours away from the inpatient ED treatment program to which they were being admitted. Many described finding such little notice of bed availability stressful and ignorant of ‘real life’ barriers such as transportation and employment. There were many other instances in which participants felt that programs and staff could have been more accommodating, and this participant’s experience shows the positive impact that appropriate accommodations can have.

Having an identity and life beyond mental illness is necessary to maintain recovery and thrive in live post-hospitalization (Conti et al., 2020). Several participants discussed the difficulty associated with planning their lives around an admission (e.g., education, housing, employment, relationships). Participant eight, who felt that admission to treatment was difficult to juggle alongside life's other demands said, "Does nobody with an eating disorder have a job?". Generally, participants did not feel supported by the healthcare system and those who populate it in this transition.

Furthermore, they felt that there was little understanding as to how these aspects of one's life might impact their ED experience and recovery journey. Participants felt that adjusting to treatment, and adjusting to life after treatment, was difficult due to the sole focus on the ED and the lack of focus on how the illness can affect all other aspects of one's life.

5.2.5 Discharge Planning and Follow-Up Post-Treatment

Participants who had the opportunity to plan their meals for the first week post-discharge, with the supervision and assistance of a dietician, felt supported in their transition out of inpatient treatment. This type of planning (i.e., planning for life post-inpatient admission) is referred to as discharge planning. A recent study based in the United Kingdom has determined that lack of discharge planning is perceived by patients and caregivers to be a barrier to continued recovery for those exiting inpatient ED treatment (Bryan et al., 2022).

India's 2017 Mental Health Care Act (MHCA) set in place policies for the treatment of people in India living with mental illness. Sections 98.1, 98.2, and 98.3 require the treating healthcare professional to work with relevant stakeholders (e.g., patient, caregivers) to determine an appropriate approach to treatment following discharge, and to ensure the development of this plan (i.e., to support the follow-through of the identified discharge plan) (Gowda et al., 2019). While there are limitations to the MHCA, its sections support participants' views on the necessity of discharge planning and therefore, warrant further exploration in the Canadian context.

Participants felt largely negative towards the lack of follow-up from inpatient treatment programs when patients are asked to leave or when they self-discharge prematurely. Participant one recalled, "I was left with zero follow-up … if you're not successful, you don't get follow-up at all". People who exit an inpatient treatment program prematurely are still in need of support for their physical and mental well-being, however; participants reported no follow-up in such circumstances. Participant seven shared their eye-opening experience of being discharged without follow-up saying, "He's like, 'Are you going to admit to purging?' [or] whatever because this is like, obviously, you're not taking in any food. I'm like, 'No'. … So, they discharged me at like, I think I was maybe 68 pounds". Considering the amount of people with EDs who require multiple admissions to inpatient treatment, the mortality rates of long-term EDs, and the poor state of health that people are in when participating in inpatient ED treatment, lack of follow-up post-premature discharge presents as inhumane.

5.3 Treatment

Lastly, participants reflected on their experiences with the aspects of, and processes associated with, adult inpatient ED treatment in Canada. Administrative discharge, self-discharging, and turning down treatment were discussed. Participants also addressed their experiences with, and perceptions of, staff, treatment methods, and the physical environment of treatment programs. People expressed their experiences with the lack of acknowledgement for SDOH, and the impact of stigma. The importance of ethical treatment and dignified care was also brought forward. Participants discussed the impact of the COVID-19 pandemic on treatment, innovation of care, and the existence of rapid admissions. A summary of these results can be found in *Appendix G; Table 2c*.

5.3.1 Administrative Discharge

Participants shared reasons for which they had been kicked out of a program, which included: exhibiting ED symptoms, challenging staff/the program, having issues with co-patients, expressing hesitancy towards treatment, struggling with staff/program expectations, losing weight, self-harming, and struggling to juggle other social factors (e.g., education, housing, employment, relationships). Participant nine described a time when they were administratively discharged for sneaking food at night, saying “They found out about it and they’re like, ‘Nope, you’re kicked out’.”. Participant three described a time that they were administratively discharged for unintentionally water loading: “The weight on the scale was so significantly high, because I had so much fluid in me … [that[I got discharged”. Participant one articulated their frustration with administrative discharge by saying,

> “It's often turned on the individual that they didn't try hard enough, you know, they didn't absorb enough when they were in the program. Like, it's not what's wrong with the system, it's what's wrong with the person. I think that really needs to shift and there needs to be a lot of adaptations and modifications made to programs to allow people to be successful because I mean, I don't know about I would hope other people would

> agree with me, but like putting your life on hold that many times. For something that's not guaranteed to work is really distressing”.

A 2007 study based at Homewood Health Centre, a residential (i.e., privately funded) ED treatment centre in Guelph, Ontario, found that 37.6% of the 186-patient sample terminated treatment prematurely. Of that 37.6%, 22.1% self-discharged, while 15.5% were administratively discharged (i.e., kicked out of the program) (Masson et al., 2007). The study stated that patients who engaged in ED behaviours, drug use, or self-harm were subject to administrative discharge. Additionally, patients who were not willing to commit to the program were at risk of administrative discharge (Masson et al., 2007). While it is necessary for adult inpatient ED treatment programs to have rules, participants of this current study felt that rules tended to be harsh, and expectations of abstinence were unrealistic.

5.3.2 Self-Discharging

Participants also shared reasons for which they had self-discharged from a program, which included being unable to put their life (e.g., education, employment, relationships) on hold for treatment, feeling that the program was not adequately treating them, feeling disconnected from life beyond an eating disorder, wanting to approach recovery in a different manner, and struggling to cope with the physical changes that result from inpatient care without sufficient psychological support. Participant seven self-discharged due to a co-patient: “She was stealing stuff from me and we got into an argument and I left after that”. Participant ten, who had discharged themselves from a program, remembered thinking, “Why am I doing this? And also, why are they doing this? Because this is not working if we're all ending up back here again”.

Self-discharging, or premature termination of treatment, is common among people with eating disorders (Dejong et al., 2012). A study based in the United Kingdom explored the patient perspectives behind self-discharging and found that people tended to terminate treatment prematurely due to difficulty managing relationships in and out of treatment, dissatisfaction with their progress in the program, unfulfilled expectations regarding the program, and challenges with constructing and maintaining an identity beyond the ED while in treatment (Vinchenzo et al., 2022). The statements brought forward by participants of this study mirror many of the same findings.

5.3.3 Turning Down Treatment

Participants shared reasons for turning down treatment once a bed became available, which included poor timing or poor accommodation in relation to social factors (e.g., education, employment, relationships, housing), difficulty committing to change, negative previous experience with treatment, unpleasant first encounter with care team at assessment, difficulty accepting lack of autonomy that comes with treatment, and feeling unworthy of care (e.g., 'not sick enough' mentality). Participant eleven, for example, said, "I was … very hesitant to do an inpatient program because I was very … set on … staying in school". Participant four also reflected on their reason for turning down treatment and said, "I just did not feel ready to commit to that level of care".

These findings mirror the results of a Denmark-based study which sought to understand the reasons that women decline ED treatment. The qualitative study, based in the perspective of those with lived experience identified five main themes contributing to turning down ED treatment. The five themes were: loss of self-identity, mistrust/fear, rigid processes associated with treatment, not feeling heard, and disagreement with treatment needs (Andersen et al., 2021).

5.3.4 Staff

Participants expressed profound respect and appreciation for program staff (e.g., nurses, psychologists, dietitians, doctors) who were knowledgeable on, and experienced with EDs and co-occurring illnesses; how to treat them, how to prevent them, and how to interact with them. According to participants, many program staff were knowledgeable and experienced on these topics, however; some were not.

It is important to acknowledge the current staffing shortage crisis occurring Canada-wide. Healthcare professionals across the country are experiencing burnout and not receiving appropriate pay. There are currently insufficient numbers of staff for the overwhelming need (Favaro, 2022). With this in mind, there are several notable concerns with the current educational curriculums for healthcare professionals. For example, medical students in Canada only engage in a total of three to five hours of education on the treatment of EDs (Tse et al., 2022). Considering the complexity and severity of EDs, and the important role that healthcare professionals play in diagnosing EDs, referring people to treatment, and treating those with EDs, three to five hours may not be enough. Participants of this study feel as though they should be receiving quality support from knowledgeable, experienced healthcare professionals before, during, and following inpatient ED treatment 24 hours a day, and 7 days a week. Participant seven expressed their frustration that the weekend staff were less specialized, compassionate, and experienced than the regular weekday staff: “I remember I went to one of them [on the weekend] and they said, ‘Could you talk to the [regular care] team about it on Monday?

And I'm like, I gotta go through the whole weekend with this thing that's in my head that I need help with?!".

Having staff that inappropriately demonstrated their power over patients, refused to trust, belittled, and made inconsiderate comments to patients was perceived as detrimental to participants' recovery and even influenced some participants to self-discharge. There were many instances with program staff that participants described as negative or detrimental to their recovery, like feeling disrespected, (e.g., "You would feel belittled, I found like, everything that came out of my mouth was inaccurate to them" (Participant One)), being made to feel inadequate, untruthful, and incapable, (e.g., "They kind of looked at me like, well you're the crazy one" (Participant Seven)) or receiving inconsiderate comments (e.g., "Oh, I wish I had half of your self-control" (Participant Five)). Most participants had a negative experience in treatment in which they disclosed to a staff member that they were struggling with treatment and this disclosure was met with punishment or shame. Many participants described a lack of empathy, compassion, and trust from program staff as a negative aspect of treatment. Some participants had been told by healthcare professionals in the inpatient treatment setting that their eating disorder was 'chronic'.

While staff who were knowledgeable and experienced on EDs were extremely supportive of participants' recovery, it was those who displayed compassion, respect, and humanity that achieved participants' highest praise. Participant two recalled a time when a staff member showed extreme compassion for the participant's situation, "[She made] me feel like she recognized how horrible it was to deal with symptoms like that".

Participant ten also expressed the importance of caring, genuine, empathetic staff members:

> “It wasn't necessarily that they needed to be like, specialists in eating disorders. They kind of just needed to be human with me, and they couldn't fix the eating disorder stuff. But just like someone being, like, present with you, and like, making you feel like you're on more equal ground with them can really make a big difference.”

Participant one made a similar observation, saying, “I think there’s a lot of power in kind of admitting as a professional in the field and saying … ‘I would love some insight on this’”.

One participant mentioned that having a singular person of colour on staff (i.e., one more than previous times the participant had been in the treatment program) was a step in the right direction and was supportive in the participant’s recovery. Participants noted that most staff were white and not representative of diverse genders. A study representing 24 countries explored ED workforce diversity and found that the majority of the 512 ED-specialized healthcare professionals who completed the study’s survey were white (73%), were women (89.6%), and were heterosexual (84.1%) (Jennings Mathis et al., 2020). These results suggest that the ED workforce is lacking in diversity on all fronts. Participants of this current study felt that a lack of diversity in staff could increase validity of the stereotype that only white women can develop EDs and receive treatment (Sonneville & Lipson, 2018).

5.3.5 Treatment Methods

Participants identified several treatment methods employed by programs that were perceived as supportive to their recovery as well as methods that were perceived as unsupportive to their recovery. These methods have been categorized as either physical or psychological.

5.3.5.1 PHYSICAL TREATMENT.

Medical monitoring is a key aspect of inpatient treatment. In fact, the main goal of this level of care is to physically stabilize patients (Madden et al., 2015). Many people entering inpatient treatment for an ED are at high risk for experiencing several medical complications because of their illness including electrolyte, hematologic, metabolic-biochemical, cardiac, and bone density abnormalities (Mehler et al., 2018). Therefore, it is crucial that patients' physical health is monitored and cared for to the utmost degree. Participants felt extremely supported when considering their physical health while in inpatient treatment. Participant two, for example, shared, "It's such a good medical facility. They were really thorough with the medical testing … that is the way I felt the most supported". Furthermore, participants described feeling particularly supported if health care practitioners took the time to explain, in lay terms, the results of various tests, meaning of the results, and indicators of improvement.

5.3.5.2 PSYCHOLOGICAL TREATMENT.

Existing Canadian literature identifies approaches such as FBT and CBT to be the gold-standard in treating EDs, meanwhile; participants of this study did not identify either as beneficial (Canadian Eating Disorders Alliance, 2019; Couturier et al., 2020; Moghimi et al., 2021; Thibault et al., 2017). Instead, participants found dialectical behavioural therapy (DBT) (e.g., “Lots of DBT, which I personally really found helpful” (Participant Four)) and recreation therapy to be the most impactful therapeutic approaches employed in their experience with inpatient ED treatment. These results support a 2017 study which showed promising results for an approach to ED treatment that combined physical exercise and dietary therapy (Mathisen et al., 2017). Participant Five expressed their appreciation for time in the garden during treatment as a method of recreation therapy, “I think it's really healing to work in the garden …[with] your hands and the earth.”. Participant two felt that the exploration of psychological treatment beyond CBT was necessary, and said:

> “I think that exploring different therapy modalities would be really helpful … [and] incorporating other things besides just the typical CBT [like] bottom-up processing…[to] help people feel safer in their bodies…Like relaxation, meditation - things like that are things that undernourished people can handle”.

Passes (i.e., opportunities to leave hospital grounds unaccompanied by staff), outings (i.e., opportunities to leave hospital grounds with staff supervision), and exposures (i.e., opportunities to safely explore potentially triggering scenarios) were all identified as supportive in participants’ recovery. No research was found regarding the benefit, or detriment, of passes, outings, and exposures (i.e., ‘real life’ scenarios), however; there has been promising new research conducted on the benefit of virtual reality in ED treatment. The study suggests that using virtual reality to simulate an anxiety-provoking situation, in a safe environment, for an individual with an ED has significant clinical value (Riva et al., 2021). One participant shared that they had the opportunity to portion some of their own meals and snacks, with guidance and approval from a specialized, registered dietician, while in treatment. Though this approach was not experienced by others in the sample, this patient found it beneficial to their recovery.

5.3.5.3 ROUTINE.

Participants appreciated having consistency and routine during their time in inpatient treatment such as having scheduled groups, programming, and activities to keep busy. Consistency and routine are key aspects of ED treatment as Participant Three stated, “I think that routine can be really powerful for people”. Many ED treatment programs enforce and encourage ‘regular’ eating patterns (i.e., three meals daily with snack in between) as a means of recovery and relapse prevention (Eshkevari et al., 2022; Gardner & Trueman, 2021) The importance of routine in ED recovery can also be confirmed when considering the impact of COVID-19 on ED risk and symptoms. Rodgers et al. (2020) determined that, alongside difficulty coping with stress and increased exposure to harmful weight control media, change to daily routine because of the pandemic contributed to an elevated ED risk and an increase in ED symptoms during that time.

5.3.5.4 CO-PATIENTS.

Some participants found that having strong relationships with co-patients positively impacted their experience with inpatient treatment. Given that inpatient programs in Canada are small (i.e., there are few patients participating in treatment at one time) and patients are often in treatment for weeks to months at a time, there is opportunity for friendship and peer support. Participants who did have positive relationships with co-patients found them to be extremely supportive of their recovery. Participant one shared, “I think the best source of support was like, turning over to your bedside mate being like, dude, I'm really struggling”. “One of my favourite things about the program was the other patients.” said participant two. Other participants felt the same, acknowledging the uniqueness of having someone to talk to that could genuinely understand and relate to what they were experiencing while in treatment. This understanding is something that is only accessible to people with lived ED experience.

Some participants also had negative experiences with their co-patients, which negatively impacted their experience in inpatient treatment. Negative experiences related to eating disorder symptoms as well as general habits and personalities. For example, participant five described co-patients as a trigger, “Being around a lot of sick people can be very triggering”. This finding mirrors other research which has explored characteristics of EDs and ED recovery and noted that social comparison is prominent and can exacerbate ED symptoms and lead to body dissatisfaction (Saunders et al., 2019). Existing research has considered co-patients as triggers in the inpatient ED treatment setting. While not always the case, co-patients can often foster peer comparison, aid in the development of new ED symptoms, and create opportunity for relapse of past behaviours (Eli, 2014).

5.3.6 Physical Environment

Some participants identified the physical environment to be a negative aspect of treatment. Characteristics of the physical environment that were perceived as negative included the décor, the cleanliness, and the presence of both ED and general psychiatric patients on the unit. In some instances, participants felt that the physical environment facilitated rule-breaking and created an unsafe space. For example, patients could easily access self-harm tools. Participant nine shared, “I was able to heat up utensils and burn myself on the stove". Participant two suggested that the physical environment of the hospital itself can be triggering for some individuals: "My trauma is in this system. Like, the triggers for my trauma are all around me right now".

It is known that people' physical environment significantly impacts their mental well-being. In fact, physical environment in healthcare setting has been found to impact patient outcomes and satisfaction (Sarıköse & Göktepe, 2022). An Australian study explored the aspects of a built environment that would be supportive of mental illness recovery. The findings suggested that the mental health aspects of the built environment should ensure safety of patients, support patient dignity, and aid in dismantling stigma attached to treating people with mental illness (Wilson et al., 2022).

5.3.7 Social Determinants of Health

According to the Public Health Agency of Canada (2016), SDOH are factors that "influence the health of populations" including income, education, culture, and gender, among other factors. It is important to note that some SDOH are modifiable, while others are not. For example, income is dependent on one's job and can therefore, be modified. Race, however, does not change over time and is therefore, non-modifiable. Participants felt that there was a lack of focus in treatment on factors beyond the eating disorder such as employment, housing, education, relationships, and co-occurring illness. Participants found that this lack of attention to SDOH made recovery difficult.

5.3.7.1 RELIGION/CULTURE.

Participant eight experienced extensive issues in treatment due to the program's inability to accommodate for religious and cultural needs. The program's lack of knowledge, skills, and support regarding this patient's religious and cultural needs caused many negative experiences in their experience with treatment. This participant recalled,

> "They were like, trying to convince me that keeping kosher was like another one of my eating disorder rules. But like, it's just cultural. Like, it's a whole community does that, though, like, I don't think it's my eating disorder. And they kept being like, you should challenge that rule".

The demographic make-up of this study's sample, the lack of diversity in the ED treatment workforce, and existing research highlights the specific populations (i.e., white, cis-gender female, thin, affluent, Christian) who access treatment and ED recovery (Sonneville & Lipson, 2018). Participant eight described their experience being an individual who does not identify with the aforementioned categories. They said, "It just made me feel like eating disorder treatment is only for like, white cisgender Christian women". They found the experience to be alienating. Furthermore, this meant that treatment methods were not individually tailored to their needs.

5.3.7.2 GENDER.

Several participants also identified ED treatment's general lack of knowledge, refusal to learn, and general dissent for the treatment of an eating disorder among those not identifying as cis-gender females was adverse in their treatment experience(s). As Participant eleven put it, "Being somebody who is like, 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". Furthermore, in reference to treatment and its ability to acknowledge gender in relation to EDs, Participant eleven shared, "It's honestly tragic how horrible they are at … doing … the bare minimum".

Transgender populations experience EDs in unique ways that are different from the experiences of cis-gender populations. For example, gender dysphoria is a common cause of ED development and maintenance among trans people (Milano et al., 2020). Alongside these complexities, transgender populations disproportionately experience barriers to accessing ED treatment (Hartman-Munick et al., 2021). Such barriers are rooted in the way that, societally, EDs are continuously perceived and treated as 'women's issues' (Holmes, 2016). Participant eight recalled an instance where a therapist within the program was particularly open about their lack of effort towards adequately serving transgender and gender non-binary individuals,

> "When I wasn't able to talk about how gender impacted my eating disorder experience, like I was like, I don't know if I'm ever gonna get better if I can't address this…When I rose the gender thing again, like my therapist told me like, well, if you don't think this program is right for you then drop out".

Acknowledging that transgender populations experience EDs (in different ways than cis-gender women do), and tailoring treatment approaches to be prepared and appropriate for all gender identities and expressions, is crucial to improving adult inpatient ED treatment for all Canadians. On a grander scale, further exploring the role of sex and gender in ED prevention, development, and treatment is necessary to achieving greater health outcomes among diverse populations impacted by eating disorders, according to the CIHR Institute of Gender and Health (2018).

Canadians of all sexes, sexual orientations, gender identities, and gender expressions can be impacted by EDs, but due to women's disproportionate risk for experiencing EDs, treatment has generally been tailored to serve cis-gender women

(Culbert et al., 2021). This leaves out a myriad of other populations who require care, such as men (including gay men), transgender populations, and gender non-binary populations. A recent health promotion initiative titled ‘Wicked Bodies’ provides a toolkit for addressing EDs among lesbian, gay, bisexual, transgender, queer, intersex, asexual, Two-Spirit, and other sexual and gender minority (LGBTQIA2S+) communities (Joy et al., 2023). This toolkit has potential to transform the ways in which EDs among LGBTQIA2S+ communities are understood and treated, and therefore warrants further exploration in the context of adult inpatient ED treatment programs and processes in Canada, especially considering the experiences of the participants of this thesis research. Another Canadian study conducted by White et al. (2022) sought to better understand the treatment experiences of LGBTQIA2S+ communities living with EDs. The study’s participants urged for more trauma and violence-informed care, greater education among staff, and a more diverse staff team in treatment. These findings mirror the recommendations presented in *Chapter 6: Recommendations*.

5.3.7.3 HOUSING.

Participant ten discussed their experience with housing uncertainty following inpatient treatment. They recounted feeling unable to discuss this uncertainty with the program staff out of fear of being kicked out of the program because that had happened to a co-patient. “It's hard to sustain a recovery when there's a lot of like, instability in your life,” they said, “but it doesn't mean that you can't, it just means that maybe you need extra support”. This experience was unsupportive in the participant’s experience in treatment and in stabilizing their housing situation post-treatment. Existing research suggests that homeless populations, particularly young people, are at risk of experiencing mental illness, but are unlikely to access mental health care services (Hughes et al., 2010). These findings bring forward the necessity of addressing housing as a human right and ensuring that people experiencing an ED are supported in securing and maintaining stable housing throughout recovery and beyond.

5.3.8 Stigma, Ethics, and Dignified Care

Some participants engaged in inpatient treatment at a ‘normal’ weight. They described feeling stigmatized by co-patients and staff, resulting in a negative treatment experience. In Canada, most inpatient treatment programs only treat AN and BN, leaving out many EDs including BED (Canadian Eating Disorders Alliance, 2019). This puts those who may not be underweight, but still experiencing the mental and physical toll of an ED, in a very stigmatized position. One participant described feeling alienated by co-patients and a cause of confusion for staff. The program was not designed to support people at a ‘normal’ weight and, therefore; many of the groups and activities were irrelevant to this participant’s experience.

Participant ten shared a story of how they felt coerced into participating in a clinical study being conducted by healthcare professionals within the program. “They were like…we don't know if we can…manage your depression…. and so, if you don't do this treatment…, we're going to have to consider whether you're, you're really committed to your recovery right now.”. Many ethical considerations go into the conduction of qualitative, patient-based research, with participant consent, confidentiality, privacy, and safety at the forefront (Canadian Institutes of Health Research et al., 2022). Coercion is strictly prohibited and should not take place as it negates voluntary participation (Canadian Institutes of Health Research et al., 2022). Conducting research with psychiatric patients also adds a layer of importance to ethical practices (Jain et al., 2017). This participants' experience with coercion brings to light the existence of patriarchy and power imbalance in adult inpatient ED treatment. Healthcare professionals are highly educated, but this should not be a reason for healthcare professionals to hold power over patients for their own gain; in this case to coerce patients into participating in the hospital's research study. Fostering agency and empowerment through patient-centred care and ethical research may have produced a different outcome.

Some people described treatment programs as 'de-humanizing' (e.g., "I generally just felt like an animal". (Participant Nine)) due to past experiences of trauma, being sedated/heavily medicated while in treatment, and being stripped of autonomy. Participant three shared, "I was heavily sedated because of my trauma, that that was the only way that I could actually eat. I can honestly say there's about three admissions that I don't remember". Participants stressed the need for treatment to be trauma informed. Trauma and violence-informed care in the context of mental health care means shifting the culture of treatment to acknowledge the fact that many patients may have had traumatic experiences, and to shift procedures to accommodate for such trauma and implement preventative measures accordingly (Mihelicova et al., 2017). Furthermore, the power imbalances between staff and patients, the sterile physical environment, and the strict rules for behaviour were perceived as degrading. Participants who had a prolonged stay (i.e., months in treatment) described feelings worn down and burnt out by the processes and culture of treatment.

5.3.9 Impacts of the COVID-19 Pandemic

The COVID-19 pandemic had many effects on the healthcare system and the programs and processes associated with inpatient eating disorder treatment in Canada. Some of the effects were perceived negatively by participants including staffing shortages, being monitored by a 'tele-sitter', having reduced passes to leave hospital grounds, having less support groups, and having less visitors. These restrictions, though in some cases necessary based on health precautions at the time, were perceived by some participants as punitive. Participant two stated, "It felt very punitive to me, I felt that I was being punished for having an eating disorder. And it's like, trust me, this is already punishment enough…you don't have to add to it". Given the benefits identified by participants of social support, interaction with life outside of the hospital, and group therapy, the effects of the pandemic on the processes associated with inpatient ED treatment were perceived as harsh.

5.3.10 Innovation

Many participants had multiple inpatient treatment experiences. Some even self-identified as 'revolving door patients'. Many participants who had done inpatient treatment several times felt that the treatment they received had not changed over time, for better or for worse. Participant nine described a conversation they had had with program staff prior to an admission: "[They say] 'What are you going to differently?' and it's like, what is the program going to do differently? Because obviously it's not working for me if I'm here again and again". Some programs had not substantially changed in a decade. Participant ten shared,

> “My mom was in eating disorder treatment. … She had anorexia when she was younger as well, too. But this was in the 60s. And honestly, the treatment that she got then was not too far off the treatment that I got, which intrigued me.”

With no nationally recognized treatment standards for adult inpatient ED programs in Canada, it is difficult to determine if programs have changed their approaches over time, but with several recent recommendation documents, there are certainly sufficient research-based guidelines to build change upon (Canadian Eating Disorders Alliance, 2019; LeBlanc, 2014; Obeid et al., 2020).

5.3.11 Rapid Admissions

Participants in this study had spent varying lengths of time in inpatient treatment. Some had spent as little as a week in treatment, some had spent over 6 months in treatment, and some had turned down treatment when offered a bed. These varying lengths were dependent on several factors, however; it was noted that participants who had attended inpatient treatment in more recent years (i.e., approximately 2015-2022) had shorter stays in treatment than those who attended inpatient treatment between 2002 and approximately 2014. Existing literature regarding the ‘gold standard’ for a length of admission is conflicting considering each patient’s individual needs (Morris et al., 2013; Strik Lievers et al., 2009). No studies were found to confirm the decrease in length of stay over time, however; lived experience from participants suggests this. Based on data collected in this study, it is likely that this is a result of increased need for inpatient treatment and pressure on the healthcare system to accommodate this need. Increased number of people in treatment for a shorter period of time may seem like a positive change, but many participants felt that their ‘short’ stays fueled relapse and subsequent admissions.

Participants who experienced a short, but ‘complete’ (i.e., patient completed the length of stay established by program staff) admission described physical and emotional repercussions associated with what they felt was a ‘rushed’ admission. Participant nine shared, with distress, their physical reaction to a rapid admission, “I think the worst time I gained 17 pounds in 5 days”. Participant one also reflected on the length of admissions and said, “Back then, you know, 13 weeks was a standard admission and now it’s like four weeks … which I think is outrageous”.

Participants felt that such rapid admissions may have been a result of the increasing need for, yet lack of resources allotted to, ED treatment programs in Canada. The demand for inpatient ED treatment in Canada has increased substantially over time, especially in the past three years (CBC/Radio Canada, 2022). Participants hypothesized that ‘rushed’ admissions consisting of rapid weight gain may be an attempt to reduce wait times and increase the number of Canadians being treated. While these outcomes sound positive, participants who experiences rapid admissions felt often felt worse upon discharge and usually required re-admission. Participant three expressed, “In my honest opinion, I would be discharged in a worse, like mentally worse than when I went in”.

Chapter 5: Results showcased the findings of the participant interviews and categorized them as participant experiences, opinions, and perspectives towards either referral, transitions, or treatment. Findings were discussed in terms of my interpretations as the researcher and in terms of how they related to any existing literature. The next chapter provides the recommendations as informed by participants, researcher interpretations, and current literature on ED treatment processes.

CHAPTER 6: RECOMMENDATIONS

Chapter 6: Recommendations presents a list of recommendations aimed at the improvement of processes associated with referral to, and participation in, Canadian adult inpatient eating disorder treatment as informed by those with lived experience. Recommendations are organized by category and are informed by the research findings. There is no significance to the order of the recommendations as they appear in this chapter. As seen in the interview guide (*Appendix D*), participants were asked to explicitly provide recommendations for the improvement of aspects of Referral, Transitions, and Treatment processes. The final recommendations are an accumulation of the suggestions brought forward in interviews, my analyses and interpretations, and feedback from participants during follow-up meetings.

6.1 Revisions

Preliminary recommendations (i.e., a draft version of recommendations) were sent via email to study participants who agreed to participate in a virtual one-on-one follow-up meeting. See *Appendix F* for the document that participants received. Participants were encouraged to review the document prior to their scheduled follow-up meeting. During the follow-up meeting, the lead researcher and the participant engaged in a semi-structured conversation (*Appendix D*) during which the participant provided the researcher feedback on the preliminary recommendations. This feedback has been described in the following paragraph and has been implemented in the remainder of this chapter.

Participant feedback on the preliminary recommendations was overwhelmingly positive. Participant eleven shared, “I feel like everything that was in the document were things that I either thought or felt or voiced my opinions on”. Those who participated in follow-up meetings felt that the recommendations were organized well, were thorough and clear, and made them feel heard. Participants appreciated the chance to share their perspective with the intention of improving adult inpatient ED treatment in Canada.

In terms of constructive feedback, participants suggested combining certain headings to make the recommendations document more concise and organized. For example, ‘*Group Treatment*’ and ‘*Immersive Eating Experience*’ were combined to create ‘*Treatment Methods*’. Participants also felt that it was necessary to prioritize the recommendations, given the number of recommendations and the reality that, though all necessary, some recommendations may take years to be implemented. Priority of recommendations is discussed in the following section of this chapter. Similarly, participants suggested increasing the specificity of some recommendations to increase their likelihood of being adopted and implemented by healthcare professionals, policymakers, and inpatient ED programs across Canada.

Follow-up meetings with participants reinforced the need for recommendations regarding trauma and violence-informed care, patient-centred care, case-by-case harm reduction practices, and increased research and education regarding how marginalized populations experience EDs and ED treatment. Furthermore, the recommendation for peer mentorship was discussed in relation to liability and was therefore reconsidered and altered to be more effective and ethical. All feedback was taken into consideration and guided the revision of the preliminary recommendations and the creation of the final recommendations.

6.2 Priority

While all final recommendations are important, and even necessary, to the improvement of adult inpatient ED treatment in Canada, it is unrealistic to believe that all recommendations can be implemented immediately. Therefore, several recommendations have been identified as top priority due to their achievability (i.e., ability to be implemented quickly and easily) and necessity (i.e., ability to have great positive impact). Compassionate care, inclusive of trauma and violence-informed and patient-centred care, should be prioritized due its achievability and necessity. Implementation of interim support is another recommendation that should be prioritized. Finally, increased resources, particularly government funding, and increased training and hiring of diverse staff, must be allocated to ED treatment. Not only would greater resources increase the number of people accessing ED treatment and recovery, but it would also create an opportunity to improve quality of care for all populations, specifically men (including gay men), transgender and gender non-binary populations, people of colour, Indigenous communities, and people living in bigger bodies. This is necessary to achieve a myriad of other recommendations and is therefore a top priority.

6.3 Positionality

As discussed in *Chapter 3: Methodology*, my positionality as a researcher played a significant role in the ways in which the study was designed, but also the ways in which the recommendations were determined and presented. My identity as a health promoter and someone with lived treatment experience impacted the ways in which I interpreted certain recommendations as necessary. Follow-up meetings and researcher reflexivity were necessary to ensuring that the perspectives of the participants were at the forefront of the research as intended.

6.4 Final Recommendations

6.4.1 Interim Support

Support should be available to people in the interim (i.e., between referral and admission) to prevent patient health deterioration and improve overall wellbeing.

6.4.1.1 COMMUNICATION. Communication between patient, program, and referring physician should be clear, timely, and constructive.

1) Upon the patient's consent, their referring physician and the inpatient program staff should collaboratively carry the bulk of the responsibility during the referral process to alleviate patient stress.
2) Maneuvering referral/admission to an inpatient program – which may be something people do not wholly wish to pursue – can be intimidating and unrealistic. Patients should be kept updated on all progress being made on behalf of the program to support their admission. For example, program staff should follow-up (e.g., bi-weekly) regarding the patient's position on the waitlist with consideration of data provided by referring physician (see *Medical Monitoring*).
3) Programs should practice transparency with patients/caregivers/referring physicians on the referral, intake, and admission processes. Patients deserve to be kept in the loop regarding such processes to make informed decisions regarding their future. For example, patients might prefer a program that practices a 'triaged' admission process as opposed to a 'first come, first served' process, or

vice versa. Being informed can help to preserve patients' autonomy during the referral process.

6.4.1.2 PEER INTERACTION. Peer interaction during the interim can help people feel more confident, prepared, and motivated going into inpatient treatment. Furthermore, peer interaction may help incoming patients feel less ambivalent towards treatment and less alone in their recovery journey.

1) Programs should consider on-boarding program champions (i.e., people who have participated in the program in the past and are in active recovery) who feel confident leading a question-and-answer seminar for incoming patients and caregivers. Program champions should be trained through existing programs offered by non-profit organizations as peer mentors to ensure patient, caregiver, and program champion wellbeing. Having a question-and-answer seminar led by a program champion would remove liability that can arise from peer mentorship during the interim, while also providing people a point of contact for program specific questions. Peer interaction even has the potential to alleviate pressure on healthcare professionals and the inpatient care team.

6.4.1.3 ACCESSIBILITY. Interim supports should be accessible to everyone on the waitlist.

1) Interim support programs and services, such as meal support, psychotherapy, dietetics, medical monitoring, and social support, must be available to incoming patients and, furthermore; must be made accessible in consideration of their lives beyond their ED. Peoples' geographical location and commitments to family, education, and employment must be accommodated when designing interim

support programs that are accessible. For example, sessions should be offered at various times and dates and should be available online, in-person, or over the phone when possible.

6.4.1.4 MEDICAL MONITORING. Medical monitoring should be prioritized between referral and admission.

1) Patients' physical wellbeing should be monitored on a regular basis (e.g., bi-weekly) and assessed by inpatient program staff. Monitoring should be done by the patient's referring physician and sent directly to inpatient program staff for review. Should a patient not have a family physician or healthcare professional who is able to complete medical monitoring, the inpatient program should assist in securing a healthcare professional capable of doing so. Many people end up seeking emergency care due to their condition deteriorating, yet the program's intake staff are not aware of this, and people have no way of contacting them to communicate this. Medical monitoring, paired with thorough communication, could help to prevent emergency hospitalizations and better support patients in the interim.

6.4.2 Individualization

Every person is different, and every ED is experienced differently – referral, transitions, and treatment processes should be conducted in recognition of this.

6.4.2.1 SUBJECTIVE REFERRAL PROCESSES. Referral methods are often rigid and based heavily on physical indicators, however; there are many other factors that contribute to one's suitability for inpatient ED treatment.

1) Referral processes (i.e., referral, assessment, and intake appointments) should be more subjective and holistic in nature. This means considering factors beyond just weight and BMI when evaluating one's need for treatment. Patients know the most about their own body and mind – if they are seeking eating disorder care, they most definitely require it.

6.4.2.2 ONE-ON-ONE SUPPORT. While group treatment has extensive benefits to ED recovery in an inpatient setting, people also appreciate one-on-one support.

1) Programs should implement more one-on-one sessions between patient and staff (e.g., social worker, occupational therapist, psychologist, psychiatrist, recreation therapist) alongside group sessions. One-on-one care allows for more individually accurate treatment overall and provides patients a space to speak freely without the risk of triggering other patients.

6.4.2.3 DIVERSE APPROACHES. Approaches to treatment should be considerate of the diversity within patients and their ED experiences to improve health outcomes.

1) ED treatment should not follow a one-size-fits-all approach. Particularly because cohort sizes in adult Canadian inpatient ED treatment programs are small, programs should work collaboratively with each patient to construct a treatment plan that is appropriate to their specific needs and circumstances.
2) Staff should be flexible with program rules when appropriate for care to be more individualized and for patients to feel more dignified.
3) Where appropriate, care providers should implement harm reduction approaches to treatment, rather than using an 'all or nothing' approach. It is important, though, to not label cases as 'chronic' when employing harm reduction methods.

6.4.2.4 AWARENESS OF SDOH. As indicated in much of the health promotion literature, the SDOH (e.g., age, gender, race, housing, education, income) are factors that "influence the health of populations" and they directly impact on how someone experiences an ED and recovery (Public Health Agency of Canada, 2016).

1) Referral, transitions, and treatment processes should be conducted in ways that acknowledge, appreciate, and respect an individual's SDOH. Further research is needed to explore the ways in which SDOH affect the ways in which different populations experience EDs and ED treatment processes.
    a. For example, someone who is age 60 will experience an ED and ED recovery differently than someone who is age 19, and therefore should be treated in consideration of this.
    b. Similarly, someone who experiences financial difficulties will experience unique challenges to recovery. Such challenges should be considered when collaboratively formulating a treatment plan.
    c. This recommendation also relates to gender, culture, race, and religion. These factors must be considered and respected during referral, transition, and treatment processes.

6.4.2.5 PATIENT-ORIENTED RESEARCH. Future research regarding EDs and the improvement of current prevention, diagnosis, referral, transition, and treatment processes must be patient-oriented and/or inclusive of the voices of those with lived ED experience.

1) Future ED research in Canada should be focused particularly on improving the health outcomes of men (including gay men), transgender and gender non-binary

populations, people of colour, Indigenous communities, those living with disabilities, and those living in bigger bodies through POR and/or with inclusion of those with lived ED experience.

6.4.3 Transition Out of Treatment

People should have the opportunity to leave treatment gradually as not to catalyze preventable subsequent admissions.

6.4.3.1 ADEQUATE TIME IN TREATMENT.

1) Patients should be allotted enough time (i.e., a timeline established collaboratively between patient and care team) in inpatient ED treatment to meet appropriate physical and psychological stability. Patients should feel safe and confident in their ability to recover outside of inpatient ED treatment before being discharged.

6.4.3.2 DISCHARGE PLANNING. Collaborative discharge planning for all patients could support patient empowerment and improve health outcomes following discharge.

1) People who are discharged prematurely (i.e., asked to leave or decided to leave on their own) should still have the opportunity to collaborate with program staff for discharge planning.
2) Post-inpatient programs (i.e., day hospital, outpatient, community-based care) should be offered and encouraged, but not forced, upon patients leaving treatment. Furthermore, these programs must be made accessible to people. For example, three dietician-supervised meals at the hospital on Mondays, Wednesdays, and Fridays at 12pm-1pm are not accessible to people with jobs, dependents, classes to attend, and no method of transportation.

6.4.4 Patient Support

No one should have to navigate the healthcare system or recover from an ED alone.

6.4.4.1 CASE WORKER. A case worker can act as an advocate for the patient, a point of contact within the program, and a guide/navigator.

1) Every patient should be appointed a case worker who is responsible for supporting the patient and their loved ones in the processes associated with referral to, and participation in, inpatient ED treatment.
    a. While all participants are aged 18+, they may not have the cognitive capacity, confidence, or knowledge of the healthcare system and their rights to appropriately advocate for themselves.
    b. Patients often do not have a point of contact within the program prior to, or during, admission. A case worker could be that for a patient and provide them with information on the program and answer questions that they may have.
    c. Many people feel unprepared for treatment when they arrive there – they are unfamiliar with the physical environment and the program rules, and they are unaware of what is expected of them due to a lack of communication. A case worker could ensure that patients are well oriented prior to, and while transitioning into, inpatient care.
    d. To be provided holistic care that is supportive of SDOH, patients must have access to a variety of healthcare professionals/services – particularly social workers, spiritual healthcare professionals, recreation therapists,

nurses, psychiatrists, and psychologists. A case worker could bridge communication between patients and these healthcare professionals.

6.4.5 Treatment Methods

Adult inpatient ED treatment should practice treatment methods that are proven to be effective according to current research in the area, while also incorporating methods said to be supportive by people with lived experience. Furthermore, alternative methods of treatment should be explored and funded.

6.4.5.1 GROUP TREATMENT. Programs should provide patients with a variety of groups daily to facilitate routine, encourage community, and offer distraction.

1) Programs should consider implementing novel, unique, and diverse groups, and types of therapy. This may look like piloting new forms of therapy and allotting time/resources to research on existing therapies that are not currently in the program (e.g., bottom-up processing, recreation therapy, art therapy, DBT, nutrition group, trauma group, relationship group, nutrition group).

6.4.5.2 IMMERSIVE EATING EXPERIENCE. People should leave inpatient treatment with the skills and confidence to continue recovery outside of the clinical setting.

1) When appropriate, patients should have the opportunity to portion out meals/snacks with guidance and support from a dietician. This prepares patients for life outside of hospital when they will have to appropriately portion every single meal/snack on their own.
    a. Patients should be involved in cooking/baking of meals/snacks.
    b. Patients should be exposed to meals/snacks outside the hospital environment (e.g., ordering from coffee shops, restaurants).

6.4.5.3 ALTERNATIVE METHODS FOR RECOVERY. Beyond inpatient treatment, and other clinical forms of care, people should have access to diverse methods for recovery.

1) ED support groups should be available to people at all stages of recovery. Other mental illnesses and addictions have ongoing recovery-focused support groups, yet this sort of programming is not common for those maintaining ED recovery. Such recovery-maintenance support groups can provide an opportunity to speak openly about challenges and triumphs in recovery. Furthermore, they can facilitate accountability through peer interaction.
2) Residential treatment should be publicly funded to improve accessibility and alleviate clinical inpatient treatment.
    a. Furthermore, a publicly funded 'ED halfway house' pilot program could be implemented to determine the success of that type of step-down process.
3) Those with EDs should have more options to recover in their communities. In order to do so, non-profit organizations require increased funding and services provided by private psychologists, dietitians, therapists, personal support workers, and nurses should be covered more holistically by health insurance.
4) Where appropriate, peer mentorship should be encouraged and facilitated. While peer interaction can be triggering for some people, others find peer interaction empowering, comforting, and motivational in ED recovery.

6.4.5.4 PATIENT-CENTRE CARE. Treatment should be operated first and foremost with the purpose of serving the needs of the patient, as identified collaboratively by patient and care provider.

1) Treatment must be trauma informed. It must be conducted in ways that acknowledge patient trauma, support patients living with past trauma, and prevent re-traumatization.

6.4.6 Stagnation

Stagnation, meaning lack of growth, innovation, and development within programs and treatment approaches on a greater scale, should be avoided when it comes to treating illnesses as unique, diverse, and deadly as EDs.

6.4.6.1 PROGRAM EVALUATION. Programs should be evaluated on a regular basis, at least annually. Areas for improvement should be acknowledged and addressed. Regular program evaluation not only has the potential to increase community engagement and improve patient outcomes, but it may also assist in advocating for greater resources and supports for ED treatment programs.

1) Programs should implement a Patient-Family Advisory Board, representative of patients, loved ones, and caregivers, that can advise program revision.

6.4.6.2 STAFF. Program staff should be compassionate, specialized in the treatment of EDs, and representative of the diverse populations impacted by EDs.

1) Hiring should be ongoing to maximize the influx of knowledge and perspectives on the treatment of EDs. Staff hired should be diverse in age, race, and gender. They should be passionate about mental health care, willing to learn, and empathetic, compassionate, and trusting. Finally, staff hired must be specialized in ED treatment to provide patients with the utmost quality of compassionate care.

2) Staff should have funded opportunities to further their learning on EDs, concurrent disorders, and treatment methods. (e.g., conferences, training opportunities (e.g., online & in-person courses/webinars), speaker panels).
    a. Staff must be educated on best practices for all populations affected by EDs, including men, transgender and gender non-binary populations, people of colour, Indigenous communities, those living with disabilities, and those living in bigger bodies.

6.4.6.3 INNOVATIVE TREATMENT METHODS. Over the last decade, substantial research has been published exploring the unique needs of people with EDs. Programs and staff should practice in alignment with new knowledge to best treat all Canadians experiencing EDs.

1) Staff should be educated in the most up-to-date methods for treating EDs and program processes should facilitate this innovation. Education and implementation are particularly needed regarding the treatment of all EDs (i.e., not just AN and BN), treatment of concurrent disorders and experiences (e.g., substance abuse, depression, post-traumatic stress disorder, gender dysphoria), and treatment of those with EDs who do not identify as straight, white, thin, cis-gender young women.
    a. Increased exploration is required to understand the ED experiences of racialized populations, men (including gay men), transgender and non-binary populations, and individuals in bigger bodies in order to effectively prevent, diagnose, and treat EDs among these populations.

6.4.7 Dignified Treatment

Inpatient treatment should not be de-humanizing or feel like a punishment.

6.4.7.1 PHYSICAL ENVIRONMENT. Those in inpatient ED treatment spend weeks to months at a time in the hospital, which means that the physical environment is impactful on their overall experience.

1) Using the resources available, programs should create a physical space for patients that is welcoming, inspiring, and comfortable instead of depressing, sterile, and cold. This might look like fresh paint, artwork, warm lighting, or comfortable blankets and cushions.

6.4.7.2 LIFE BEYOND THE HOSPITAL. Similar to the importance of considering an individual's SDOH is understanding that many people require employment, education, relationships etc. in order to thrive outside of inpatient treatment, even beyond their ED.

1) It should be a priority to maintain all facets of a patient's life while in treatment, in whatever way possible. The program should work with the patients, employers, educators, and loved ones to determine and implement an appropriate treatment plan to allow this.

6.4.7.3 COMPASSION. As indicated by the participants, compassion can go a long way in fostering trust between patient and practitioner, facilitating a positive experience for the patient, and catalyzing a 'successful' inpatient journey.

1) Referral/assessment/intake processes should be conducted with high levels of compassion, empathy, understanding, and support for the patient. This requires the healthcare professional to acknowledge and appreciate a patient's feelings & attitudes (e.g., stress, ambivalence, bravery), use sensitive language & good

‘bedside manner’, offer thorough & clear explanations, show their ‘human side’, and practice collaboration. This type of care follows principles of patient-centered care.

2) Programs and staff must avoid stripping people of their autonomy and independence while in treatment – this may mean altering the patient/practitioner power dynamic, collaborating with the patient, listening to their needs/requests, and encouraging personal decision-making.

6.4.8 Early Intervention

All forms of EDs should be prevented as often as possible with early intervention. Not only would early intervention help to alleviate the clinical treatment system, but it could also help to reduce stigma and prevent severe EDs.

6.4.8.1 SCREENING. Various settings should facilitate ED screening for all populations to support early intervention for EDs.

1) Screening for EDs should take place in elementary, middle, high, and post-secondary school settings. To detect EDs in older populations, screening should take place at annual physician appointments for all ages.

6.4.8.2 COMMUNITY-BASED TREATMENT. Many non-profit organizations exist across Canada to provide ED support, however; they often have limited capacity because they rely on grants and donations.

1) Community-based eating disorder treatment that is low-barrier deserves increased funding. This type of treatment should not require a diagnosis, should have the capacity to treat people of all EDs, ages, races, genders, and incomes.

Community-based treatment should be more plentiful, especially in small towns that are not served by clinical treatment facilities.

6.4.9 Stigma

Stigma surrounding who experiences EDs, who deserves treatment for EDs, and even the stigma surrounding seeking care is harmful to everyone impacted by EDs. Implementing the recommendations in this document may combat existing stigma, as could the following active methods for stigma reduction.

1) Educational curriculums, at all levels of education, should be updated to accurately reflect EDs, who experiences them, and how they can be treated.
2) People with lived ED experience should be included in the development of policies, guidelines, and practices that will directly affect them.
3) Referral, transitional, treatment, and hiring processes should reflect the diversity of populations impacted by EDs.

6.4.10 Resources

Having sufficient resources (i.e., funding, staff, beds, programming) is paramount to increasing accessibility of treatment and ultimately improving health outcomes for those affected by EDs.

1) Greater funding must be allocated to adult inpatient ED treatment to accomplish many of the recommendations. For example, funding can increase the number of people able to access treatment at one time and can be used to increase size, diversity, and impact of staff team.

2) Patients, caregivers, and staff should be encouraged and supported in advocating to relevant policymakers for increases to resources allocated to ED treatment in Canada.
3) Advocacy has the potential to kick start change, foster empowerment, and reduce stigma.

Chapter 6: Recommendations described, in detail, the list of recommendations as informed by findings from *Chapter 4: Demographics*, interpretations and analyses from *Chapter 5: Results*, and participant perspectives and feedback collected during interviews and follow-up meetings. *Chapter 7: Conclusion* reflects on the study in its entirety, and discusses the next steps in terms of dissemination, application, and further research.

CHAPTER 7: CONCLUSION

Chapter 7: Conclusion considers this research in terms of its significance and contributions to the field of health promotion. The limitations and strengths of the study are also disclosed, as well as plans for dissemination of results.

7.1 Significance of Study

This research is significant in that it addresses several gaps in existing literature relating to inpatient ED treatment. As discovered in *Chapter 2: Literature Review*, existing research lacks the perspectives of those with lived experience that comes with qualitative data collection. Furthermore, much of the current literature is not relevant in the Canadian context, is focused specifically on youth, and is not up to date. This study helps address knowledge gaps in that it is specific to adults, it is based in Canada, it is qualitative, and it is reflective of experiences within the last decade.

Apart from addressing gaps in existing literature, the findings of this study are significant; some findings support existing literature, while others bring attention to topics not yet highlighted in current research. For example, the benefits of social support, autonomy and agency, discharge planning, and treatment methods like DBT and recreation therapy have been explored in the past and are further supported by the perspectives of this study's participants (Bryan et al., 2022; Chronister et al., 2015; Conti et al., 2020; Mathisen et al., 2017). Meanwhile, topics such as the decline of people' health upon referral to inpatient treatment, the need for strong interim support and communication, the value of accommodating and considering people's needs beyond their ED in treatment (e.g., employment, race, gender, relationships), and the negative impact of rapid admissions have not yet been explored in existing research. These new discoveries, and the participant support of existing research findings, make this study significant.

Finally, this research is significant in that it positively impacts several populations. It provides a space for participants to share their story and an opportunity for others with inpatient ED experience to find community and validity. It gives the public a chance to dispose of existing stereotypes and grow in their understanding of what life with an ED looks like. Furthermore, this research provides healthcare professionals and policymakers with guidelines for the improvement of adult inpatient ED treatment to better serve Canadians who require care.

7.2 Contributions to the Field of Health Promotion

This study and its findings make a positive contribution to the field of health promotion in several ways. For example, this study fills gaps in the existing ED research, further supports current literature, explores new findings, involves collaboration between researcher and participants, and produces results that can be applied to real-world situations. These are aspects that health promotion research should set out to achieve (Woodall et al., 2018). Health promotion research should also employ research designs and methods that are appropriate for understanding the context of the research topic (Koelen et al., 2001). This study, being qualitative in nature, differs much from the existing ED literature which is often quantitative.

Furthermore, this research addressed two central concepts to the profession and practice of health promotion: strengthened community action and reorientation of health services and policies (World Health Organization, 1986). Community development and systemic change were fundamental in this work. Providing people with lived experience the opportunity to share their perspectives and opinions on the improvement of programs and processes associated with adult inpatient ED treatment in Canada cultivated a space for individual and population empowerment. While empowerment is not something that can be forced upon people, it is something that I tried to facilitate in conducting this study. Participants were clearly appreciative of the opportunity to have their voice heard and expressed their gratitude to me for such an opportunity. Participant two said, “Thank you for doing this. Thank you for letting me be a part of it”.

It is hoped that those who interact with the findings of this study will find connections in the stories of the participants and feel inspired to seek or create community to combat the challenges associated with being impacted by an ED and to push for the changes necessary to improving care for Canadians who require it. Aside from community development and empowerment, this study also contributes to the field of health promotion in that it seeks to make significant change to existing processes and systems, in this case, the mental healthcare systems in Canada to advance health equity. Novel findings and participant-informed recommendations that results from this research provide a clear guide for healthcare professionals and policymakers to the improvement of existing programs and processes associated with adult inpatient ED treatment in Canada.

Additionally, this research serves as a form of advocacy; bringing awareness to a health issue that is often overlooked. As discussed under *Dissemination Plans*, this research and the recommendations that resulted from it will be shared with several relevant stakeholders in diverse settings and ways to increase its reach and impact. Simply conducting the research is not sufficient given the urgent need for transformation of current programs and processes associated with adult inpatient ED treatment in Canada. In sharing the findings and recommendations widely, I will be increasing the likelihood that improvements are made, and I will be honouring my participants as well as other Canadians impacted by EDs.

7.3 Limitations of this Study

While this study is novel and significant in many ways, it does possess limitations. For example, data collected were reflective only of the programs which participants' have had experience being referred to and/or participating in. Considering that young, white, females are most likely to seek and access Canadian inpatient ED treatment, many study participants identified with those criteria (Sonneville & Lipson, 2018). Furthermore, stigma and historical inaccessibility of care may have deterred populations of certain ages, genders, and races/ethnicities from participating in the study (Becker et al., 2010). This limitation is discussed further in *Chapter 4: Demographics.* To address this limitation, future research should explore the perspectives of those who hold diversities in terms of age, gender identity, sexual identity, diagnosis, race/ethnicity, geographic location, and diagnosis. Identities are complex and contested, which further exagerates the need for future exploration of EDs to be conducted using intersectional approaches to data collection and analysis.

7.4 Dissemination Plans

The results will be presented in the form of an infographic to participants and organizations who shared the recruitment poster. The infographic, which can be seen in *Appendix F*, will be shared via email with recipients (upon successful defence of thesis) who will have the opportunity to share widely. The infographic serves as a knowledge translation tool to make the research and its results more digestible for multiple audiences, regardless of academic knowledge on the subject. A revised version of the final recommendations document will also be shared with participants and other relevant stakeholders (*Appendix F*).

Future dissemination of the research will occur through presentations at conferences, publication of a journal article, and public lectures. Examples of such conferences and meetings might include the International Conference on Feeding and Eating Disorders (July 2023), the International Conference on Eating Disorder Treatment (August 2023), and the Nova Scotia Health Annual General Meeting (Summer 2023). This type of dissemination will seek to gain attention from the public, as well as key stakeholders in ED treatment. These stakeholders may include people with lived ED experience, family/friends of people with lived experience, other researchers studying similar topics, general health care professionals, specialized ED clinicians, and policymakers in health care.

7.5 Next Steps

This research will be disseminated as per the methods described above. It is crucial that the results and recommendations are widespread, with particular focus on groups that can implement necessary change, to make positive change in the processes associated with referral and participation in Canadian adult inpatient ED treatment. It is owed not only to the participants of this study, but every single Canadian affected by EDs that treatment is structured, accessible, and adequate in serving their needs.

Further research is required to determine the ways in which referral, transitional, and treatment processes and systems can be conducted to properly serve those requiring care. Future research should be grounded in lived experience, with particular focus on the experiences of people of colour, Indigenous communities, people living in bigger bodies, and a diversity of sexual orientations, gender identities, and gender expressions. Additionally, future research should ensure the inclusion of participants from each adult inpatient ED treatment program in Canada. Finally, the impacts of the COVID-19 pandemic on adult inpatient ED treatment in Canada warrant further exploration.

Most importantly, those who interact with this research must act upon its contents. Whether it be seeking mental health care for oneself or encouraging others to do so, beginning future research following the above guidelines, implementing the recommendations, advocating for Canadians with EDs, or simply sharing this research to all. Action fuels change, and immediate change is required to ensure the needs of those living with EDs are appropriately addressed.

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APPENDIX A

Recruitment Tools

1) Poster

Improving Canadian Clinical Eating Disorder Treatment: Perspectives of Nova Scotians with Lived Experience

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MA HPRO Thesis, Dalhousie University

HAVE YOU BEEN REFERRED TO A CLINICAL EATING DISORDER TREATMENT PROGRAM IN CANADA?

I would love to hear about your experience!

One-on-one in-person interview (approx. 1 hour) on Dalhousie University's Halifax campus and one-on-one virtual follow-up session (approx. 30 mins.).

Participants will be compensated **$20** for their time.

Participants must:
- Be fluent in English
- Currently reside in Nova Scotia
- Have been referred to an **Inpatient Eating Disorder Treatment Program in Canada** while aged **18 years or older** between the years **2018 and 2022**

For more information, contact **catherine.armour@dal.ca**

REB File # [BLANK]

2) Email Script

Dear [BLANK],

I hope that this message finds you well.

My name is Catherine Armour and I am a student at Dalhousie University's Master of Arts Health Promotion program. I am conducting qualitative research to fulfill my thesis requirements for the program. Titled 'Improving Inpatient Eating Disorder Treatment: Perspectives of Canadians with Lived Experience', my research will seek to produce recommendations for the improvement of current referral and participation processes related to inpatient eating disorder treatment programs in Canada informed by people who have been referred to and/or participated in such programs.

I believe that people within your community would offer valuable insight on this topic and I'd like to invite you to share the attached recruitment poster with your members if you feel that my study aligns with your values. As outlined in the poster, those interested in participating should contact me via email at Catherine.Armour@dal.ca. This study has been approved by Dalhousie's Research Ethics Board (REB File # 2022-6155). Please note that any existing relationships between prospective participants and the lead researcher won't be affected by the decision to participate or to decline participation.

I'd be happy to answer any questions that you might have in regards to my study and I look forward to hearing back from you. Thank you for your consideration.

Best,

Catherine Armour

3) Oral Script

Hi there! My name is Catherine Armour and I am a student at Dalhousie University's Master of Arts Health Promotion program. I am conducting qualitative research to fulfill my thesis requirements for the program. Titled 'Improving Inpatient Eating Disorder Treatment: Perspectives of Canadians with Lived Experience', my research will seek to produce recommendations for the improvement of current referral and participation processes related to inpatient eating disorder treatment programs in Canada informed by those who have been referred to and/or participated in such programs. Would you be willing to display this poster in your [lobby/storefront/office] to help me recruit participants? Please let me know if you have any questions or concerns regarding my study. You can refer any interested people to contact me via email at Catherine.Armour@dal.ca. Please note that any existing relationships between prospective participants and the lead researcher won't be affected by the decision to participate or to decline participation. Thank you!

APPENDIX B

Screening Tool

1) Email Correspondence with Potential Participant

Hello [NAME],

Thank you for your interest in being a participant in my study!

Before we work together to determine a date and time for our virtual one-on-one interview, I'd like to confirm a few things. First, can you please confirm that you meet the following requirements.

You are:

- Fluent in English
- Currently residing in Canada
- Someone who has been referred to an inpatient eating disorder treatment program in Canada between the years 2012 and 2022 while aged 18 years or older
- Not currently participating in an inpatient eating disorder treatment program

Next, can you please confirm that you are available to meet with me for a virtual one-on-one interview August 2022?

I've attached the consent form to this email, which will provide you further information on the study. You are not required to sign the form just yet; this will be done prior to commencing the interview. You are encouraged to ask me any questions you may have in regard to your participation in the study. I will be happy to clarify anything with you!

If you meet these requirements and are still interested in participating in the study, we can collaboratively plan for the interview. Please note that any existing relationships between prospective participants and the lead researcher won't be affected by the decision to participate or to decline participation. I look forward to hearing from you.

Best,

Catherine Armour

APPENDIX C

Consent Form

DALHOUSIE
UNIVERSITY

Consent Form

Project title: Improving Inpatient Eating Disorder Treatment: Perspectives of Canadians with Lived Experience

Lead researcher: Catherine Armour, Dalhousie University MA Health Promotion Candidate, catherine.armour@dal.ca

Other researchers
Dr. Debbie Martin, Dalhousie University, debbie.martin@dal.ca
Dr. Jacqueline Gahagan, Mount Saint Vincent University, jacqueline.gahagan@msvu.ca
Dr. Sarah Kirk, Dalhousie University, sara.kirk@dal.ca
Dr. Becky Spencer, Dalhousie University, becky.spencer@dal.ca

Funding provided by: CIHR CGS-M

Introduction

We invite you to take part in this research study conducted by Catherine Armour, a Master of Arts (Health Promotion) student at Dalhousie University. Choosing whether or not to take part in this research is entirely your choice. There will be no impact on the services you receive if you decide not to participate in the research. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit, risk, inconvenience, or discomfort that you might experience. Discuss any questions you have about this study with Catherine Armour. Please ask as many questions as you like. If you have questions later, please contact Catherine at catherine.armour@dal.ca. Please note that any existing relationships between prospective participants and the lead researcher won't be affected by the decision to participate or to decline participation.

Purpose and Outline of the Research Study

Existing research on inpatient eating disorder treatment is largely based outside of Canada, focused on youth programs, and lacking the perspective of individuals with lived experience. The purpose of this proposed study is to address this gap in the literature and gain insight to the perspectives, experiences, and opinions that individuals who have been referred to Canadian inpatient eating disorder treatment have towards improving such programs. Information gathered from participants will be used to identify ways in which existing treatment can be improved to better serve Canadians requiring care. Data will be collected via interviews and follow-up meetings.

Who Can Take Part in the Research Study

You may participate in this study if you are currently residing in Canada, fluent in the English language, have been referred to an adult (i.e., ages 18 years and older) inpatient eating disorder treatment program in Canada between the year 2012 and 2022, and are not currently participating in an inpatient eating disorder treatment program. Contrarily, you may not participate in this study if you are not currently residing in Canada, are not fluent in the English language, have not been referred to an adult (i.e., ages 18 years and older) inpatient eating disorder treatment program in Canada between the years 2012 and 2022, or are currently participating in an inpatient eating disorder treatment program.

What You Will Be Asked to Do

If you decide to participate in this research, you will be asked to attend one 60-minute (approximate) virtual interview session and one 30-minute (approximate) virtual follow-up session with Catherine Armour. The one-on-one interview will take place virtually on Microsoft Teams. The interview session will be audio-recorded for accuracy and for the creation of a transcript. The interview session will involve several questions and prompts from Catherine. The one-on-one virtual follow-up session (occurring on Microsoft Teams) will have the purpose of conveying Catherine's general initial findings to ensure that they accurately reflect the information that was shared by participants during interviews. This meeting will also be audio-recorded for accuracy. Participants can expect to participate in the follow-up meeting approximately 6-weeks following their interview.

Possible Benefits, Risks and Discomforts

Benefits: Participating in the study may benefit you through personal empowerment, and your participation may improve the inpatient eating disorder treatment experiences of other Canadians in the future.

Risks: The risks associated with this study are moderate; there is possibility for emotional discomfort or distress in retelling your experiences with inpatient eating disorder treatment. You will have the opportunity to take breaks during the interview session. Furthermore, connections to free community mental health care resources (e.g, Eating Disorders Nova Scotia, NSH Eating Disorder Clinic, Hopewell Eating Disorder Support Centre, Body Brave) will be available should you require them.

Compensation / Reimbursement

Participants will receive $15 upon participation in the interview. Following the follow-up meeting, participants will receive an additional $5.

How your information will be protected:

Privacy: Your participation in this research will only be known to Catherine Armour and her supervisor, Dr. Debbie Martin.

Confidentiality: The information that you provide will be kept confidential. Only

Catherine Armour and Dr. Debbie Martin will have access to this information. Catherine and Dr. Martin have an obligation to keep all research information confidential. Dr. Martin will have access to this information only for data retention purposes. All your identifying information (such as your name and contact information) will be securely stored separately from your research information. The information you provide during the research process will be stripped of any identifiable information. Once data has been anonymized, it may be shared only with the co-supervisors of the study, Dr. Debbie Martin (Dalhousie University) and Dr. Jacqueline Gahagan (Mount Saint Vincent University). During the study, all electronic data will be stored on a password protected USB drive. The USB drive will be locked when not in use. Physical data, including the password protected USB drive, will be stored in a locked cabinet located in a secure office accessible only to Catherine Armour. Catherine will describe and share her findings in a thesis, a journal article, and presentations at conferences. Any quotes that are shared will not be identifiable.

Security: The researcher will use her Dalhousie University credentials for the Microsoft Teams meeting, which will ensure that the Teams meeting recordings are securely stored in Canada. During the live Teams meeting, audio and video content is routed through the United States, and therefore may be subject to monitoring without notice, under the provisions of the US Patriot Act while the meeting is in progress. After the meeting is complete, meeting recordings made by Dalhousie are stored in Canada and are inaccessible to US authorities. An external handheld recorder will be used as backup to record the interview and the follow-up meeting. Immediately after each session, data recorded on the recorder will be uploaded to a password-protected USB drive on the researcher's password-protected computer prior to being destroyed.

Limits to confidentiality: Catherine and Dr. Debbie Martin will not disclose any information about your participation in this research unless compelled to do so by law. That is, in the unlikely event that Catherine witnesses during your interview or follow-up meeting that you are an adult in need of protection, or suspect it, she is required to contact authorities. Although all data will have been anonymized at this point, it is possible during the follow-up meetings that participants may be able to identify other participants if they are well versed on each other's experiences beyond the study. While every effort will be made to maintain confidentiality, there is a very minor risk of being identified by other participants.

Data retention: Any identifying information (i.e., contact information) you provide will be destroyed following the completion of the study. Anonymized transcripts and signed consent forms will be stored securely in Dr. Debbie Martin's office on Dalhousie campus for 5 years following the completion of the study before being irreversibly destroyed.

If You Decide to Stop Participating

You are free to leave the study at any time. If you decide to stop participating during the study, you can decide whether you want any of the information that you have provided up to that point to be removed or if you will allow the primary researcher to use that information. After participating in the interview portion of the study, you can decide for up to 5 weeks if you want your data removed. After that time, it will become impossible for the primary researcher to remove it because it will already be anonymized, analyzed, or published.

How to Obtain Results

The primary researcher will provide you with a short description of group results in the form of an infographic when the study is finished. No individual results will be provided. You can obtain these results by including your contact information at the end of the signature page.

Questions

Catherine is happy to talk with you about any questions or concerns you may have about your participation in this research study. Please contact Catherine Armour at catherine.armour@dal.ca at any time with questions, comments, or concerns about the research study.

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at (902) 494-3423, or email: ethics@dal.ca and reference REB file # 20XX-XXXX.

Conflict of Interest

As someone who has participated in Canadian inpatient eating disorder treatment and is an active advocate for eating disorder care in Nova Scotia, Catherine Armour may have a personal relationship to individuals who wish to participate in the study. Please note that any existing relationships between prospective participants and the lead researcher won’t be affected by the decision to participate or to decline participation.

Signature Page

Project Title: Improving Inpatient Eating Disorder Treatment: Perspectives of Canadians with Lived Experience

Lead Researcher: Catherine Armour, Dalhousie University MA Health Promotion Candidate, catherine.armour@dal.ca

I (the research participant) have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to take part in one interview that will occur virtually on Microsoft Teams and that the interview will be audio-recorded. I understand that I have been asked to take part in one follow-up meeting that will occur virtually on Microsoft Teams and that the meeting will be audio-recorded. I understand direct quotes of things I say may be used without identifying me. I agree to take part in this study. My participation is voluntary, and I understand that I am free to withdraw from the study at any time, until 5 weeks after my interview is complete.

______________________________ ____________________________ ____________

Name Signature Date

Please provide an email address below if you would like to be sent a summary of the study results.

Email address: __________________.

APPENDIX D

Data Collection Tools

1) Interview Guide

During this interview, I will be asking you questions about your experience(s) being referred to adult inpatient eating disorder treatment in Canada, and any recommendations you may have for the improvement of such programs and processes. All questions are voluntary. You may choose to skip or refuse any question I ask. You are free to leave the study at any time. If you decide to stop participating during the study, you can decide whether you want any of the information that you have provided up to that point to be removed or if you will allow me to use that information. After participating in the interview portion of the study, you can decide for up to 5 weeks if you want me to remove your data. After that time, it will become impossible for me to remove it because it will already be anonymized, analyzed, or published. Following this interview, you can expect to participate in the follow-up meeting with me in approximately 6 weeks.

Am I able to clarify any elements of the study or your participation in the study?

Thank you for consenting to participation in this interview. Please take the time that you need to answer the questions I ask and alert me if you'd like to take a break or conclude the interview at any time. I'd like to first discuss with you your experience or experiences of being referred to inpatient eating disorder (ED) treatment in Canada.

1) Referral process

- What did the referral process(es) entail?
    - E.g., forms, measurements
- Who made the referral(s)?
    - E.g., myself, parent/guardian, friend, significant other, physician
- How did you feel about being referred to inpatient treatment?
    - E.g., excited, nervous, scared, compliant, neutral, resistant
- What was the experience of being referred like for you?
- Did you feel supported in that process?
    - Why or why not?
- How do you think the process may have gone more smoothly, or is there anything that could have been done differently to have made it a better experience for you overall?
- How many times have you been referred to inpatient treatment as a minor?
- How many times have you been referred to inpatient treatment as an adult?
- Which adult inpatient ED programs have you been referred to in Nova Scotia or in Canada? Where were these programs located?
    - Of these adult programs, how many have you been admitted to?
    - Of these adult programs, which ones were you admitted to?
- How long was the wait between referral to program and admission?
- Upon admission to an inpatient program, did you participate in the treatment?
    - Follow-up for those who did not participate
        - Why did you not participate in the treatment you were referred to?

        - What barriers prevented you from participating in treatment?
        - What processes would you like to see put in place to have facilitated participation?

Thank you for sharing with me your experience in being referred to inpatient treatment. Next, I'd like to discuss transitional periods in relation to your referral(s) to inpatient treatment before we discuss your experience of participating in the program(s). By transitional periods I mean the processes involved in beginning and concluding inpatient treatment.

2) Transition to treatment

- Describe the transition into inpatient treatment
    - Can you tell me about times when you felt supported in your transition to inpatient treatment?
    - Can you tell me about times when not feel supported in your transition to inpatient treatment?
- Describe your transition out of inpatient treatment
    - Can you tell me about times when you felt supported in your transition out of inpatient treatment?
    - Can you tell me about times when you did not feel supported in your transition out of inpatient treatment?

Thank you for being so open in discussing your transitional periods in and out of inpatient treatment. I'll now be asking you a few general questions about your experience in treatment, before moving on to elements of the program(s) that you found to be most and least supportive.

3) Treatment process

- How long did you remain in treatment?
- Did you follow through with treatment until discharge?
    - Why or why not?
- Describe the general format of the treatment you were provided
    - E.g., physical environment, programming, staff, other patients, social network

4) Can you tell me about times when you felt really supported in the program(s)? Consider elements such as the:
    - Physical environment
    - Programming
    - Staff
    - Other patients
    - Social network
5) Can you tell me about times when you did not feel supported in the program(s)? Consider elements such as the:
    - Physical environment
    - Programming
    - Staff
    - Other patients
    - Social network
6) Improvements

- If you could have designed the program(s) yourself, are there things about it that you would have changed?
- Are there policies that informed your treatment that you would have changed?
    - Leave passes?
    - Family visits?
    - Participation in certain elements?
    - Lavatory regulations?
    - Dress code?
- Given the limited resources for this type of service in Canada, what would you recommend to policy makers as a key area that they should focus on in addressing the issues you have stated in question 5?
- What other types of policy or programming recommendations would you like to make to the provincial government?

Your experiences and perspectives are so valuable and I am grateful that you have been willing to share them with me. As we near the end of the interview, I'm interested in gathering some population-based information from all participants as I'll be taking demographics into account when analyzing the interview data.

7) Demographics

- How old are you currently?
- How would you describe your ethnicity?
- How would you describe your gender identity?
- How would you describe your sexuality?

I have two more question for you before we wrap up.

8) Closing

- Is there anything else that you'd like to share that I didn't ask you about?
- Do you have any questions for me?

That concludes our interview. I'd like to express how grateful I am to you for sharing your experiences and perspectives with me during this interview. Once I have performed a preliminary analysis of the entire data set, I will be sharing the collective recommendations with each participant individually in a virtual follow-up meeting to ensure that I have understood our conversations in a way that accurately reflects your experiences and perspectives. I will be in touch via email in approximately 6 weeks to organize your follow-up meeting. Thank you for joining me today!

2) Follow-up Meeting Guide

1) Communication between patient, program, and referring physician should be clear, timely, and constructive.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

2) Support should be available to people in the interim (i.e., between referral & admission) to prevent patient deterioration and improve overall wellbeing.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

3) Patients should be ‘met where they’re at’ in order to improve equity of access to care.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

4) SDOH (e.g., age, gender, race, housing, education, income) are factors beyond one’s control that impact their health, and they are directly related to how someone experiences an eating disorder and recovery.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

5) A little bit of compassion can go a long way in fostering trust between patient and practitioner, facilitating a positive experience for the patient, and catalyzing a ‘successful’ inpatient journey.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

6) More resources (e.g., staff, beds, programming) = more access to treatment = less people dying from eating disorders.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

7) Nobody should have to navigate the healthcare system or recover from an eating disorder alone.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?

    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

8) People should leave inpatient treatment with the skills and confidence to continue recovery outside of the clinical setting.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

9) People experiencing eating disorders deserve to have connections with others who have experience with recovery.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

10) Inpatient treatment should not feel like a punishment, resemble an institution, or be de-humanizing.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?

- Do you have any further comments in regard to this recommendation?

11) Programs should provide patients with a variety of groups daily to facilitate routine, encourage community, and offer distraction.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

12) Stagnation should be avoided when it comes to illnesses as unique, diverse, and deadly as eating disorders.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

13) Every person & eating disorder is different – referral, treatment, and discharge processes should be conducted in recognition of this fact.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

14) People should have the opportunity to leave treatment gradually as not to catalyze preventable subsequent admissions.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

15) Severe and deadly eating disorders should be prevented as often as possible with early intervention.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

16) Active methods for reducing stigma around eating disorders & treatment must be employed.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?
    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

17) Beyond inpatient treatment, and other clinical forms of care, people should have ages to other methods for recovery.

- Do you feel that this recommendation accurately represents the information you provided to me during our interview?
    - Why or why not?
- Do you feel that this recommendation is meaningful, should it be adopted?

    - Why or why not?
- In what ways should this recommendation be changed to more accurately reflect your experiences, opinions, and perspectives as an individual with lived eating disorder experience?
- Do you have any further comments in regard to this recommendation?

Is there anything else you’d like to share with me?
Do you have any questions for me?

APPENDIX E

Follow-up Documents

Message to Those Not Eligible for Participation

Hello [name],

I hope that this message finds you well.

Thank you again for your interest in participating in my study! Upon reviewing the information that you provided in your email, I am sorry to inform you that you are ineligible to be a participant in the research study according to the [inclusion/exclusion criteria OR availability for interview].

I want to iterate that your eating disorder experience is valid and that your perspectives and opinions are meaningful. While you are not able to participate in this particular study, I encourage you to continue to seek ways to share your story.

I can understand how your participation up to this point may have brought about difficult emotions, feelings, and memories. If so, I encourage you to consult the attached resource sheet which provides information on several mental health supports that are available to you.

As a reminder, any information you provided in our earlier correspondence will be destroyed and will not be used in the research study.

Thank you again for your interest in participating in this research study!

Best,

Catherine Armour

Resource Sheet

Eating Disorders Nova Scotia - https://eatingdisordersns.ca/

We believe that no one should have to face an eating disorder alone. We believe in inspiring hope, increasing understanding, and offering meaningful support at all stages of recovery. All our services are available without a referral or a diagnosis.

NIED - https://nied.ca/

NIED assists and supports people coping with the effects of Eating Disorders by providing access to educational, informational and other recovery-oriented resources related to the prevention and treatment of Eating Disorders and related mental illnesses in Canada.

NEDIC - https://nedic.ca/

NEDIC provides information, resources, referrals and support to Canadians affected by eating disorders.

Kids Help Phone - https://kidshelpphone.ca/

Kids Help Phone is Canada's only 24/7 e-mental health service offering free, confidential support to young people in English and French.

Body Brave - https://www.bodybrave.ca/

As a leader driving change, Body Brave is a charity providing accessible eating disorder treatment and support, as well as advancing community training and education.

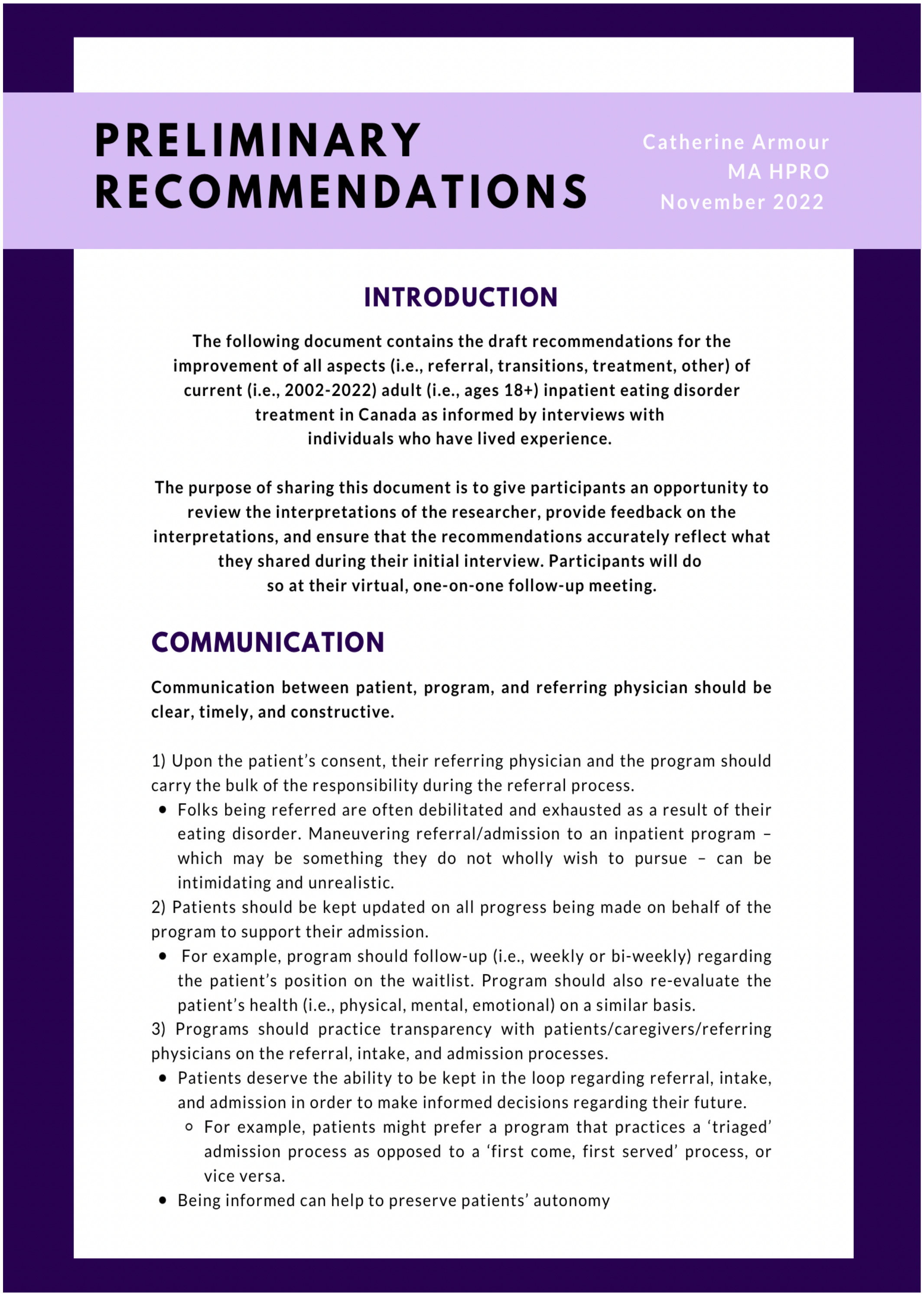
Ninety Percent Society - @ninetypercentsociety on Instagram

This Dalhousie University student-run group is dedicated to supporting students experiencing an eating disorder.

APPENDIX F

Knowledge Translation Documents

1) Draft Recommendations Document



PRELIMINARY RECOMMENDATIONS

Catherine Armour
MA HPRO
November 2022

INTRODUCTION

The following document contains the draft recommendations for the improvement of all aspects (i.e., referral, transitions, treatment, other) of current (i.e., 2002-2022) adult (i.e., ages 18+) inpatient eating disorder treatment in Canada as informed by interviews with individuals who have lived experience.

The purpose of sharing this document is to give participants an opportunity to review the interpretations of the researcher, provide feedback on the interpretations, and ensure that the recommendations accurately reflect what they shared during their initial interview. Participants will do so at their virtual, one-on-one follow-up meeting.

COMMUNICATION

Communication between patient, program, and referring physician should be clear, timely, and constructive.

1) Upon the patient's consent, their referring physician and the program should carry the bulk of the responsibility during the referral process.
- Folks being referred are often debilitated and exhausted as a result of their eating disorder. Maneuvering referral/admission to an inpatient program – which may be something they do not wholly wish to pursue – can be intimidating and unrealistic.

2) Patients should be kept updated on all progress being made on behalf of the program to support their admission.
- For example, program should follow-up (i.e., weekly or bi-weekly) regarding the patient's position on the waitlist. Program should also re-evaluate the patient's health (i.e., physical, mental, emotional) on a similar basis.

3) Programs should practice transparency with patients/caregivers/referring physicians on the referral, intake, and admission processes.
- Patients deserve the ability to be kept in the loop regarding referral, intake, and admission in order to make informed decisions regarding their future.
  - For example, patients might prefer a program that practices a 'triaged' admission process as opposed to a 'first come, first served' process, or vice versa.
- Being informed can help to preserve patients' autonomy

INTERIM SUPPORT

Support should be available to people in the interim (i.e., between referral & admission) to prevent patient deterioration and improve overall wellbeing.

1) Patients should have access to peer mentorship (i.e., support from individuals who have experience with ED recovery through the given inpatient program) during the interim.

- This would allow folks to find community, positive inspiration, and comfort.
- It would provide folks a point of contact (that is not a 'professional') for questions specific to the program.
- Peer mentorship could alleviate the responsibilities of healthcare professionals/the inpatient care team.

2) Accessible (e.g., could be virtual sessions) interim support programs, ideally through the hospital, must be implemented specifically for folks who are on the waitlist for treatment.

- Not only would this ensure less folks slip through the cracks, it would be an opportunity for the inpatient program to medically monitor folks as a means for triaging.

3) Medical monitoring should be prioritized between referral and admission. Many folks end up seeking emergent care due to their condition deteriorating, yet the program's intake staff are not aware of this and folks have no way of contacting them to communicate this.

ACCOMMODATIONS

Patients should be 'met where they're at' in order to improve equity of access to care.

1) Patients should be offered in-person, virtual, and phone appointments for assessments and follow-ups during the referral process. Furthermore, any medical monitoring (i.e., weigh-ins, bloodwork, heart rate/blood pressure) should be completed by the referring physician and then provided to the program.

- Removes barriers like transportation and scheduling conflicts.
- May help patients feel more comfortable and safe.
- Could alleviate program's resources – meaning a possibility for increased interim support/communication.

AWARENESS OF SOCIAL DETERMINANTS OF HEALTH (SDOH)

SDOH (e.g., age, gender, race, housing, education, income) are factors beyond one's control that impact their health, and they are directly related to how someone experiences an eating disorder and recovery.

1) Social determinants of health (i.e., race, age, housing, gender, education, etc.) must be considered in terms of how each individual patient might experience them and how these SDOH affect an individual's ED and recovery experiences.
2) Referral, transitions, and treatment processes should be conducted in ways that acknowledge, appreciate, and respect an individual's SDOH.

- Example: Someone who is age 60 should be treated differently for their ED than someone who is age 19.
- Example: Someone who experiences financial difficulties should be treated differently for their ED than someone who does not.

COMPASSION

A little bit of compassion can go a long way in fostering trust between patient and practitioner, facilitating a positive experience for the patient, and catalyzing a 'successful' inpatient journey.

1) Referral/assessment/intake processes should be conducted with high-levels of compassion, empathy, understanding, and support for the patient.

- This requires the healthcare professional to: acknowledge and appreciate a patient's feelings & attitudes (i.e., stress, ambivalence, bravery), use sensitive language & good 'bedside manner', offer thorough & clear explanations, show their 'human side', and practice collaboration.

MORE RESOURCES

More resources (i.e., staff, beds, programming) = more access to treatment = less folks dying from eating disorders

1) All Canadians living with eating disorders deserve to receive treatment

- While this is a vague recommendation, it is necessary in accomplishing many other recommendations. That being said, patients/caregivers and staff should be encouraged and supported in advocating to relevant policymakers for these increases.
    - This increases likelihood of change, facilitates empowerment, and reduces stigma.

CASE WORKER

Nobody should have to navigate the healthcare system or recover from an eating disorder alone.

1) Each patient should be appointed a case worker. This person can act as an advocate for the patient, a point of contact within the program, and a guide/navigator.

- Advocate: While all participants are aged 18+, they may not have the cognitive capacity, confidence, or knowledge about the healthcare system and their rights to appropriately advocate for themselves.Point of Contact:
- Patients often do not have a point of contact within the program. A case worker could be that for a patient – provide them information on the program and answer questions that they may have.
- Guide/Navigator: Many people feel unprepared for treatment when they arrive there – they are unfamiliar with the physical environment, they are unfamiliar with the program rules, and they are unaware of what is expected of them (due to lack of communication). A case worker could ensure that patients are well oriented prior to, and while transitioning into, inpatient care.

2) A case worker could act as a liaison for patients and the healthcare practitioners.

- In order to be provided holistic care that is supportive of SDOH, patients must have access to a variety of healthcare professionals/services – particularly social workers, spiritual healthcare professionals, recreation therapists, nurses, psychiatrists and psychologists. A case worker could bridge communication between patient and these healthcare professionals.

IMMERSIVE EATING EXPERIENCE

Folks should leave inpatient treatment with the skills and confidence to continue rcovery outside of the clinical setting.

1) When appropriate, patients should have the opportunity to portion out meals/snacks with guidance from a dietician.

- Prepares patients for life outside of hospital, when they will have to appropriately portion every single meal/snack on their own.

2) Patients should be involved in cooking/baking of meals/snacks eaten at the program.

3) Patients should be exposed to meals/snacks outside the hospital environment.

- i.e., ordering from coffee shops, restaurants, etc.

PEER MENTORSHIP

Folks experiencing eating disorders deserve to have connections with others who have experience with recovery.

1) Programs should implement apeer mentorship program.
- Folks often find the support of their co-patients to be helpful because they are going through similar challenges in treatment. However, co-patients can sometime be triggering at the same time. Peer mentors (folks who are successfully recovering and have experience with inpatient) would bridge this gap.

HUMANIZE THE EXPERIENCE

Inpatient treatment should not feel like a punishment, resemble an institution, or be de-humanizing.

1) More uplifting physical environment.
- Less depressing and sterile décor.
- Unit specific to folks with eating disorders

2) Inclusion of more aspects of 'real life'.
- Similar to the importance of considering an individual's SDOH is understanding that many folks require employment, education, relationships etc. in order to survive outside of inpatient treatment, even beyond their ED.
    - It should be a priority to maintain these aspects of one's life while in treatment, in whatever way possible. The program should work with employers, educators, loved ones to determine and implement an appropriate treatment plan to allow this.

3) Shift focus away from numbers (i.e., weight, BMI) and on to psychological, emotional, and social needs.

4) Programs and staff must avoid stripping folks of their autonomy and independence while in treatment – this may mean altering the patient/practitioner power dynamic, collaborating with the patient, listening to their needs/requests, and encouraging personal decision-making.
- This facilitates self-confidence & empowerment, and can reduce stigma.

GROUP TREATMENT

Programs should provide patients with a variety of groups daily to facilitate routine, encourage community, and offer distraction.

1) Programs should consider implementing new, unique, and diverse groups and types of therapy into their program. This may look like piloting new forms of therapy and allotting time/resources to research on existing therapies that are new to the program.
- Example: bottom-up processing, recreation therapy, art therapy, CBT/DBT. nutrition group, trauma group, relationship group, nutrition group, etc.

STAGNATION

Stagnation should be avoided when it comes to illnesses as unique, diverse, and deadly as eating disorders.

1) Programs should be re-evaluated often. Areas for improvement should be acknowledged and addressed. Patient/caregiver input/feedback must be sought and acted upon.

- Example: a patient/caregiver consultation group

2) Hiring should be ongoing.

- Staff hired must be representative of diverse populations – particularly in terms of gender, race, and culture.
- Staff hired must be passionate about mental health care, willing to learn, and empathetic, compassionate, and trusting. Furthermore, they must be specialized to treat eating disorders.

3) Staff should have funded opportunities to further their learning on eating disorders, concurrent disorders, and treatment methods. (i.e., conferences, courses (online & in-person), speaker panels)

- Increased education needed in regards to treating eating disorders beyond AN, treating concurrent disorders, treating patients holistically, and treating folks who don't identify as young, thin, white, straight, cis-gender women.

INDIVIDUALIZATION

Every person & eating disorder is different - referral, treatment, and discharge processes should be conducted in recognition of this fact.

1) Referral/assessment/intake must consider factors beyond numbers (i.e., weight, BMI, heart rate)

- Patients know the most about their own body and mind – if they are seeking eating disorder care, they most definitely require it.
- Programs should practice subjectivity and holistic assessment.

2) Programs should implement more one-on-one sessions between patient and staff (i.e., social worker, occupational therapist, psychologist, psychiatrist, recreation therapist) alongside group sessions.

- Allows for more individually accurate treatment overall.
- Provides a space for patients to speak freely without the risk of triggering other patients.

2) Programs should work to offer patients treatment that fits their specific needs.

- ED treatment should not follow a one-size-fits-all approach. Particularly when cohort sizes in programs are so small, each patient should have an individualized treatment plan to reflect their specific situation.

3) Staff should be flexible with program rules when appropriate in order for care to be more individualized and for patients to feel less de-humanized.

STEP-DOWN APPROACH

Folks should have the opportunity to leave treatment gradually as not to catalyze preventable subsequent admissions.

1) Patients should be allotted enough time in inpatient treatment to meet appropriate physical and psychological stability. Patients should feel safe and confident in their ability to recover outside of inpatient treatment before being discharged.
2) Folks who are discharged prematurely (i.e., asked to leave or decided to leave on their own) should still collaborate with program staff for discharge planning. Nobody should be left to their own devices following an admission.
3) Post-inpatient programs (i.e., day hospital, outpatient, community-based care) should be offered and encouraged (but not forced upon) patients leaving treatment. Furthermore, these programs must be made accessible to folks.

- Example: Three dietician-supervised meals at the hospital on Mondays, Wednesdays, and Fridays at 12pm-1pm are not accessible to folks with jobs, dependants, classes to attend, and no method of transportation.

EARLY INTERVENTION

Severe and deadly eating disorders should be prevented as often as possible with early intervention.

1) Screening for eating disorders should take place in elementary, middle, high, and post-secondary school settings.
2) Community-based eating disorder treatment that is low-barrier deserves increased funding.

- This type of treatment should not require a diagnosis, should have the capacity to treat folks of all EDs, ages, races, genders, incomes.
- This type of treatment should be more plentiful, especially in small towns that are not served by clinical treatment facilities.
- Can reduce stigma & alleviate healthcare system

STIGMA

Active methods for reducing stigma around eating disorders & treatment must be employed.

1) Reducing stigma in the mental healthcare system and beyond might involve:

- Updating educational curriculums to accurately reflect EDs
- Listening and hearing the opinions of those with lived ED experience
- Changing referral/treatment/discharge process, and hiring processes, to serve and represent all people who experience EDs
    - Regardless of age, gender, race, culture, etc.

ALTERNATIVE METHODS FOR RECOVERY

Beyond inpatient treatment, and other clinical forms of care, folks should have access to other methods for recovery.

1) Eating disorder support groups should be available to folks at all stages of recovery.
- Example: AA & NA programs
    - An opportunity to speak openly about challenges and triumphs in recovery.
    - Having a sponsor to keep you accountable.

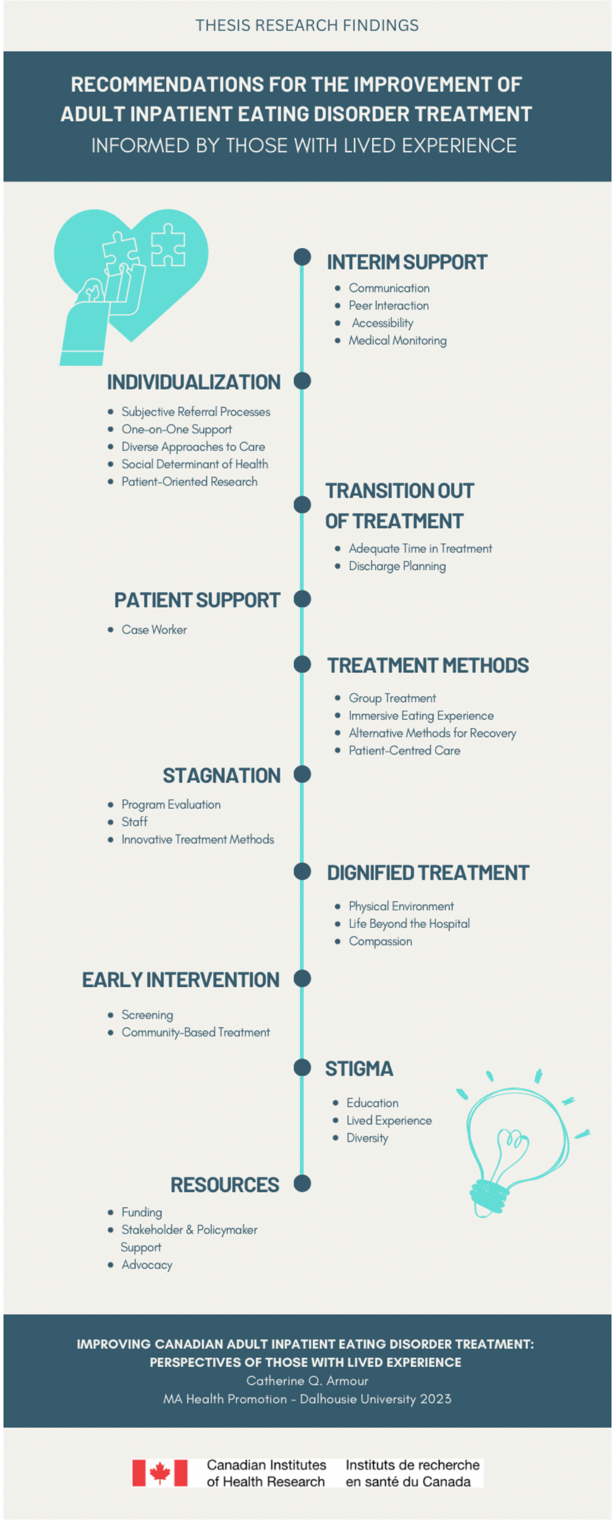
2) Residential treatment should be publicly funded to improve accessibility and alleviate clinical inpatient treatment.
- Furthermore, a publicly funded 'eating disorder halfway house' pilot program could be implemented to determine the success of that type of step-down process.

3) Folks with eating disorders should have more options to recover at home.
- Better coverage for private psychologists, dieticians, therapists, PSWs, nurses.

FINAL COMMENTS

This document is by no means an exhaustive list of reccommendations - rather a starting point as I continue data collection.
Some reccommendations overlap each other, which will be fixed later on. After follow-ups, I will include your feedback, and create a more inclusive, full document with anonymized quotes from interviews.
Thank you for your input up to this point. I can't wait to see what we make of this going forward!

2) Recommendations Infographic



THESIS RESEARCH FINDINGS

RECOMMENDATIONS FOR THE IMPROVEMENT OF ADULT INPATIENT EATING DISORDER TREATMENT
INFORMED BY THOSE WITH LIVED EXPERIENCE

INTERIM SUPPORT
- Communication
- Peer Interaction
- Accessibility
- Medical Monitoring

INDIVIDUALIZATION
- Subjective Referral Processes
- One-on-One Support
- Diverse Approaches to Care
- Social Determinant of Health
- Patient-Oriented Research

TRANSITION OUT OF TREATMENT
- Adequate Time in Treatment
- Discharge Planning

PATIENT SUPPORT
- Case Worker

TREATMENT METHODS
- Group Treatment
- Immersive Eating Experience
- Alternative Methods for Recovery
- Patient-Centred Care

STAGNATION
- Program Evaluation
- Staff
- Innovative Treatment Methods

DIGNIFIED TREATMENT
- Physical Environment
- Life Beyond the Hospital
- Compassion

EARLY INTERVENTION
- Screening
- Community-Based Treatment

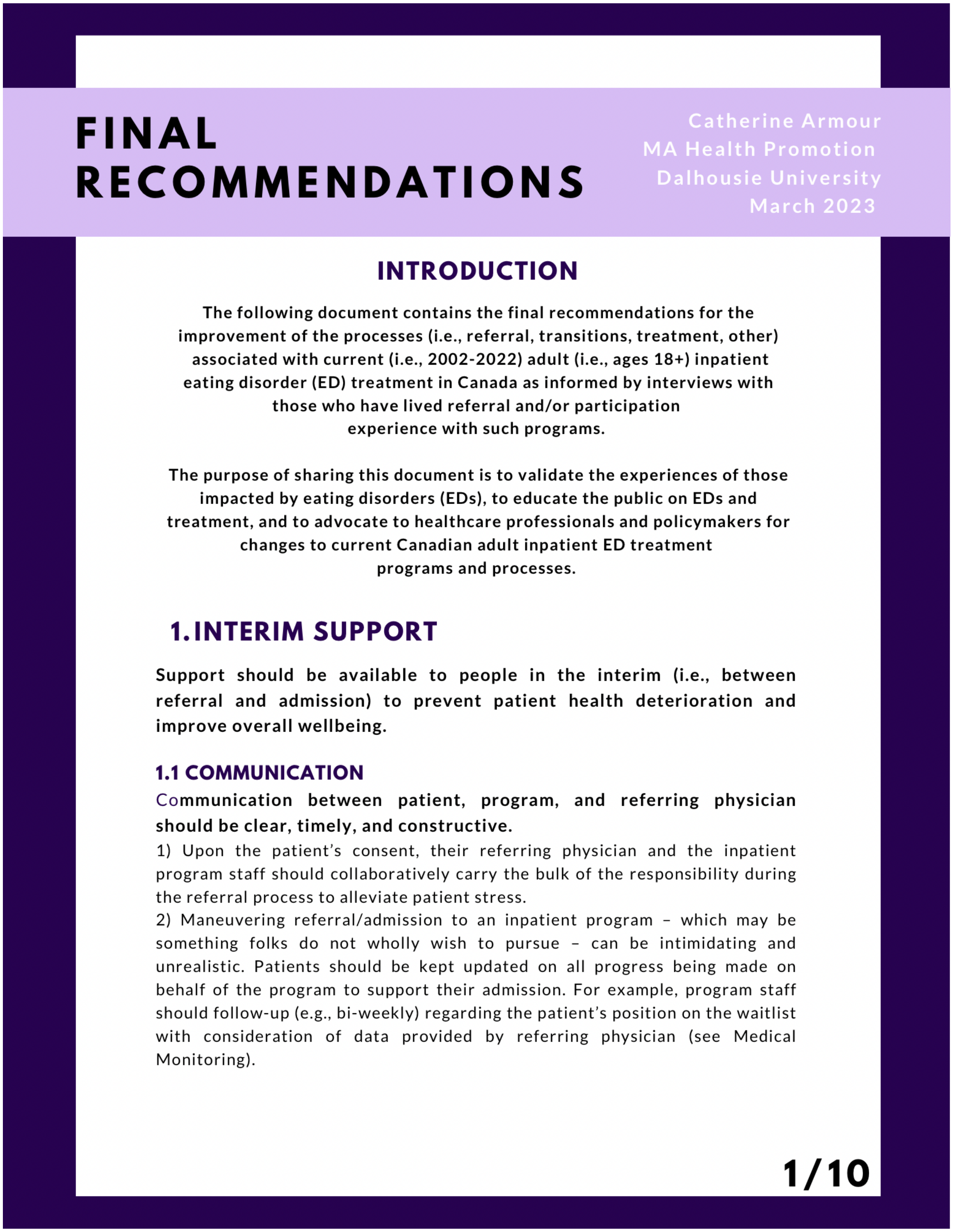
STIGMA
- Education
- Lived Experience
- Diversity

RESOURCES
- Funding
- Stakeholder & Policymaker Support
- Advocacy

IMPROVING CANADIAN ADULT INPATIENT EATING DISORDER TREATMENT: PERSPECTIVES OF THOSE WITH LIVED EXPERIENCE
Catherine Q. Armour
MA Health Promotion - Dalhousie University 2023

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

3) Final Recommendations Document



FINAL RECOMMENDATIONS

Catherine Armour
MA Health Promotion
Dalhousie University
March 2023

INTRODUCTION

The following document contains the final recommendations for the improvement of the processes (i.e., referral, transitions, treatment, other) associated with current (i.e., 2002-2022) adult (i.e., ages 18+) inpatient eating disorder (ED) treatment in Canada as informed by interviews with those who have lived referral and/or participation experience with such programs.

The purpose of sharing this document is to validate the experiences of those impacted by eating disorders (EDs), to educate the public on EDs and treatment, and to advocate to healthcare professionals and policymakers for changes to current Canadian adult inpatient ED treatment programs and processes.

1. INTERIM SUPPORT

Support should be available to people in the interim (i.e., between referral and admission) to prevent patient health deterioration and improve overall wellbeing.

1.1 COMMUNICATION

Communication between patient, program, and referring physician should be clear, timely, and constructive.

1) Upon the patient's consent, their referring physician and the inpatient program staff should collaboratively carry the bulk of the responsibility during the referral process to alleviate patient stress.

2) Maneuvering referral/admission to an inpatient program – which may be something folks do not wholly wish to pursue – can be intimidating and unrealistic. Patients should be kept updated on all progress being made on behalf of the program to support their admission. For example, program staff should follow-up (e.g., bi-weekly) regarding the patient's position on the waitlist with consideration of data provided by referring physician (see Medical Monitoring).

1.2 PEER INTERACTION

Peer interaction during the interim can help folks feel more confident, prepared, and motivated going into inpatient treatment. Furthermore, peer interaction may help incoming patients feel less ambivalent towards treatment and less alone in their recovery journey.

1) Programs should consider on-boarding program champions (i.e., folks who have participated in the program in the past and are in active recovery) who feel confident leading a question-and-answer seminar for incoming patients and caregivers. Program champions should be trained through existing programs offered by non-profit organizations as peer mentors to ensure patient, caregiver, and program champion wellbeing. Having a question-and-answer seminar led by a program champion would remove liability that can arise from peer mentorship during the interim, while also providing folks a point of contact for program specific questions. Peer interaction even has the potential to alleviate pressure on healthcare professionals and the inpatient care team.

1.3 ACCESSIBILITY

Interim supports should be accessible to everyone on the waitlist.

1) Interim support programs and services, such as meal support, psychotherapy, dietetics, medical monitoring, and social support, must be available to incoming patients and, furthermore; must be made accessible in consideration of their lives beyond their ED. Peoples' geographical location and commitments to family, education, and employment must be accommodated when designing interim support programs that are accessible. For example, sessions should be offered at various times and dates and should be available online, in-person, or over the phone when possible.

1.4 MEDICAL MONITORING

Medical monitoring should be prioritized between referral and admission.

1) Patients' physical wellbeing should be monitored on a regular basis (e.g., bi-weekly) and assessed by inpatient program staff. Monitoring should be done by the patient's referring physician and sent directly to inpatient program staff for review. Should a patient not have a family physician or healthcare professional who is able to complete medical monitoring, the inpatient program should assist in securing a healthcare professional capable of doing so. Many folks end up seeking emergency care due to their condition deteriorating, yet the program's intake staff are not aware of this, and folks have no way of contacting them to communicate this. Medical monitoring, paired with thorough communication, could help to prevent emergency hospitalizations and better support patients in the interim.

2.4 AWARENESS OF SOCIAL DETERMINANTS OF HEALTH (SDOH)

As indicated in much of the health promotion literature, the SDOH (e.g., age, gender, race, housing, education, income) are factors that "influence the health of populations" and they directly impact on how someone experiences an ED and recovery (Public Health Agency of Canada, 2016).

1) Referral, transitions, and treatment processes should be conducted in ways that acknowledge, appreciate, and respect an individual's SDOH. Further research is needed to explore the ways in which SDOH affect the ways in which different populations experience EDs and ED treatment processes.

- For example, someone who is age 60 will experience an ED and ED recovery differently than someone who is age 19, and therefore should be treated in consideration of this.
- Similarly, someone who experiences financial difficulties will experience unique challenges to recovery. Such challenges should be considered when collaboratively formulating a treatment plan.
- This recommendation also relates to gender, culture, race, and religion. These factors must be considered and respected during referral, transition, and treatment processes.

2.5 PATIENT-ORIENTED RESEARCH (POR)

Future research regarding EDs and the improvement of current prevention, diagnosis, referral, transition, and treatment processes must be patient-oriented and/or inclusive of the voices of those with lived ED experience.

1) Future ED research in Canada should be focused particularly on improving the health outcomes of men (including gay men), transgender and gender non-binary populations, people of colour, Indigenous communities, those living with disabilities, and those living in bigger bodies through POR and/or with inclusion of those with lived ED experience.

3.TRANSITION OUT OF TREATMENT

Folks should have the opportunity to leave treatment gradually as not to catalyze preventable subsequent admissions.

3.1 ADEQUATE TIME IN TREATMENT

1) Patients should be allotted enough time (i.e., a timeline established collaboratively between patient and care team) in inpatient ED treatment to meet appropriate physical and psychological stability. Patients should feel safe and confident in their ability to recover outside of inpatient ED treatment before being discharged.

3.2 DISCHARGE PLANNING

Collaborative discharge planning for all patients could support patient empowerment and improve health outcomes following discharge.

1) Folks who are discharged prematurely (i.e., asked to leave or decided to leave on their own) should still have the opportunity to collaborate with program staff for discharge planning.

2) Post-inpatient programs (e.g., day hospital, outpatient, community-based care) should be offered and encouraged, but not forced, upon patients leaving treatment. Furthermore, these programs must be made accessible to folks. For example, three dietician-supervised meals at the hospital on Mondays, Wednesdays, and Fridays at 12pm-1pm are not accessible to folks with jobs, dependents, classes to attend, and no method of transportation.

4. PATIENT SUPPORT

No one should have to navigate the healthcare system or recover from an ED alone.

4.1 CASE WORKER

A case worker can act as an advocate for the patient, a point of contact within the program, and a guide/navigator.

1) Every patient should be appointed a case worker who is responsible for supporting the patient and their loved ones in the processes associated with referral to, and participation in, inpatient ED treatment.

- While all participants are aged 18+, they may not have the cognitive capacity, confidence, or knowledge of the healthcare system and their rights to appropriately advocate for themselves.
- Patients often do not have a point of contact within the program prior to, or during, admission. A case worker could be that for a patient and provide them with information on the program and answer questions that they may have.
- Many people feel unprepared for treatment when they arrive there – they are unfamiliar with the physical environment and the program rules, and they are unaware of what is expected of them due to a lack of communication. A case worker could ensure that patients are well oriented prior to, and while transitioning into, inpatient care.
- To be provided holistic care that is supportive of SDOH, patients must have access to a variety of healthcare professionals/services – particularly social workers, spiritual healthcare professionals, recreation therapists, nurses, psychiatrists and psychologists. A case worker could bridge communication between patients and healthcare professionals.

5.TREATMENT METHODS

Adult inpatient ED treatment should practice treatment methods that are proven to be effective according to current research in the area, while also incorporating methods said to be supportive by people with lived experience. Furthermore, alternative methods of treatment should be explored and funded.

5.1 GROUP TREATMENT

Programs should provide patients with a variety of groups daily to facilitate routine, encourage community, and offer distraction.

1) Programs should consider implementing novel, unique, and diverse groups and types of therapy. This may look like piloting new forms of therapy and allotting time/resources to research on existing therapies that are not currently in the program (e.g., bottom-up processing, recreation therapy, art therapy, dialectical behavioural therapy (DBT), nutrition group, trauma group, relationship group, nutrition group).

5.2 IMMERSIVE EAITNG EXPERIENCE

Folks should leave inpatient treatment with the skills and confidence to continue recovery outside of the clinical setting.

1) When appropriate, patients should have the opportunity to portion out meals/snacks with guidance and support from a dietician. This prepares patients for life outside of hospital when they will have to appropriately portion every single meal/snack on their own.

- Patients should be involved in cooking/baking of meals/snacks.
- Patients should be exposed to meals/snacks outside the hospital environment (e.g., ordering from coffee shops, restaurants).

5.3 ALTERNATIVE METHODS FOR RECOVERY

Beyond inpatient treatment, and other clinical forms of care, folks should have access to diverse methods for recovery.

1) ED support groups should be available to folks at all stages of recovery. Other mental illnesses and addictions have ongoing recovery-focused support groups, yet this sort of programming is not common for those maintaining ED recovery. Such recovery-maintenance support groups can provide an opportunity to speak openly about challenges and triumphs in recovery. Furthermore, they can facilitate accountability through peer interaction.

2) Residential treatment should be publicly funded to improve accessibility and alleviate clinical inpatient treatment.

- Furthermore, a publicly funded ‘ED halfway house’ pilot program could be implemented to determine the success of that type of step-down process.

3) Those with EDs should have more options to recover in their communities. In order to do so, non-profit organizations require increased funding and services provided by private psychologists, dietitians, therapists, personal support workers, and nurses should be covered more holistically by health insurance.
4) Where appropriate, peer mentorship should be encouraged and facilitated. While peer interaction can be triggering for some folks, others find peer interaction empowering, comforting, and motivational in ED recovery.

5.4 PATIENT-CENTRED CARE

Treatment should be operated first and foremost with the purpose of serving the needs of the patient, as identified collaboratively by patient and care provider.
1) Treatment must be trauma informed. It must be conducted in ways that acknowledge patient trauma, support patients living with past trauma, and prevent re-traumatization.

6. PATIENT SUPPORT

Stagnation, meaning lack of growth, innovation, and development within programs and treatment approaches on a greater scale, should be avoided when it comes to treating illnesses as unique, diverse, and deadly as EDs.

6.1 PROGRAM EVALUATION

Programs should be re-evaluated on a regular basis, at least annually. Areas for improvement should be acknowledged and addressed.
1) Programs should implement a Patient-Family Advisory Board, representative of patients, loved ones, and caregivers, that can advise program revision.

6.2 STAFF

Program staff should be compassionate, specialized in the treatment of EDs, and representative of the diverse populations impacted by EDs.
1) Hiring should be ongoing to maximize the influx of knowledge and perspectives on the treatment of EDs. Staff hired should be diverse in age, race, and gender. They should be passionate about mental health care, willing to learn, and empathetic, compassionate, and trusting. Finally, staff hired must be specialized in ED treatment to provide patients with the utmost quality of compassionate care.
2) Staff should have funded opportunities to further their learning on EDs, concurrent disorders, and treatment methods. (e.g., conferences, training opportunities (e.g., online & in-person courses/webinars), speaker panels).

- Staff must be educated on best practices for all populations affected by EDs, including men, transgender and gender non-binary populations, people of colour, Indigenous communities, those living with disabilities, and those living in bigger bodies.

6.3 INNOVATIVE TREATMENT METHODS

Over the last decade, substantial research has been published exploring the unique needs of folks with EDs. Programs and staff should practice in alignment with new knowledge to best treat all Canadians experiencing EDs.

1) Staff should be educated in the most up-to-date methods for treating EDs and program processes should facilitate this innovation. Education and implementation are particularly needed regarding the treatment of all EDs (i.e., not just AN and BN), treatment of concurrent disorders and experiences (e.g., substance abuse, depression, post-traumatic stress disorder, gender dysphoria), and treatment of those with EDs who do not identify as straight, white, thin, cis-gender young women.

- Increased exploration is required to understand the ED experiences of racialized populations, men (including gay men), transgender and non-binary populations, and individuals in bigger bodies in order to effectively prevent, diagnose, and treat EDs among these populations.

7. DIGNIFIED TREATMENT

Inpatient treatment should not be de-humanizing or feel like a punishment.

7.1 PHYSICAL ENVIRONMENT

Those in inpatient ED treatment spend weeks to months at a time in the hospital, which means that the physical environment is impactful on their overall experience.

1) Using the resources available, programs should create a physical space for patients that is welcoming, inspiring, and comfortable instead of depressing, sterile, and cold. This might look like fresh paint, artwork, warm lighting, or comfortable blankets and cushions.

7.2 LIFE BEYOND THE HOSPITAL

Similar to the importance of considering an individual’s SDOH is understanding that many folks require employment, education, relationships etc. in order to thrive outside of inpatient treatment, even beyond their ED.

1) It should be a priority to maintain all facets of a patient’s life while in treatment, in whatever way possible. The program should work with the patients, employers, educators, and loved ones to determine and implement an appropriate treatment plan to allow this.

7.3 COMPASSION

As indicated by the participants, compassion can go a long way in fostering trust between patient and practitioner, facilitating a positive experience for the patient, and catalyzing a ‘successful’ inpatient journey.

1) Referral/assessment/intake processes should be conducted with high levels of compassion, empathy, understanding, and support for the patient. This requires the healthcare professional to: acknowledge and appreciate a patient’s feelings & attitudes (e.g., stress, ambivalence, bravery), use sensitive language & good ‘bedside manner’, offer thorough & clear explanations, show their ‘human side’, and practice collaboration. This type of care follows principles of patient-centered care.

2) Programs and staff must avoid stripping folks of their autonomy and independence while in treatment – this may mean altering the patient/practitioner power dynamic, collaborating with the patient, listening to their needs/requests, and encouraging personal decision-making.

8. EARLY INTERVENTION

All forms of EDs should be prevented as often as possible with early intervention. Not only would early intervention help to alleviate the clinical treatment system, but it could also help to reduce stigma and prevent severe EDs.

8.1 SCREENING

Various settings should facilitate ED screening for all populations in order to support early intervention for EDs.

1) Screening for EDs should take place in elementary, middle, high, and post-secondary school settings. To detect EDs in older populations, screening should take place at annual physician appointments for all ages.

8.2 COMMUNITY-BASED TREATMENT

Many non-profit organizations exist across Canada to provide ED support, however; they often have limited capacity because they rely on grants and donations.

1) Community-based eating disorder treatment that is low-barrier deserves increased funding. This type of treatment should not require a diagnosis, should have the capacity to treat folks of all EDs, ages, races, genders, and incomes. Community-based treatment should be more plentiful, especially in small towns that are not served by clinical treatment facilities.

9.STIGMA

Stigma surrounding who experiences EDs, who deserves treatment for EDs, and even the stigma surrounding seeking care is harmful to everyone impacted by EDs. Implementing the recommendations in this document may combat existing stigma, as could the following active methods for stigma reduction.

1) Educational curriculums, at all levels of education, should be updated to accurately reflect EDs, who experiences them, and how they can be treated.
2) People with lived ED experience should be included in the development of policies, guidelines, and practices that will directly affect them.
3) Referral, transitional, treatment, and hiring processes should reflect the diversity of populations impacted by EDs.

10.RESOURCES

Having sufficient resources (e.g., funding, staff, beds, programming) is paramount to increasing accessibility of treatment and ultimately improving health outcomes for those affected by EDs.

1) Greater funding must be allocated to adult inpatient ED treatment to accomplish many of the recommendations. For example, funding can increase the number of folks able to access treatment at one time and can be used to increase size, diversity, and impact of staff team.
2) Patients, caregivers, and staff should be encouraged and supported in advocating to relevant policymakers for increases to resources allocated to ED treatment in Canada.
3) Advocacy has the potential to kick start change, foster empowerment, and reduce stigma.

FINAL COMMENTS

These recommmendations were informed by
participants of a study titled
'Improving Adult Inpatient Eating Disorder Treatment:
Perspectives of Canadians with Lived Experience'.
For more information regarding the study. its findings,
and the priority of the above recommendations,
contact Catherine Armour at catherine.armour@dal.ca

APPENDIX G

Table 2a

Chapter Five: Results, Summary of 'Referral' Findings

Themes/Findings	Discussion
Feelings Toward Referral and Future Admission	- Feelings of guilt, ambivalence, and shame are common among participants and other people with EDs - May be exacerbated by sigma associated with experiencing, and accessing treatment for, an ED - Lack of resources may contribute to this stigma
Decline of Physical and Mental Health Upon Referral	- All participants experienced a decline in physical and mental health upon referral - Stigma, lengthy wait times, and low/fleeting motivation to recovery were identified as contributors
Agency and Autonomy	- Patient agency, power, ability, choice, and autonomy during referral processes were identified as supportive to recovery
Social Support Network	- Supportive family & friends are beneficial during the referral (and transition and treatment) processes - Having a supportive, caring, and self-aware referring physician was identified as beneficial to recovery - Participants who had an existing connection within the program were admitted quickly in comparison to others
Wait Times	- Most participants waited approximately 6 months after referral before being admitted - The longest wait time was 15 months - Wait times in Canada have increased substantially since the beginning of the COVID-19 pandemic

Themes/Findings	**Discussion**
Intake Procedures	- Participants appreciated intake assessments that were conducted slowly, with empathy, and with opportunity to collaborate with healthcare providers and ask questions, however; this was often not the case - Participants noticed a lack of transparency and communication during intake procedures, and the need for a point of contact - Several participants experienced a confidentiality breach during this time
Interim Support	- Pre-admission programming and other forms of interim support were identified as supportive of recovery - Knowledgeable referring healthcare providers were supportive of recovery in the interim - Participants who experienced co-occurring illnesses felt unsupported during the interim

Table 2b

Chapter Five: Results, Summary of 'Transitions' Findings

Themes/Findings	**Discussion**
Multiple Admissions	- Many participants had been in and out of treatment many times, self-identifying as 'revolving-door' patients
Culture and Respect	- Participants described a 'culture shock' upon entry to treatment - Transitions often used 'all or nothing' and 'tough love' approaches - Disrespect and belittlement were common during transitions
Orientation	- Having a point of contact within the program, receiving a program handbook, touring the facility, and meeting staff members prior to admission were identified as supportive in helping participants feel oriented in their transition - Participants who did not receive such an orientation felt lost and unsafe in their transition into treatment
Autonomy and Accommodation of Needs	- Some participants felt there was a lack of trust from care providers during the transition, a lack of participant agency/autonomy, and a lack of self-reflection on behalf of the program itself during transitions - When programs could accommodate the needs of patients entering care, participants felt supported in their transition into treatment

Themes/Findings	**Discussion**
Autonomy and Accommodation of Needs (continued)	- Contrarily, when needs beyond one's ED were not acknowledged, nor accommodated for, participants felt unsupported
Discharge Planning and Follow-Up Post-Treatment	- Participants appreciated when they were able to engage in collaborative discharge planning - Participants unsupported by the lack of follow-up upon administrative or self-discharge from a program

Table 2c

Chapter Five: Results, Summary of 'Treatment' Findings

Themes/Findings	**Discussion**
Administrative Discharge	- Many participants had been administratively discharged from a program - Some felt that their reason for being administratively discharged was unfair
Self-Discharging	- Reasons for self-discharge: unable to put life on hold, inadequate treatment, disconnection to life beyond ED, requiring different approach to recovery, difficulty coping with physical changes
Length of Stay	- Participants spent as little as one week and as much as over 6 months in treatment - Those who participated in more recent (i.e., 2015-2022) years generally had shorter admissions than those who participated in treatment longer ago (i.e., pre-2015)
Turning Down Treatment	- Reasons for turning down treatment: poor timing, needs not accommodated, difficulty committing to change, negative past experience, unpleasant intake assessment/referral procedures, difficulty accepting lack of autonomy, feeling unworthy of care
Staff	- Participants appreciated staff who were compassionate and knowledgeable/experienced on treating and working with people with EDs - Participants all had negative experiences with staff as well, specifically staff that demonstrated their power over patients inappropriately, refused to trust, were disrespectful or belittling, and those who made inconsiderate comments - Participants particularly did not appreciate staff who responded to disclosure of symptom presence with punishment - Participants also noted the lack of diversity of staff members

Themes/Findings	**Discussion**
Treatment Methods: Physical and Psychological	- Medical monitoring and knowledge translation of a patient's physical health were identified as important physical treatment methods - Participants identified DBT and recreation therapy as the most supportive psychological treatment methods - Aspects of treatment that incorporated 'real-life' scenarios were perceived to be beneficial to participants
Routine	- Having routine and being kept busy was supportive to participants' recovery
Co-Patients	- Co-patients were identified to be both supportive and unsupportive to participants' recovery
Physical Environment	- Participants identified the décor, the lack of cleanliness, and the lack of an ED-specific unit to be negative aspects of the physical environment
SDOH: Culture/Religion, Gender, and Housing	- Several instances were discussed in which SDOH such as religion/culture, gender, and housing were not acknowledged or appropriately accommodated for during treatment, which was perceived as unsupportive to recovery
Stigma, Ethics, and Dignified Care	- Entering treatment at a 'normal' weight involved being stigmatized by co-patients and staff - One participant was coerced into participating in a program's research study - Participants found the lack of trauma and violence-informed care and the power imbalance between staff and patient to be de-humanizing
Impact of the COVID-19 Pandemic	- Participants who participated in treatment during the pandemic were particularly impacted due to a lack of social support and especially low resources
Innovation	- Programs lacked innovation
Rapid Admission	- Participants felt that some admissions were being done rapidly to admit more patients, however; this approach resulted in harmful outcomes for patients