

## TRANSITION INTERVENTION FOR YOUTH WITH EATING DISORDERS

ASSESSING THE FEASIBILITY OF AN INTERVENTION FOR ADOLESCENTS  
AND PARENTS TRANSITIONING OUT OF PEDIATRIC EATING DISORDER  
SERVICES: A MIXED METHODS STUDY

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the  
Requirements for the Degree Master of Science

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out of Pediatric Eating Disorder Services: A Mixed Methods Study

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## **LAY ABSTRACT**

Most programs that specialize in treating children with eating disorders discharge patients when they turn 18. This sudden change often leaves youth without a solid plan to continue this care as an adult. Currently, no known interventions exist to help with this problem. In our study, ten adolescents and their parents completed five activities designed to improve their transition into adult mental health care. Interviews, reflections, and questionnaires were used to explore multiple outcomes, such as how many or the duration to complete these activities and where they plan to go for adult mental health treatment. Adolescents and parents completed most of the supports, described them as easy and helpful, and set up a plan for their future care. The activities in this study have the potential to improve this difficult transition for youth and families affected by eating disorders and should be further studied.

## **ABSTRACT**

*Background.* The continuation of eating disorders from adolescence into adulthood often requires youth to undergo a healthcare transition from pediatric to adult eating disorder services. This transition is difficult, uncoordinated, and puts affected adolescents at an increased risk of relapse. Although transition barriers and recommendations have been identified, no known interventions exist to support youth and families transitioning to adult eating disorder services.

*Methods.* Over a three-month period, ten 17-year-old adolescents and their parents (n=9) completed up to five intervention components designed to prepare them for the transition out of pediatric eating disorder treatment in Hamilton, Ontario. A convergent parallel mixed methods design was used to assess intervention feasibility, the nature of transition, and other outcomes, with equal emphasis on the quantitative data, where measures were collected using a single arm pre-post design, and qualitative data, which comprised of written reflection entries and interview data, was informed by Qualitative Description, and analyzed using qualitative content analysis.

*Results.* Quantitative data pertaining to chosen feasibility indicators showed that adolescents and parents completed an average of 73% and 78% of expected components respectively, all within the three-month intervention period. Findings generated from the qualitative data indicated that participants found the intervention helpful, convenient, and easy to navigate. Of the seven adolescents interviewed, most were planning to transition to their family doctor, a private therapist, or both, while awaiting entry to specialized adult mental health care.

*Conclusions.* This intervention is acceptable, feasible, and highlights likely care pathways among transition-age youth with eating disorders. These findings support the continuation of this research using more rigorous study designs to examine the effectiveness of this intervention in larger and more diverse samples.

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To the adolescents and parents in my study, I want to thank you for your strength, candor, and vulnerability while working together and your willingness to complete this intervention and multiple data collection measures over a considerable amount of time. Sharing your or your child's eating disorder experience is not easy, and this does not go unnoticed.

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## **LIST OF ALL ABBREVIATIONS AND SYMBOLS**

AN	Anorexia Nervosa
ARFID	Avoidant/Restrictive Food Intake Disorder
BED	Binge-Eating Disorder
BN	Bulimia Nervosa
CaNAM	Carers Needs Assessment Measure
ED	Eating Disorder
ED-RR	Eating Disorder Readiness Ruler
EDE-Q	Eating Disorder Examination Questionnaire
EDSIS	Eating Disorders Symptom Impact Scale
FBT	Family-Based Treatment
MCH PED Program	McMaster Children’s Hospital Pediatric Eating Disorder Program
MILESTONE	Managing the Link and Strengthening Transition from Child to Adult Mental Health Care in Europe
OSFED	Otherwise Specified Feeding or Eating Disorder
PACCS-C	Patient and Carer Collaboration Scale – Carer
RCT	Randomized Controlled Trial
SMSAG-Y	Self-Management Skills Assessment Guide – Youth Report
SMSAG-P	Self-Management Skills Assessment Guide – Parent Report
TRAM	Transition Readiness and Appropriateness Measure
TRAQ	Transition Readiness Assessment Questionnaire
TROM	Transition Related Outcome Measures

## **DECLARATION OF ACADEMIC ACHIEVEMENT**

I, Maria Nicula, declare my thesis to be my own research work. I am the sole author of this thesis document and was involved in all stages of the research project under the supervision of Dr. Jennifer Couturier. The following individuals contributed to the editing and refinement of my thesis work and acted as the members of my thesis committee: Dr. Jennifer Couturier, Dr. Melissa Kimber, Dr. Khrista Boylan, and Dr. Christina Grant. To my knowledge, the content of this document does not infringe on any copyrights.



## **CHAPTER 1: INTRODUCTION**

### **1.1 Eating Disorders in Youth**

Eating disorders (EDs) are severe, distinctive, and biologically based psychiatric illnesses that affect the overall health of those affected (Bhattacharya et al., 2020; Robinson et al., 2015; Schmidt et al., 2016). Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Binge Eating Disorder (BED) represent three of the more well-known EDs (Galmiche et al., 2019). The Diagnostic and Statistical Manual of Mental Disorders recognizes these EDs, as well as Avoidant/Restrictive Food Intake Disorder (ARFID) and Other Specified Feeding or Eating Disorder (OSFED)—each of which have unique diagnostic criteria (American Psychiatric Association, 2022).

The all-cause and suicide mortality risks of EDs, specifically for AN, are markedly higher than other mental disorders (Chesney et al., 2014); this finding is true not only within clinical samples, but also in the general population of Canada (Pedram et al., 2021)—where the present thesis takes place. If left untreated or not treated properly, EDs can have a chronic course and have the potential to permeate into one’s physical, psychological, social, and occupational areas of life (Bhattacharya et al., 2020; Neumark-Sztainer et al., 2011; Robinson et al., 2015). Most EDs have an onset during adolescence (between the ages of 15 to 19), a period of significant and highly sensitive development, and they often persist into one’s adulthood (Bhattacharya et al., 2020; Schmidt et al., 2016; Treasure et al., 2005). These disorders are highly comorbid with other serious medical and psychiatric conditions, such as depression and anxiety (Bhattacharya et al., 2020). Caregivers of individuals with EDs are also strongly affected, as they often feel more distressed than the individual with the disorder (Matthews et al., 2018). This has

been attributed to the egosyntonic (defined as compatible with one's beliefs, behaviours, or thoughts) nature of these disorders (Matthews et al., 2018), which has the potential to hinder the affected individual's motivation for recovery or treatment engagement (Gregertsen et al., 2017; Vitousek et al., 1998). EDs are also costly for our healthcare system. In 2017 and 2018, Canada spent an average of \$24,017 on each person with an ED, which is 1.79 times more than what is spent on a person with schizophrenia (Stone et al., 2021).

A systematic review comprised of 94 studies found that the lifetime prevalence (proportion of the population that had the condition at any point in one's life) of any type of ED among adult women and men are 8.4% and 2.2%, respectively (Galmiche et al., 2019). When considering the major EDs, the lifetime prevalence for women and men for AN was 1.4 % and 0.2%, for BN was 1.9% and 0.6%, and for BED was 2.8% and 1.0%. With respect to youth, an older study using a sample of 4,746 American youth from middle or high school found the point prevalence (individuals who met diagnostic criteria at a set point in time) of these same disorders to be 0.04% and 0% for AN, 0.3% and 0.2% for BN, and 1.9% and 0.3% for BED among girls and boys (Ackard et al., 2007). One of the only studies exploring ED epidemiology among adolescents in a Canadian sample (n=3,043, Grades 7 to 12) found that, among girls and boys, 4.46% and 2.21% met criteria for a full-threshold ED, while 5.08% and 1.14% met criteria for any subthreshold ED; more specifically, between girls and boys, 1.41% and 0.41% met criteria for clinical/subclinical AN, 5.70% and 2.04% for clinical/subclinical BN, 0.68% and 0.16% for BED (Flament et al., 2015).

As evident from these prevalence estimates, females are significantly more likely to be diagnosed with an ED (Bhattacharya et al., 2020; Galmiche et al., 2019; Udo & Grilo, 2018). The variation in the epidemiological estimates of EDs in the literature is likely due to differences

in the type of prevalence reported (e.g., point or lifetime), choice of research methods, the ED diagnostic criteria or thresholds used, and characteristics of each sample, which makes it difficult to confidently ascertain accurate prevalence rates for EDs (Bhattacharya et al., 2020; Galmiche et al., 2019). Importantly, available prevalence and cost estimates have been generated from data on those who have been diagnosed or treated for an ED which excludes subclinical and undiagnosed individuals who do not seek diagnosis or treatment for their symptoms (Nicula et al., 2022; Stone et al., 2021).

The COVID-19 pandemic is a significant contributor to the changing prevalence of EDs, and has been described as unmasking “a global eating disorder public health crisis that was already building” (Katzman, 2021). A recent Canadian study found that new AN and Atypical Anorexia Nervosa (AAN) diagnoses and hospitalizations both significantly increased in patients presenting to six tertiary-care hospitals across Canada during the first wave of the pandemic (March to November 2020), compared to pre-pandemic timepoints (January 2015 to February 2020) (Agostino et al., 2021). In this study, patients who were diagnosed during the first wave also had significantly worse markers of disease severity, including faster progression, greater mean weight loss, and lower heartrate.

Treatments for EDs can be complex, depending on individual needs, and usually involve psychological therapy, medical supervision, medication, and/or nutritional counselling (Bhattacharya et al., 2020). According to clinical practice guidelines, the strongest evidence-based treatments for EDs include Family-Based Treatment (Lock & Le Grange, 2015)—specifically for youth with AN and BN—and Cognitive-Behavioural Therapy (Couturier et al., 2020; Hay et al., 2014). Patients can receive these treatments in either inpatient or outpatient care settings (Bhattacharya et al., 2020). In recent years, the COVID-19 pandemic has complicated

the provision of ED treatment, due to disruptions in service delivery and the extension of waitlists from months to years (Spettigue et al., 2021; Spigel et al., 2021; Weissman & Hay, 2022).

## **1.2 The Problem of Transition**

The continuation of EDs into adulthood often requires youth receiving pediatric treatment to transfer their care to adult mental health services (Broad et al., 2017; Treasure et al., 2005). In the province of Ontario in Canada, patients receiving care from pediatric programs are required to transfer their care to adult care by the age of 18 (Schraeder et al., 2019; Toulany et al., 2019).

At this point of transition, Canadian adolescents with EDs unfortunately experience interruptions in their treatment because of poor transition planning (Dimitropoulos et al., 2013; Nadarajah et al., 2021). This experience leaves adolescents to feel anxious, lonely, and stressed (Nadarajah et al., 2021), causing some patients to turn back to their eating disorder to gain a sense of control (Lockertsen et al., 2020a). Since adolescents are no longer required to involve their parents in their care after turning 18, parents report feeling lonely, distressed, lost, and powerless from the lack of information and support, and overwhelmed with the responsibility placed on them to manage or seek support for their child's ED, while trying to fulfill other obligations (Lockertsen et al., 2021; Nadarajah et al., 2021; Singh, 2009).

This discontinuity in care can lead transition-age adolescents with EDs to disengage from services and to deteriorate with regards to their disorder (Dimitropoulos et al., 2013; Lockertsen et al., 2020b). Additionally, youth with EDs face an increased risk of relapse post-transition (Dimitropoulos et al., 2015; Lockertsen et al., 2021). Of 15 Canadian youth from a qualitative study who had recently transitioned out of pediatric care, six relapsed immediately after

transition even after pursuing ongoing treatment while the remaining nine relapsed within a few years of discharge from pediatric care (Dimitropoulos et al., 2015). Patients reported only being followed more closely when they were unstable or in crisis (Lockertsen et al., 2020a).

The healthcare transition for adolescents with EDs out of pediatric care upon turning 18 is disjointed, causes distress, and requires evidence-based solutions. In response to the emerging dilemma of difficult and unsuccessful healthcare transitions among youth with chronic illnesses, Blum and colleagues published a commentary in 1993 establishing a definition of transition, stating a call-to-action, and proposing suggested clinical and research areas that merit improvement (Blum et al., 1993).

### **1.3 What is an optimal transition?**

Blum and colleagues define transition as the “purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centered to adult-oriented health care systems”, with the optimal goal of transition being “to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive” (Blum et al., 1993). Blum’s call-to-action has cultivated significant interest in developing and evaluating ‘markers’ of transition success, as well as transition-related programming that is tailored to meet the needs of adolescents with specific conditions. For instance, Singh and colleagues proposed four criteria that are necessary to constitute an optimal transition for adolescents with mental health needs: (1) information transfer (i.e., in the form of a comprehensive referral letter to the adult provider), (2) a period of parallel care between pediatric and adult services, (3) transition planning (i.e., a meeting involving the youth, their

carer, and the pediatric and adult provider), and (4) continuity of care (i.e., enrolment or engagement with adult care soon after the transition) (Singh et al., 2010).

It is important to distinguish transition from the word transfer, as they often used interchangeably. Transfer is defined as “the event when responsibility for healthcare is passed from a child health provider to an adult health provider” (Colver et al., 2020). Both are centred around healthcare, but transfer is limited to that realm, while transition should ideally consider other developmental needs for this age group to meet its true definition (Singh, 2009; Singh et al., 2010). To acknowledge that this transfer does not occur in a silo, the healthcare sector is encouraged to address the adolescents’ context, community, culture, and relationships to tailor the transition, as no one approach will be equally successful for all (American Academy of Pediatrics et al., 2002). By helping adolescents navigate and meet developmentally appropriate goals (i.e., moving out of their parent’s home) in conjunction with their treatment goals, it is more likely that their transition will be successful (Vostanis, 2005).

## **1.4 Transition Experiences, Barriers, and Facilitators**

### **1.4.1 Youth with Chronic Physical Conditions**

Data from a 2000-2001 American survey found that only 16.53% of 4332 youth with special healthcare needs had a discussion with their healthcare provider (HCP) about how their healthcare needs may change in adulthood, developed a plan to address these changes, and saw an adult care doctor (Scal & Ireland, 2005). In the early days of acknowledging transition as an issue, researchers sought to identify barriers that impede youth with chronic illnesses from making a successful transition. To start, adolescents with various physical conditions (e.g., disabilities, diabetes, cystic fibrosis, special healthcare needs) and their parents perceived adult

care to be inferior and more “business-like” compared to the familiar and comforting care provided in the pediatric realm (Gray et al., 2018; Reiss et al., 2005; van Staa et al., 2011). These negative perceptions led adolescents making the transition to fear losing their relationship with their pediatric HCPs and to resist establishing trust with new staff. It is possible that the ambivalence or negative beliefs held by pediatric HCPs about adult care communicated that transition is something to be feared to adolescents and parents (van Staa et al., 2011). Although both parties understand that this transition is necessary for their disorder, parents reported being more anxious about the upcoming transition than the young adults were, making it hard for them to trust their child to take responsibility of their treatment, ultimately causing tension in the relationship. The lack of knowledge and self-management skills among adolescents was also reported as a barrier due to their dependency on parents to navigate their care (Gray et al., 2018).

Both pediatric and adult HCPs agree that pediatric care pampered patients, while adult services left youth and parents to fend for themselves (van Staa et al., 2011). However, adult HCPs sustain that most young people are ready to be more involved in their care, as they have voiced feeling ‘patronized’ in the pediatric setting and by parents. Pediatric HCPs qualify that this intense oversight is necessary due to poor treatment adherence, high drop-out rates, and psychosocial problems. Additionally, the provision of illness education at time of diagnosis during childhood often allows stakeholders to assume that the patient is equally as informed about how their illness will manifest in adolescents and beyond—which poses as another transition barrier (Gray et al., 2018). Finally, a lack of access to adult care has also been reported to play a role in low rates of optimal transition among chronically ill adolescent populations.

Overall, most young adults living with chronic physical illnesses and their parents found this transition to be more difficult than anticipated and the consensus among all stakeholders was

that the transition process should be improved (van Staa et al., 2011). In addition to the barriers that are present for those with physical conditions however, it is also crucial to also explore the unique challenges faced by mentally ill adolescents to better understand the experience of youth with eating disorders during transition.

#### 1.4.2 Youth with Mental Disorders

As the mental health field grew, the problem of difficult and uncoordinated transitions was brought to the attention of clinicians and researchers from the field, who carried out similar qualitative work in their populations. In the late 2000's, Singh and colleagues led the TRACK study, which was seminal in providing evidence for the current state of transitional care for mentally ill youth (Singh et al., 2008; Singh et al., 2010). As part of this project, the team found that existing transition protocols in England did not specify how youth should be prepared for transition, differed in various important procedures and logistics, and did not adequately address how to ensure continuity of care for those not accepted by adult services (Singh et al., 2008).

Of 154 adolescents identified by the TRACK study who reached transition age, 90 (58%) continued to adult services while the remaining 64 (42%) did not fully transition (Singh et al., 2010); importantly, only 4 of the 90 who transitioned met Singh's four criteria for an optimal transition, outlined earlier. Similar results were found in a recent study that retrospectively studied the care pathways of 760 youth in pediatric services who qualified for adult treatment (Reneses et al., 2022); 56% of young people in that sample dropped out of pediatric treatment before transitioning to adult services, representing a "black hole" in this process. When considering these high drop-out rates however, it is important to note that treatment drop-out rates among children and adolescents, more generally, ranges from 28-75% and are highly



dependent on study methodology (de Haan et al., 2013; Reneses et al., 2022). Some known reasons for this break in care include differences in pediatric and adult HCPs' expectations of the adolescent in terms of autonomy and competence (Loos et al., 2018) and the youths' preference for self-management (Sheppard et al., 2018). The lack of recognition among adolescents of their need for help limits their continued search for treatment options (Zachrisson et al., 2006)—especially given that parents often initiate this treatment on their behalf during childhood (Ryan et al., 2015). Some barriers that hinder youth seeking or continuing with mental health treatment, that are unique from those faced by individuals with physical illnesses, include the preference to rely on themselves, a lack of mental health literacy, and not recognizing symptoms as warning signs (Loos et al., 2018). On a systemic level, most pediatric clinics for mental health services do not have a clearly defined destination program in the adult system, unlike services provided to individuals with chronic physical disorders (Schraeder et al., 2019). In Canada, many mental health services outside of the hospital are not covered by the healthcare system (Stunden et al., 2020); Canadian youth have experienced a financial burden related to accessing adult-focused care and have found many resources to be inaccessible or expensive, and as a result, some prefer pharmacological treatment.

Although eating disorders are comprised of both medical and psychological aspects, the outlined transition barriers expressed by youth with physical and mental illnesses respectively are not sufficient to understand the unique challenges faced by adolescent with an eating disorder. For this, a tailored exploration of their experience is necessary.

### 1.4.3 Youth with Eating Disorders

In recent years, a select group of researchers have identified transition barriers from the perspectives of youth with EDs, their parents, and their HCPs. Early qualitative work was led by Canadian researcher Dr. Gina Dimitropoulos and their team based in Calgary, Alberta, followed by Lockertsen and colleagues from Norway, and finally, Nadarajah, Couturier, and colleagues based locally at McMaster Children's Hospital in Hamilton, Ontario, Canada.

Starting with the patient perspective, youth reported being inadequately prepared for transition (Lockertsen et al., 2020a; Nadarajah et al., 2021), evidenced by the rare, inconsistent, and lately-timed transition planning discussions with their pediatric HCPs (Dimitropoulos et al., 2015; Nadarajah et al., 2021). Similar to youth with chronic illnesses, participants found pediatric care to be a “warmer” and “more caring” environment, with high involvement from their parents (Lockertsen et al., 2020a). Suddenly, they were expected to manage their own recovery in adult care, and parents were treated like “distant relatives”. Youth initially held back from their new HCPs as it takes time to develop a comfortable therapeutic relationship and because they felt that the adult HCPs held preconceptions of their disorder (e.g., that they were not self-sufficient). Having to repeatedly explain their story and history to potential adult HCPs was also draining (Lockertsen et al., 2020a; Nadarajah et al., 2021). Whether real or imagined, a lack of access to adult services (e.g., long waitlists, geographical distance from adult program, rigid admissions criteria, inflexible or single treatment modalities) was enough to deter adolescents from pursuing continued treatment (Dimitropoulos et al., 2015). Youth experienced a discontinuity in professional support while waiting for entry to adult care on the aforementioned long waitlists (Nadarajah et al., 2021) and those who relapsed in their ED attributed this to a lack of monitoring from HCPs (Dimitropoulos et al., 2015). Although family doctors are well-placed

to support adolescents during their transition given their purview over the individual across the lifespan (Schraeder et al., 2019), youth felt that their family doctors could not sufficiently support their care after transition, due to a lack of ED-related knowledge (Dimitropoulos et al., 2015; Nadarajah et al., 2021). The barriers offered by parents of youth with EDs align with those outlined by adolescents more generally, such as incompetency of family physicians to support the adolescent during transition and strict admissions criteria to enter adult services (Lockertsen et al., 2021). However, parents also noted that a lack of support for parents and the adolescents' discharge from the pediatric program prior to being capable or ready as barriers to transition.

One well-documented transition barrier for youth with EDs identified by HCPs is the marked difference between pediatric and adult treatment approaches and philosophies (Dimitropoulos et al., 2013; Lockertsen et al., 2020b; Winston et al., 2012). In the pediatric treatment setting, the participation of the child can be involuntary, treatment is often based around family interventions, such as Family-Based Treatment (FBT), and, regardless of the precise treatment, parents are typically highly involved (Dimitropoulos et al., 2013; Winston et al., 2012). Meanwhile, adult treatment focuses solely on the affected individual, requires voluntary participation, and is based upon self-management approaches, such as Cognitive Behavioural Therapy (CBT), which encourages the patient to take control over their own care and recovery. The significant shift in treatment approach faced by adolescents who have come to rely on familial support contributes to the potential difficulty of this transition in care (McGorry, 2007; Winston et al., 2012).

The differing approaches employed by pediatric and adult care cultivate mistrust between these two settings which may lead HCPs to inadvertently convey their biases or beliefs about the opposite program when working with the adolescent, as reported in one qualitative study

(Lockertsen et al., 2020b). Pediatric HCPs have reported focusing on ending the therapeutic relationship prior rather than on transitioning the adolescent to adult care due to negative beliefs (e.g., adult care is unsupportive and cut-throat), while adult HCPs believe that pediatric care “mothers” the patient too much and do not adequately prepare them for the adult service. Some adult HCPs acknowledge the benefits of parent involvement—as asking a newly-transitioned young adult to take on too much responsibility too soon can cause relapse—and thus encourage the adolescent to involve or invite their parents. Finally, some barriers that HCPs from both realms agree on include they sometimes lack the confidence to deliver developmentally-appropriate care that meets patient and parents’ high expectations (Lockertsen et al., 2020b) and that transition should be based on an adolescent’s readiness, rather than their age (Dimitropoulos et al., 2013).

The overlap in identified transition barriers for youth affected by physical conditions, mental illness, and EDs indicates that this experience is rather universal. With these experiences and barriers in mind, it is now important to consider stakeholder recommendations to improve the transition process.

### **1.5 Stakeholder-Proposed Recommendations for Improving Transition**

In response to the barriers that make transition difficult, stakeholders (e.g., youth, parents, HCPs) affected by chronic physical and mental illnesses made recommendations that can be used to inform ways to support youth with eating disorders through this period. As Gray and colleagues acknowledged, a lot of transition work is “developing independent of other chronic conditions and cross-disease resources are under-utilized” (Gray et al., 2018). Since type of condition was not associated with any difference in responses about barriers (van Staa et al.,

2011), it is encouraged to apply any recommendations thought to be helpful, as they are not restricted to any specific disorders (Colver et al., 2020; Gray et al., 2018).

Many of the documented recommendations concern pediatric treatment itself, prior to transition planning. Over time, HCPs from the pediatric team should foster independence and autonomy within the adolescent; this can be done by gradually integrating them in care-related decisions, asking youth what they want their transition to look like, using youth-appropriate language, giving them more responsibility during appointments and teaching them more about their condition, informing them of the rationale behind their chosen treatments, as well as seeing them alone for part of the visit and regularly assessing their transition readiness (Blum et al., 1993; Dimitropoulos et al., 2015; Dimitropoulos et al., 2013; Gray et al., 2018; Nadarajah et al., 2021; Reiss et al., 2005; van Staa et al., 2011). Adolescents should be provided with tools and opportunities to develop and practice these practical self-management skills (Dimitropoulos et al., 2013; Nadarajah et al., 2021)—such as learning when to seek support for their ED or a potential relapse—by doing a test run prior to entering adult care (Dimitropoulos et al., 2015). This will ultimately also promote the adolescent’s confidence in managing their health condition (Colver et al., 2020) well before the transition itself, and will prepare them for other life changes at this time, such as moving from home or going to university (Dimitropoulos et al., 2013).

As age of transition approaches, it is key that planning should start as early as possible, even in early adolescence (Gray et al., 2018) or at time of diagnosis (Reiss et al., 2005), to allow the adolescent and family enough time to plan (Nadarajah et al., 2021; Singh et al., 2010), make decisions, and understand their choices (van Staa et al., 2011). The pediatric team should have a more active role in transition planning (Lockertsen et al., 2020a), but this should be balanced with their high workload and time constraints (Nadarajah et al., 2021). Pediatric HCPs should

formally close the therapeutic relationship to allow the adolescent to move on and facilitate the development of new relationships with their adult HCPs (Reiss et al., 2005). Other considerations for success at time of transition are to be sensitive to or avoid carrying out this healthcare transfer simultaneously with other life transitions (American Academy of Pediatrics et al., 2002; Singh et al., 2010) and to value these other aspects of development when supporting youth through this transition (Vostanis, 2005).

The adolescent should meet the adult HCP provider before transition (Colver et al., 2020), with some recommending that this process is facilitated by the pediatric HCP (Gray et al., 2018; Lockertsen et al., 2020a). The most popular pre-discharge recommendation is to have a meeting with the pediatric and adult HCPs, family, and adolescent (Nadarajah et al., 2021; van Staa et al., 2011) to discuss the upcoming transition (Dimitropoulos et al., 2015); one paper also suggested for primary care to be involved in this joint planning (Colver et al., 2020).

Stakeholders recommended that the adolescent (and parent) should at least meet the adult HCPs prior to transfer or even tour adult settings to alleviate concern (Dimitropoulos et al., 2015; Gray et al., 2018). Some emphasize the importance of active involvement by adult services in this process prior to discharge, as sitting on a waitlist is “unacceptable” (Singh et al., 2010).

Adolescents and parents should receive education from providers on the importance of a developmentally- appropriate and coordinated transition (Rosen et al., 2003), how pediatric and adult care settings and cultures differ (Dimitropoulos et al., 2015; Dimitropoulos et al., 2013; Reiss et al., 2005; Singh et al., 2010) and what to expect from adult services (Singh et al., 2010). This could be presented in the form of a booklet with information about the transition process (Nadarajah et al., 2021). Framing transition as a positive event, like a graduation, and emphasizing the benefits of adult care (e.g., developmentally appropriate, less time-consuming

clinic visits, adolescent is treated like an adult) is important for this education (Gray et al., 2018). To stay organized, one solution is to use checklists (van Staa et al., 2011), a logbook (Singh et al., 2010), or a structured plan (Gray et al., 2018) during transition. An app called “Thought Spot” is a Canadian app designed to improve help-seeking among transition-age youth with mental health concerns that has recently been evaluated on its usability and user engagement (Shi et al., 2021). Although the app exhibited low levels of long-term user engagement, this offers a starting point as another tool that can be used to motivate and help youth continue treatment.

There was a well-documented need for a designated transition coordinator or navigator during this period (Dimitropoulos et al., 2013; Singh et al., 2010), so that they may identify young people requiring transition support, prepare them for the transfer, connect them with future resources, help them navigate new healthcare systems, and offer post-transfer support (Dimitropoulos et al., 2019; Gray et al., 2018; Nadarajah et al., 2021). Parents should be involved (Dimitropoulos et al., 2013; Nadarajah et al., 2021; van Staa et al., 2011) and supported (Blum et al., 1993) throughout the transition process, but this should be sensitively negotiated and balanced with the autonomy of the adolescent (Nadarajah et al., 2021; Singh et al., 2010). As part of the education, parents can also be informed of their changing role and receive guidance on how to gradually transition responsibility for their health management to their child (Dimitropoulos et al., 2013; Gray et al., 2018). Lastly, communication between the pediatric and adult services can be enhanced by providing a standardized, comprehensive referral letter or a “transition passport”, detailed with a risk assessment and the adolescent’s medical history, to the future adult program (Dimitropoulos et al., 2013; Nadarajah et al., 2021; Reiss et al., 2005; Singh et al., 2010). Support groups and peer support have also been highlighted in the literature —both to provide hope and connection to resources for parents from other parents of children with the

disorder and to uplift and motivate youth after hearing from others who have recovered from an eating disorder (Beveridge et al., 2019; Cleverley et al., 2020; Couturier et al., 2020; Franklin et al., 2019). Peer support approaches can be used during the transition period to expose those adolescents and parents to others' transition experiences.

After discharge, adolescents should communicate with the pediatric HCPs or a family member as a monitoring mechanism, which can offer support, accountability, and potentially help with transition success (Dimitropoulos et al., 2015; Lockertsen et al., 2021). Pediatric HCPs can also check in with the adult HCPs a few months after transfer (Gray et al., 2018). Given the distress experienced by families of individuals with EDs, it may be helpful for them to be involved in the adolescents' adult ED care—not only the transition—in a way that respects legal and relationship boundaries of the patient, but also allows for discussion of treatment plans (Boland et al., 2022; Colver et al., 2020; Lockertsen et al., 2020a). Youth have requested that adult HCPs tailor their clinical approach to their transition wishes (Colver et al., 2020), to be more welcoming and responsive to their needs (van Staa et al., 2011), and understand that they need time to open up (Lockertsen et al., 2020a).

Many suggestions at the systemic and policy level were also made. Rather than be determined by an age cut-off, transition timing should be flexible and depend on a combination of other factors to determine an adolescent's appropriate time for transition, such as developmental readiness, psychological needs, emotional stability, complexity of condition, adolescent and family characteristics, and the availability of skilled adult HCPs (Blum et al., 1993; Dimitropoulos et al., 2013; Singh et al., 2010; van Staa et al., 2011). Given their unique position to monitor youth across the lifespan (Schraeder et al., 2019), family doctors should be involved in the post-transition medical care for young adults with EDs (Dimitropoulos et al.,



2013; Rosen et al., 2003). In response to the documented inadequacy of knowledge among primary care practitioners about EDs, they should receive more training about how to medically manage patients transitioning between ED services (Nicula et al., 2022) and how to re-orient their clinical interactions to address their growth in maturity and self-management (American Academy of Pediatrics et al., 2002). In fact, pediatric and adult HCPs would also benefit from training on how to deliver developmentally appropriate care (Colver et al., 2020; Rosen et al., 2003) to address the distinct subcultures between pediatric and adult services (Reiss et al., 2005) to build their clinical competency when addressing transition-related and other needs of their patients (Lockertsen et al., 2021; Lockertsen et al., 2020b). Other recommended changes for at the systemic level include a need for pediatric and adult services to fund transition-focused care (Colver et al., 2020), a period of parallel care and extended pediatric healthcare provision past the age of 18 (Nadarajah et al., 2021) or transition-specialized clinics and care pathways (van Staa et al., 2011), efforts to make adult services more financially and administratively accessible to adolescents with chronic health conditions (Rosen et al., 2003), offering pediatric and adult HCPs more opportunities to collaborate more closely together (van Staa et al., 2011). Overall, HCP organizations should commit, as a whole organization, to provide better transitional healthcare (Colver et al., 2020).

## **1.6 Interventions Developed to Improve Transition**

### **1.6.1 Transition Interventions Implemented in Youth with Chronic Physical Conditions**

Based on recommendations from the literature, there is a body of research that has examined transition interventions that have been implemented among adolescent populations with physical health conditions (Campbell et al., 2016; Colver et al., 2020). A 2016 Cochrane

review found two American, one Canadian, and one Australian trials that evaluated the effectiveness of interventions aimed at improving the transition of care for adolescents with chronic physical conditions from pediatric to adult services (Campbell et al., 2016). Transition interventions may lead to slight improvements in disease management and transition readiness, but not to improvements in well-being or quality of life. There was little or no difference in rates of transfer from pediatric to adult care at 12-months-follow-up. This highlights the lack of evidence to guide the development of transitional care, as there are only four studies focused on evaluating proposed interventions to support this transition. This evidence is also limited in its applicability as it only follows adolescents for a maximum of one-year post-transition and does not report on long-term outcomes.

A more recent Canadian randomized control trial (RCT) with 205 young adults with type 1 diabetes (T1D) were randomized to receive the transition program (with a transition coordinator) or standard care (Spaic et al., 2019). Participants who received the intervention reported feeling more satisfied with their care and having less distress over their illness than those who received standard care. However, these benefits were not sustained at follow-up, as there was no significant difference between groups in the number of adolescents who attended at least one clinic visit in the adult diabetes clinic. Although this study addressed one of the more popular recommendations made in the literature—a transition coordinator—adjustments are necessary to ensure that similar interventions predict higher uptake of transition-age youth into adult treatment.

An observational cohort study based in the UK invited 374 youth with T1D, cerebral palsy, or autism spectrum disorder and an associated mental health problem to participate in any of nine transition supports over the course of four years (Colver et al., 2018). The most highly

used supports were a coordinated team, an age-banded clinic, and holistic life-skills training. Appropriate parent involvement, promotion of health self-efficacy, and meeting with adult team before transition were associated with improvements in self-reported well-being, satisfaction with services, and autonomy in one's appointments. The most notable aspect of this study was that it offered participants with the choice of supports, which is a recommendation made in recent qualitative ED work (Nadarajah et al., 2021) to allow patients to pick the ones that are most suitable to their circumstances. Although this study sample was mostly comprised of youth with physical conditions, a proportion of the sample did have mental health needs, meaning these results may be more relevant for the ED population of interest EDs in the current study.

#### 1.6.2 Transition Interventions Implemented in Youth with Mental Health Needs

Compared to chronic physical conditions, little comparable work has been done in the mental health field (Singh, 2009). Recently however, many of the researchers from the TRACK study, which highlighted a need for models to improve transition for youth with mental health needs, are leading the MILESTONE (Managing the Link and Strengthening Transition from Child to Adult Mental Health Care in Europe) study, which is intended to address this need in Europe (Tuomainen et al., 2018). Two transition-related measures will be developed, following patient-reported outcome measure development guidelines, and implemented by this team to evaluate the larger cohort study (Santosh, Adams, et al., 2020); specifically, the two measures are the Transition Readiness and Appropriateness Measure (TRAM) which will help clinicians assess readiness and appropriateness and the Transition Related Outcome Measures (TROM) which will evaluate transition outcomes. To date, the TRAM has been validated using a subsample of the cohort study and has good reliability (Santosh, Singh, et al., 2020). The

MILESTONE study will randomize 840 transition-age youth from eight European countries to receive the intervention (a monitored transition using the TRAM as a decision aid) or usual care (Singh et al., 2017). The study is likely underway, as no results have been published yet.

Although promising, this research program is specific to Europe, non-specific to EDs, involves an intervention that does not address many of the recommendations outlined in the literature, and there is a pressing need for intervention now, with prevalence rates of ED cases rising in Canada (Agostino et al., 2021).

### **1.7 Study Rationale**

Many of the papers that explored the transition needs of youth with physical conditions were published over two decades ago (American Academy of Pediatrics et al., 2002; Blum et al., 1993; Rosen et al., 2003) and began to explore interventions to support the transition period in the last decade (Campbell et al., 2016; Colver et al., 2018; Spaic et al., 2019). For populations with mental health needs, this research process was delayed by around ten years, both when exploring barriers (Singh, 2009; Singh et al., 2010) and testing interventions that are still underway (Singh et al., 2017; Tuomainen et al., 2018). This lag can be at least partly attributed to mental health stigma, which affected the distribution of research funds. In 2003, only 5% of Canadian health research budgets were for mental health, when one in five Canadians were affected by mental illness at the time (Arboleda-Florez, 2003). This pattern of research delay is occurring even later for the ED field, possibly as an extension of the continued stigma and lack of knowledge about EDs in the general population (Nicula et al., 2022; O'Connor et al., 2021; Puhl & Suh, 2015). Since barriers and recommendations for the transition experienced by youth with EDs have only been published in the last decade (Dimitropoulos et al., 2015; Dimitropoulos

et al., 2013; Lockertsen et al., 2021; Lockertsen et al., 2020a, 2020b; Nadarajah et al., 2021), it is only expected that there is no known empirical evidence for stakeholder-informed transition interventions that are specifically for ED populations. Importantly, some existing research studies interventions that are adjacent to this gap in the literature and practice but do not address this issue specifically; these include interventions designed to help adult patients transition from more to less intensive forms of ED treatment (Bryan et al., 2021) or from inpatient to outpatient adult care (Adamson et al., 2019), as well as an open trial assessing the feasibility and acceptability FBT that was adapted for transition-age youth (Dimitropoulos et al., 2018). Although this last intervention is helpful for transition-age youth, it is an adaptation and extension of an existing pediatric treatment rather than being focused on supporting transition to adult care.

Although transition is a vulnerable and difficult period for youth with any illness that can persist into adulthood, the lack of research, interventions, protocols, and supports focused on improving the transition for youth with EDs is particularly concerning, given the potential consequences at play without continued treatment. In response to this gap identified in the literature (Nadarajah et al., 2021), the following study will assess the feasibility of a transition intervention for transition-age youth with EDs and their families.

## **CHAPTER 2: METHODOLOGY**

### **2.1 Declaration of Problem**

Canadian adolescents with EDs have reported having challenges when transitioning out of pediatric care (Nadarajah et al., 2021), which puts them at a high risk of relapse and disengagement with future services (Dimitropoulos et al., 2015). Although many recommendations have been made in the literature to address barriers to transition, none have been applied in an intervention to support youth and their parents through the transition out of pediatric ED care, nor has such an intervention been evaluated.

### **2.2 Study Purpose**

The main purpose of the present study was to assess the feasibility of a literature- and stakeholder-informed intervention designed to improve the transition out of pediatric care among a sample of adolescents with EDs and their parents from Hamilton, Ontario. Feasibility studies are a crucial starting point given their emphasis on determining whether an intervention can be done and how it should be evaluated, prior to committing to larger-scale research that would evaluate its effectiveness (Eldridge et al., 2016) .

Quantitative and qualitative data were also collected to address five secondary purposes of the study—details of how these aims were met will follow. Firstly, the feasibility of the research processes and measures utilized in the study was assessed, so that recommended or necessary changes are made when evaluating this intervention in the future. Also, capturing the number of adolescents who transitioned offered a raw snapshot of how many adolescents arrived at their destination program. The intervention experience from the perspectives of the

adolescents and parents were qualitatively captured to provide context and feedback on the helpfulness of the intervention. Lastly, changes in various participant outcomes related to transition success before and after the intervention provided a preliminary indication of intervention effectiveness.

### 2.3 Research Questions

To address these study purposes, multiple research questions were posed in the present study. The two mixed methods research questions each consisted of a central mixed methods question and associated quantitative and qualitative subquestions (Creswell & Plano Clark, 2018). The PICO(T) and EPPiC question development guidelines were used to prepare the remaining four purely quantitative and qualitative research questions, respectively (Kalu, 2019; Riva et al., 2012).

The primary mixed methods research question of this study was:

- 1) What is the feasibility of the intervention?
  - a. What are the rates of completion and duration to complete the intervention and each component among participating adolescents and parents? (*Quantitative*)
  - b. What are the perspectives of adolescents and parents regarding the convenience, accessibility, timing, and ease of the intervention and each component?  
(*Qualitative*)

The following secondary research questions were also addressed in this study:

- 2) What is the feasibility of the research processes and measures?
  - a. What are the rates of recruitment and retention as well as completion and duration to complete each study measure among adolescents and parents? (*Quantitative*)

- b. What are the perspectives of adolescents and parents regarding the convenience, accessibility, timing, and ease of study communication and measures?  
*(Qualitative)*
- 3) At the end of the study, what adult mental health supports are adolescents planning to transition to, and how many have successfully transitioned to their planned adult care destination within one-month following their 18<sup>th</sup> birthday? *(Qualitative)*
- 4) What are adolescents' and parents' perspectives and experiences of the intervention throughout the transition and at post-intervention? *(Qualitative)*
- 5) Among participating adolescents, what are the differences in their self-reported a) range and severity of eating disorder symptoms, b) readiness for transition, c) awareness of their condition and ability to make relevant healthcare decisions, and d) readiness and motivation to change various ED symptoms and behaviours, from pre- to post-intervention? *(Quantitative)*
- 6) Among participating parents, what are the differences in their self-reported a) burden and impact of ED symptoms on their lives, b) needs, c) self-efficacy and collaboration among other carers, and d) perception of their child's awareness of their condition and ability to make relevant healthcare decisions, from pre- to post-intervention? *(Quantitative)*

## **2.4 Mixed Methods Study Design**

A convergent mixed methods design, specifically the parallel-database variant (Creswell & Plano Clark, 2018), was used to assess the primary study outcome of intervention feasibility in the present thesis. Following this design, qualitative and quantitative data were collected in parallel, analyzed independently, and then merged during the interpretation phase. The



quantitative strand followed a single-arm pre- and post-test design that involved the collection of self-report measures from a sample of 10 adolescents and parents preparing for a transition out of pediatric ED services and the quantitative tracking of feasibility-related information. The qualitative strand of the study was guided by the principles of Qualitative Description, which informed the collection of written reflections and conduct of post-intervention interviews with participants from the same sample. After separate analysis, quantitative and qualitative data was integrated using a narrative approach—a description of quantitative and qualitative findings side-by-side (Fetters et al., 2013)—with the purpose of converging, corroborating, and comparing findings from each strand to reach a comprehensive understanding of intervention feasibility. Although both strands shared equal importance, the interpretation of the merged results began with quantitative data and was complemented by qualitative data—known as the explanatory unidirectional model of guiding analysis in convergent mixed method studies (Moseholm & Fetters, 2017). This approach was used to frame and organize the integration of the two research strands and to provide a comprehensive understanding of the phenomena of interest. *Appendix B* provides a detailed chart of the methodology and data used to address each of our primary and secondary research questions.

Compared to other mixed methods designs, the convergent parallel approach was chosen for this study for multiple reasons (Creswell & Plano Clark, 2018). Firstly, the efficiency of collecting and analyzing both qualitative and quantitative data simultaneously was ideal for the limited time offered by a Master's timeline. This design also had better alignment with purpose of the study—understanding the perceptions and reality of the feasibility of the intervention—than the sequential order of other designs would have. Similarly, the present study's purpose of integration—to converge, corroborate, and compare data from the qualitative and quantitative

approaches—fit well with the convergent design (Onwuegbuzie & Collins, 2007). If the purpose of integration was to develop a quantitative measure or intervention or to explain significant results, an exploratory or explanatory sequential design may have been used, respectively.

Lastly and more generally, a mixed method approach was chosen for this study as it offers the advantages of both quantitative and qualitative methods, which is otherwise not possible when using a strictly qualitative or quantitative research design (Doyle et al., 2009). While quantitative research is lauded for its ability to draw conclusions for large numbers of people, examine probable causes and effects, and introduce limited bias, it has been criticized for being largely researcher-driven and failing to directly consider participants' experiences in the context or setting they live in (Creswell, 2013; Creswell & Plano Clark, 2018). Meanwhile, qualitative research allows the researcher to capture participants' experiences of a phenomenon within their context and provide rich detail, but these findings have limited generalizability due to the small sample used and their interpretation is highly dependent on the researcher. Used together, the strengths of one approach can address the weaknesses of the other. Therefore, the results of a study using a mixed method approach are likely to be more useful and comprehensive when answering research questions (Johnson et al., 2007).

## **2.5 Sampling Strategy**

Compared to purely quantitative or qualitative research, sampling decisions are typically more complex in mixed methods research as they need to accommodate both research components and depend on the time order and purpose of mixing data (Onwuegbuzie & Collins, 2007) To frame the sampling approach for this convergent parallel mixed methods study, an identical concurrent mixed sampling design was used because the quantitative and qualitative

phases occurred concurrently and used the same participants (Onwuegbuzie & Collins, 2007). After considering the methodology literature on sampling techniques, a combination of three techniques were employed—convenience, criterion, and maximum variation sampling—to generate an understanding of how feasible the proposed intervention is. If future research is recommended based on the results of this feasibility study, subsequent mixed methods projects can utilize more probabilistic sampling approaches that follow sample size calculations to reach adequate power when generalizing the findings from the sample to the target population.

Convenience sampling, a sampling approach used by researchers when selecting settings, groups, or individuals that are available and willing to participate (Collins, 2010; Palinkas et al., 2015), was used to recruit the sample. Thus, any interested and eligible participants who were interested to participate were considered for study selection. The factors that influenced the selection of this sampling choice over other probabilistic sampling techniques are outlined in the limitations section of this thesis. Secondly, criterion sampling is a purposive sampling technique that allows for the selection of settings, groups, or individuals, that represent one or more criteria important to the study (Collins, 2010; Palinkas et al., 2015). Here, adolescents and parents who met the eligibility criteria listed in Table 1 were considered for the study for a variety of research- and literature-related purposes. Lastly, maximum variation sampling is used by researchers when the goal is to maximize the range of perspectives and experiences captured in the study (Collins, 2010; Palinkas et al., 2015). To gather a diverse sample in the singular setting of MCH PED, measures were taken to ensure that the adolescents and parents in the study range in terms of ED type (e.g., AN, BN, BED, ARFID) and transition readiness.

**Table 1.** Study Participant Eligibility Criteria and Rationale

	<b>Eligibility Criteria</b>	<b>Purpose</b>
<b>Adolescents</b>	17-years-old	This is the age right before youth are required to transition out of pediatric care in Canada.
	Receiving treatment for their diagnosed ED from McMaster Children’s Hospital’s Pediatric Eating Disorder (MCH PED) Program in Hamilton, Ontario	Participants are required to have an ED and be receiving pediatric treatment for it, as this is the transition population that the intervention is targeting.
	Preparing for a healthcare transition from MCH PED to any ED or mental health program or treatment (e.g., local adult ED services, family doctor monitoring, private psychologist/dietician, low-intensity group intervention) in the next 3-6 months, based on pediatric healthcare providers’ recommendation	The reason for only recruiting adolescents from this program in Hamilton, Ontario is to establish the proof-of-concept of this intervention, tailored to the local context. The decision to involve adolescents who are 3-6 months away from their 18 <sup>th</sup> birthday was informed by recent research that recommended that transition should be planned a year prior to turning 18 (Nadarajah et al., 2021); however, with the timeline of this Master’s thesis, this had to be closer to 3-6 months. This criterion was originally restricted to only those transitioning to the local adult ED program. However, the waitlist for this program for all EDs was estimated to be more than one year due to the recent pandemic. The adolescents in the study and those who were otherwise eligible decided to transition to other forms of care—such as their family doctor, private therapy, or outpatient mental health care for a different mental illness. For this reason, this criterion was expanded to include people transitioning to formal adult care elsewhere.
<b>Parents</b>	Parent or Guardian of an adolescent who meets criteria listed above	The parent or guardian should be involved or related in the care of the adolescent of interest.
<b>Pair</b>	English-speaking	Both criteria were included to ensure that participants could understand and access the study.
	Access to computer with functioning microphone with reliable internet	
	Both parties are interested to partake in the study	To capture the perspectives of both the adolescent and parent in the study.

### 2.5.1. Sample Size

The desired sample size for this mixed methods feasibility study is 10 adolescent-parent pairs—20 participants in total. Evidence indicates that a sample size of 30 is appropriate for a quantitative feasibility study (Lancaster et al., 2004). When collecting interview data for a qualitative study, minimal sample size suggestions range from six to 12 participants (Collins, 2010). Considering these suggestions from the literature, a sample size of 20 participants was reasonable to meet the goals of the current study. Furthermore, capturing both the adolescent and parents' perspectives about transition and having multiple sources of qualitative data (e.g., reflections, interviews) strengthens and compensates for what could be argued to be a small sample size. It is also notable that qualitative researchers often do not rely upon definitive rules when determining the appropriate sample size for their study as this is highly dependent upon the research question, type of qualitative approach used, and the study purpose (Bradshaw et al., 2017; Creswell & Plano Clark, 2018).

## **2.6 Project Timeline**

From project conception to thesis defense, this Master's project took place over a period of 20 months (January 15, 2021 to August 12, 2022) and included a 12-month intervention and data collection period; for a detailed project timeline, see *Appendix A*. The study was open to participant recruitment only during the first nine months of the intervention period (May 15, 2021, to February 14, 2021) to allow all participants to complete the 3-month intervention and to allow researchers to capture whether the adolescent had transitioned to post-pediatric care one-month after their 18<sup>th</sup> birthday. All recruitment, communication, and data collection for the study

was done virtually using SignNow, Qualtrics, and Zoom Healthcare in response to the social distancing policies due to the COVID-19 pandemic.

## **2.7 Recruitment**

The graduate student of the present study (MN) and the supervisor (JC) collaborated with leadership staff at the MCH PED program to recruit eligible adolescents, and their parents, throughout the recruitment period (July 2021 to February 2022). Therapists and pediatricians in the program were asked to identify eligible participants, show them (and their parent, if present) the study flyer, and ask if they would be interested in participating. If interested, adolescents and parents were able to e-mail MN or fill out a contact form with their names and contact information using a link on the flyer or the therapist connected the adolescent or parent with MN through a bridging e-mail. Once interest had been indicated, MN reached out to the adolescent and parent using the provided contact information to organize a time for an orientation meeting. Both the adolescent and parent were contacted about their interest in the study individually to ensure both parties' interest prior to planning an orientation. If the adolescent or the parent did not respond after three contact attempts, MN ceased recruitment efforts.

## **2.8 Participant Activities**

After confirming their interest in the study, the adolescent, parent, and MN planned a time to meet for a short (15 to 20 minute) orientation meeting. Both parties received a blank version of the appropriate consent form to review or prepare questions, and the link for the call after deciding upon a date and time for the orientation meeting. In this meeting, MN led the pair through eligibility screening questions, a discussion about the study rationale, an outline of what

is expected of them during intervention and for data collection, and the risks and benefits of the study. After all questions have been asked and they feel comfortable to continue, participants are asked to sign their respective consent form during the meeting using SignNow. After logging off from the orientation meeting, an e-mail is sent to each participant with an ethics-approved crisis resource list, intervention study materials, and the Qualtrics links for the Adolescent or Parent Baseline Measure Package (to be completed post-orientation) and reflections (to be completed throughout the intervention). Participants were instructed to complete the intervention components and their associated Reflections over the following three months and to notify MN when they were done.

The adolescent and parent receive an e-mail reminder about the study and incomplete intervention components halfway through the three-month period. Once all components are completed or after three months (whichever comes sooner), each participant is provided with a Qualtrics link to complete the appropriate Post-Intervention Measure Package and invited to partake in an individual qualitative interview. Once these are complete, each participant receives a \$25 gift card as a thank you for participating in the study. If the interview takes place before the adolescent's birthday, MN reaches out to the adolescent one month after their 18<sup>th</sup> birthday to ask about the status of their transition to any post-pediatric treatment or program for their ED. For a visual representation of the adolescent and parent's study activities, see *Appendix A*.

## **2.9 Intervention**

The intervention under study was developed for this Master's project and has multiple components that were informed by recommendations from the literature, a stakeholder meeting, and clinical expertise of JC. Only recommendations and suggestions that the team could carry

out with the limited resources and time available for this Master’s project were implemented. An intervention comprised of five unique components, elaborated upon below, was designed and delivered in the present study. The intervention components available to the adolescent and parent are pictured in *Appendix A*.

- 1) **Youth-to-Youth Session:** Each adolescent was invited to participate in a virtual hour-long session moderated by MN and hosted by a young adult who transitioned from MCH PED to a local adult ED program. The selection of the young adult who led the Youth-to-Youth Sessions occurred during a virtual discussion with local stakeholders about this intervention prior to study start; one stakeholder invited this young adult to the meeting, who volunteered to fill this role. Given that they had lived experience of the ED transition and were not in crisis—eligibility criteria that align with Canadian peer support standards (Peer Support Canada, 2022)—this selection was appropriate. In the first half of the session, this Youth-to-Youth Session presenter described their experiences transitioning from pediatric to adult ED care and offered guidance and reassurance about the process to the adolescents attending the session. Participants were encouraged to ask questions and share their transition plans, questions, and fears with the group. This aspect of the intervention was informed by the research in support of peer support in ED populations (Beveridge et al., 2019; Couturier et al., 2020).
- 2) **Parent-to-Parent Session:** Similarly, parents were invited to participate in a virtual hour-long session moderated by MN and led by two parents of children who experienced this healthcare transition from the MCH PED program to local adult ED care or private therapy. These parents were selected using the same process as above: they were invited to the pre-study stakeholder meeting that discussed this intervention and volunteered to



host the Parent-to-Parent Sessions. Their involvement was considered appropriate according to peer support standards (Peer Support Canada, 2022) as they were not in crisis and held lived experience as parents of children who transitioned out of pediatric ED treatment. Following the same format, the two Parent-to-Parent Session presenters led a presentation of their experiences, explained differences between pediatric and adult care, provided suggestions on how to gradually pass healthcare responsibilities onto their child, and offered hope and motivation for the participants in the group. Next, study parents discussed their child's transition and asked questions. This intervention component was supported by the transition literature that underlines the importance of involving and supporting parents throughout the transition process (Blum et al., 1993; Dimitropoulos et al., 2013; Nadarajah et al., 2021; van Staa et al., 2011), including educating parents on their changing role, how to gradually let go of their child's health management to the adolescent, and what to expect from adult care (Dimitropoulos et al., 2015; Dimitropoulos et al., 2013; Gray et al., 2018; Reiss et al., 2005; Singh et al., 2010). This component was also reinforced by research that has suggested a need for peer support for parents of individuals with EDs (Couturier et al., 2020; Franklin et al., 2019).

- 3) **Transition Meeting:** Right after each pair was consented to the study, the pediatric therapist (from the MCH PED Program) was notified via e-mail that they were to facilitate the Transition Meeting with the adolescent during a regularly-scheduled therapy session within the next three months. In the chosen session, the pediatric therapist initiated a conversation with the adolescent and the parent (if invited by the adolescent) about the upcoming transition. This conversation was structured using a meeting guide (provided digitally to all parties prior to the meeting) and a video featuring clinicians

from the local adult ED program about what the adult ED program offers (provided only to the pediatric therapist to be shown in-session). The components of the Transition Meeting were informed by the literature on healthcare transition; specifically, the formal conversation about transition facilitated by the pediatric care provider and the video that captured the differences between pediatric and adult care services and what to expect from adult services (Blum et al., 1993; Dimitropoulos et al., 2015; Dimitropoulos et al., 2013; Lockertsen et al., 2020a; Reiss et al., 2005; Singh et al., 2010).

- 4) **Family Doctor Contact:** Each adolescent was invited to set up a virtual or in-person meeting with their family doctor to notify them of the upcoming transition and discuss how the doctor could support them during their transition out of pediatric care. Once again, the adolescent also had the choice of involving their parent in this component. In the post-orientation e-mail, the adolescent and parent were provided with a short meeting guide to help guide this conversation and a brochure developed by NEDIC and Body Brave for primary care providers that could be provided to their family doctor. The primary care brochure included important and helpful tips on how to manage the care of an individual with an ED (e.g., what vital signs to measure, what blood and ECG tests to order). The Family Doctor Contact component was informed by the recommendation in the literature to involve family doctors in the transition process (Dimitropoulos et al., 2013; Rosen et al., 2003), while the brochure provided to the adolescent and parent was included due to the well-documented lack of ED knowledge among primary care providers (Dimitropoulos et al., 2015; Lockertsen et al., 2021; Nadarajah et al., 2021).
- 5) **Navigation Guide:** As the final attachment in the post-orientation e-mail, the last component of the intervention was an eight-page guide written for the adolescent and

parent outlining the importance of transition planning, differences between pediatric and adult care, as well as links and contact information for various adult care options and resources. This guide was meant to act as a written representation of the information adolescents and parents would have been exposed to during the study. It was integrated into the intervention with the recommendation that a booklet with transition-important information is offered to adolescents and parents (Nadarajah et al., 2021).

In sum, adolescents were asked and expected to complete the Youth-to-Youth Session, Transition Meeting, Family Doctor Contact, and Navigation Guide and parents were expected to complete the Parent-to-Parent Session and Navigation Guide, given that the Transition Meeting and Family Doctor Contact required an invitation from the adolescent. However, participants were permitted to complete as many components as they wanted to or had time for and in the order they wanted. This was informed by one study that suggested adolescents and parents approaching a transition in ED care should be offered a suite of interventions so that they can choose the ones that would be most suitable to their circumstances (Nadarajah et al., 2021).

## **2.10 Data Collection and Analysis**

The study outcomes are informed by the primary and secondary research questions of the current thesis: (1) feasibility of the intervention (*primary*), (2) feasibility of the research processes and measures, (3) the nature of intended and actual transition, (4) participants' perspectives and experience of the intervention, and (5, 6) change in adolescent and parent outcomes. Many of these study outcomes have a qualitative and quantitative component and are captured using the same data collection measures. To make sense of this complex data plan, this section is organized by quantitative followed by qualitative methodology, with a discussion of

study outcomes and data collection, analysing, and reporting throughout. See *Appendix A* for a visual timeline of data collection for study participants. See *Appendix B* for a full chart depicting this study's data, including study outcomes, measures used, and corresponding analysis.

### 2.10.1 Quantitative Methodology

*Feasibility of the Intervention.* Intervention feasibility was captured quantitatively at the end of the study using data collected through a tracking sheet organized by MN following pre-determined feasibility indicators (listed in Table 2). Rates of completion and duration to complete were chosen as feasibility indicators because this may indirectly indicate the ease with which participants could complete the intervention. Some metrics within the reflections are used to inform these indicators (e.g., time-stamped dates). These results were reported using frequencies and descriptive statistics (i.e., mean, standard deviation, range) in a tabular format. Outliers identified through stem-and-leaf boxplots for data pertaining to the duration to complete measures, reflections, and interviews were extracted.

*Feasibility of Research Processes and Measures.* Additionally, the feasibility of the research processes and measures (Study Outcome #2) will also be captured quantitatively using the feasibility indicators described in Table 3. Completeness and duration were the chosen indicators for the feasibility of the research process as it represents how easy it was for them to participate in the study. These indicators are informed by the contact tracking sheet organized by MN and various metrics built into the reflections and Baseline and Post-Intervention Measure Packages on Qualtrics. This information is a proxy for burden/measure feasibility in conjunction with your qualitative data. These results were also reported using frequencies and descriptive statistics (i.e., mean, standard deviation, and range) in a table.

**Table 2.** Quantitative Indicators for Intervention Feasibility

<b>Indicator</b>	<b>Pre-Determined Success Criteria</b>	<b>Formula</b>
Completion rate of each intervention component, by adolescents and parents	100% completion rate for each expected intervention component No a priori criteria for parents to complete non-required components (i.e., Transition Meeting and Family Doctor Contact)	Number of adolescents/parents in the study that completed each intervention component (X) divided by the number of adolescents/parents in the study (Y) = Z, the completion rate of each intervention component
Completion rate of entire intervention (only including the expected intervention components), by adolescents and parents	100% completion rate of all expected components in the intervention (i.e., four for adolescents, two for parents)	Number of completed intervention components (X) divided by the number of expected intervention components (Z), divided by the total adolescents/parents in the study (Y) = A, the completion rate of the entire intervention
Average time (in days) for adolescents and parents to complete each component, from start of intervention (including standard deviation and range)	Given that participants are allowed to complete the intervention components in the order that they would like, there are a priori criteria for this indicator except that it is under the three-month mark	The number of days for each adolescent/parent to complete each intervention component since the beginning of their 3-month intervention (X) divided by the number of adolescents/parents in the study (Y) = Z, the average time to complete each component
Average time (in days) for adolescents and parents to complete the entire intervention, from start of intervention (including standard deviation and range)	Three months	The number of days for each adolescent/parent to complete all intervention components they wanted to since the beginning of their 3-month intervention (X) divided by the number of adolescents/parents in the study (Y) = Z, the average time to complete the intervention

**Table 3.** Quantitative Indicators for Feasibility of Research Processes and Measures

Indicator	Pre-Determined Success Criteria	Formula
<b>Research Processes</b>		
Recruitment rate	No a priori criteria	$(\# \text{ of consented pairs})/(\# \text{ of eligible pairs that showed interest in the study}) = \text{recruitment rate}$
Retention rate	No a priori criteria	$(\# \text{ of participants who completed the intervention and all necessary data collection measures})/(\# \text{ of consented participants}) = \text{retention rate}$
<b>Research Measures</b>		
Completion rate of each measure	No a priori criteria	<p><i>For Measure Packages and Interview:</i> <math>(\# \text{ of participants who completed each measure})/(\# \text{ of participants consented to the study}) = \text{completion rate of required measures}</math></p> <p><i>For Reflections:</i> <math>(\# \text{ of participants who completed the reflection for the relevant component})/(\# \text{ of participants who participated in that component}) = \text{completion rate of each reflection}</math></p>
Proportion of missing data at the item level	0.05 (5%) or less is considered inconsequential (Dong & Peng, 2013; Schafer, 1999)	<i>For each measure, at each timepoint:</i> $(\# \text{ of missing items across all participants})/(\text{total } \# \text{ of items in the measure}) * (\# \text{ of respondents of the measure at that timepoint}) = \text{proportion of missing data at the item level}$
Proportion of missing data at the scale level	0.05 (5%) or less is considered inconsequential (Dong & Peng, 2013; Schafer, 1999)	<i>For each measure, at each timepoint:</i> $(\# \text{ of missing scales across all participants})/(\text{total } \# \text{ of scales in the measure}) * (\# \text{ of respondents of the measure at that timepoint}) = \text{proportion of missing data at the scale level}$
Average time (in minutes) to complete each study measure (i.e., Qualitative Interview) (including standard deviation and range)	No a priori criteria	$(\# \text{ of minutes to complete each measure})/(\# \text{ of respondents of that measure}) = \text{average time (in minutes) to complete the measure}$
Average time (in days) to complete the study (including standard deviation and range)	Three months	$(\# \text{ of days between completion date of Baseline Measure Package to complete date of Post-Intervention Interview for each participant who completed the study})/(\# \text{ of participants who completed the study}) = \text{average time (in days) to complete the study}$

*Change in Adolescent Outcomes.* Study Outcome #5 was designed to explore the differences in various intervention-important outcomes using quantitative study measures. Each adolescent was asked to complete a set of questionnaires at baseline and post-intervention—resulting in two separate measure packages: Baseline Adolescent Measure Package and the Post-Intervention Adolescent Measure Package. The measures included in each package are listed directly below (refer to *Appendix A* for a visual representation of the data collected for these study outcomes):

Demographic Questionnaire. Developed by MN and JC, this measure asked participating adolescents to state their sex, gender, date of birth, school grade, ethnicity, type of eating disorder, length of eating disorder, date of diagnosis, and type of treatment received to date. This demographic data was analyzed using descriptive statistics and frequencies and were reported in a tabular format.

Eating Disorder Examination Questionnaire (EDE-Q 6.0). Adolescents were asked to complete this measure at baseline and at post-intervention. The EDE-Q 6.0 is a gold standard self-report measure intended for individuals with EDs that assesses the presence, frequency, and severity of ED symptoms (e.g., restricting, bingeing, purging, laxative use, exercising) (Fairburn & Beglin, 2008) and was chosen for the researchers to understand if or how the sample's ED symptomology changed throughout the study. This measure contains 28 Likert-scale items (where responses range from 0 to 6) and is comprised of four subscales: restraint, eating concerns, shape concerns, and weight concerns. Higher scores indicate increased ED symptom presence, frequency, and severity. The EDE-Q 6.0 also asks respondents to report on their height, weight, and menstrual patterns (if applicable). An average of the item responses under each subscale and for all 28 items are calculated to report the mean subscale and global scores,

respectively (Taib et al., 2021). This measure was developed with the aim of making the Eating Disorder Examination, which is originally an investigator-based interview, a self-report measure (Fairburn & Beglin, 1994). When compared to the Eating Disorder Examination, the EDE-Q was found to have good concurrent validity and acceptable criterion validity (Mond et al., 2004) and versions of this measures adapted to specific countries—such as Malaysia—were also found to exhibit high reliability and validity (Taib et al., 2021).

Transition Readiness Assessment Questionnaire (TRAQ). This tool, to be completed by the adolescent at both timepoints, assesses adolescent and young adult self-management and healthcare utilization skills before and during healthcare transition (Wood et al., 2014). It was used in the present study to reflect how these skills before and after the intervention. The TRAQ presents respondents with 20 items regarding areas important for transition to adult health care that are organized into five domains: medication management, appointment management, health issue tracking, interactions with providers, and daily activity management. Participants are asked to select one of five responses regarding their perceived ability in each area, ranging from 0 (“No, I do not know how”) to 4 (“Yes, I always do this when I need to”). Higher scores indicate increased levels of self-reported self-management and healthcare utilization skills. Items comprising of the subscale and total scores are reported as averages. This measure was originally developed by Wood and colleagues to develop a transition readiness assessment tool to help evaluate interventions to support successful healthcare transition among youth with special healthcare needs (Wood et al., 2014); it has high internal reliability (Cronbach’s alpha of 0.94) and good criterion validity.

Self-Management Skills Assessment Guide. Completed at both timepoints, this survey assesses the respondent’s perception of the adolescent’s awareness of their health condition and



the adolescent's ability to make decisions relevant to healthcare needs (Williams et al., 2011). There are two versions of this measure, one that is completed by the youth about themselves (SMSAG-Y) and the other that is completed by the parent about the adolescent (SMSAG-P). The response options for 21 items that are presented in a Likert format, ranging from 1 ("Strongly Disagree") to 5 ("Strongly Agree"), with higher scores indicating increased adolescent awareness of their condition and healthcare-related decision-making ability. The mean of all 21 items is calculated to report a total score. This measure was included in this study to track participants' perceptions of the adolescent's knowledge and decision-making skills that are important for their upcoming healthcare transition. Developed by Canadian researchers and clinicians for youth with special needs during their transition, the psychometric properties of this measure are strong (Williams et al., 2011); scores of this measure showed evidence of concurrent validity with a measure of general adaptive functioning and the internal consistency of this measure was high, with a Cronbach's alpha of 0.89 for the youth report.

Eating Disorder Readiness Ruler (ED-RR). This final measure completed by adolescents addresses readiness and motivation to change various ED symptoms and behaviours among individuals with AN and BN. Psychometric properties of this scale are also strong (St-Hilaire et al., 2017); the measure has good internal consistency and shows convergent validity and predictive validity. The ED-RR contains 18-identically structured Likert-scale items organized in two sections. Although this measure is not specific to transition, it was chosen for this study because it reflects adolescents' readiness and motivation for change.

The first section (Questions 1-9) asks the respondent how ready they are to change nine ED-related attitudes or behaviours (e.g., restricting, use of diuretics) by selecting one of 11 response options available (ranging from 1 to 10), with labels above the scale reading "not ready

to change”, “unsure” “ready to change”, to “trying to change”, with a “Don’t do” option available. An average is taken for the participants’ responses to these nine items, comprising the Readiness to Change subscale.

The second section (Questions 10-18) asks the respondent to express the extent to which they would make a change in the same nine attitudes or behaviours for others or themselves. Here, participants select a response from 0% to 100% (separated by intervals of 10), with labels above the scale reading “not very much for me”, “about half for me”, and “mostly for me”, with a “Don’t do” option available. Two scores are calculated from this section of the ED-RR (St-Hilaire et al., 2017). To compute the Controlled Motivation subscale, a score of 1 is assigned to responses ranging from 0 to 30% for these nine items and, for the Autonomous Motivation subscale, a score of 1 is assigned to responses ranging from 80 to 100% for the same items. All other responses in this section (from 40 to 70%) are given a score of 0. Total scores are added to compute the scores for Controlled and Autonomous Motivation, which range from 0 to 9. Higher Controlled and Autonomous Motivation subscale scores indicate that participants are externally (for others) and internally (for themselves) motivated to change their ED attitudes or behaviours, respectively.

Data Analysis. Repeated measures paired *t*-tests were performed on the subscale and total scores for each of these validated measures from baseline to post-intervention. If the data for each measure at each timepoint was not normally distributed according to the results of Shapiro-Wilk tests, the Wilcoxon signed-rank test was used. Given that no hypotheses were formed, the two-sided *p*-value was used to determine significance. Missing data was transformed to the group mean for that item.

*Change in Parent Outcomes.* Study Outcome #6 is intended to explore the change in outcomes among parents from pre- to post-intervention. Each parent was asked to complete a set of questionnaires at baseline and post-intervention—organized into the Baseline Parent Measure Package and the Post-Intervention Parent Measure Package. The following measures are included in the measure packages (refer to *Appendix A* for a visual representation of the data collected for these study outcomes):

Demographic Questionnaire. Developed by MN and JC, this measure asked participating parents to report upon their sex, gender, age, ethnicity, relationship to adolescent (e.g., parent, stepparent, guardian), marital status, household income, highest level of education achieved, number of people in household, number of children cared for, number of children (apart from participating adolescent) who have an eating disorder and corresponding details, and whether the parent has had an eating disorder and corresponding details. All demographic data was analyzed using descriptive statistics and frequencies and were reported in a tabular format.

Eating Disorders Symptom Impact Scale (EDSIS). This measure, to be completed by the parent at both timepoints, assesses caregivers' appraisal of the impact that AN and BN symptoms of their ill relative had on their own well-being (Sepulveda et al., 2008). Knowing that parents experience significant distress when caring for their child's ED symptoms (Matthews et al., 2018), caregiver burden was captured to assess if it changes after receiving the intervention. Respondents are asked to note the frequency over the past month of 24 experiences (e.g., "how often have you thought about feeling that I have let her/him down"), using a 5-option Likert scale from 0 ("never") to 4 ("nearly always"). These items are organized into four domains: nutrition, guilt, dysregulated behaviour, and social isolation. Sums are computed for the items in the whole measure and under each domain to report the total and subscale scores of the EDSIS.

Higher scores indicated more negative appraisals on specific aspects of caregiving. The original authors found the EDSIS to have an acceptable reliability (Cronbach's alpha ranged from 0.84-0.90) and moderate convergent validity with other measures measuring similar constructs (Sepulveda et al., 2008).

Carers Needs Assessment Measure (CaNAM). Developed by Haigh and Treasure using the input of carers of people with AN (Haigh & Treasure, 2003), the CaNAM measure assesses the needs of carers of individuals with an ED. It is to be completed by the parent in the study at both timepoints of the study. There are 47 Likert-scale items in this survey that fall under four domains: information about eating disorders (14 items), support from people/organizations (13 items), support for self (5 items), and areas where the respondent may want more help (15 items). The scoring of each item depends on the subscale, but typically ranges from: 0, the need has not been met and they would like more information or support; 1, they do not require information or support; or 2, this is a met need, and they have sufficient information or support. Therefore, higher scores indicate increased degrees of met informational and support needs related to EDs. Rather than report upon the frequencies of response for each item as is done in the original paper (Haigh & Treasure, 2003), another method involves only the responses of unmet ("0") and met needs ("2") by transforming their values to 0 and 1 respectively, and calculating the sum of items for each of the first three subscales and the total (Whitney et al., 2007); this approach will be used in the following study to report CaNAM results. The internal consistency of the CaNAM total and subscales are high, with the exception of support for self (Cronbach's Alpha = 0.61) (Whitney et al., 2007).

Patient and Carer Collaboration Scale – Carer (PACCS-C). As the final measure completed by the parent at both timepoints, the PACCS-C assesses the perceived level of

confidence among caregivers of individuals with an ED when faced with situations commonly associated with EDs. There are no studies that report on the development or validation of this measure. It is important to capture to represent parents' self-efficacy related to their child's ED as parental involvement changes before, during, and after healthcare transition and may change as the study progresses. Respondents are asked to report their confidence level when engaging in 33 different ED-related management techniques using 11 response options from 0 ("Almost never") to 100 ("Almost Always"), separated by intervals of 10. An average of all 33 items is computed to produce the total PACCS-C score. Higher scores indicate increased parent self-reported confidence to manage in situations related to their ill relative's ED.

Self-Management Skills Assessment Guide. This survey assesses the respondent's perception of the adolescent's awareness of their health condition and the adolescent's ability to make decisions relevant to healthcare needs (Williams et al., 2011). The parent version of this measure (SMSAG-P) was completed by the parent at baseline and at post-intervention. Like the SMSAG-Y, this measure was found to have concurrent validity with another measure that assesses general adaptive functioning and the internal consistency of the parent report was high, with a Cronbach's alpha of 0.93 (Williams et al., 2011). (For a detailed explanation of this measure, visit the appropriate heading under *Change in Adolescent Outcomes*.)

Data Analysis. Repeated measures paired *t*-tests were performed on the subscale and total scores for each of these validated measures from baseline to post-intervention. If the data was not normally distributed for each measure and timepoint according to the results of Shapiro-Wilk tests, the Wilcoxon signed-rank test was used. Given that no hypotheses were formed, the two-sided *p*-value was used to determine significance. Missing data was transformed to the group mean for that item.

*Data Reporting.* The descriptive and frequency summaries as well as repeated measures analyses will be reported in the results section in text and using a tabular format. The integration of quantitative data pertaining to the two mixed methods study outcomes will be compared against the relevant qualitative findings to yield a commentary about similarities and discrepancies between data gathered via the two approaches.

### 2.10.2 Qualitative Methodology

*Design.* Qualitative data collection and analysis in this study will follow the Qualitative Description (QD) design. This qualitative design—also referred to as basic or fundamental description—is used when researchers want to closely reflect participants’ experiences of the phenomenon of interest with minimal abstraction or interpretation (Sandelowski, 2000). Compared to more interpretive qualitative designs—such as interpretive description, phenomenology, and grounded theory—QD is appropriately suited for studies where time or resources are limited, when using a mixed methods approach, and when direct descriptions of phenomena are needed to help contextualize and provide nuance to research questions (Bradshaw et al., 2017; Sandelowski, 2000). For these reasons, QD was chosen as the qualitative design to guide the present study’s data collection and analysis.

*Data Collection.* Qualitative data was collected from adolescents and parents using two approaches—reflections and the Post-Intervention Qualitative Interview. Participants are asked to complete reflections, short written entries, using a provided Qualtrics link after completing each intervention component (see *Appendix C* to see the reflections). The adolescent is expected to complete four entries, one each following the completion of the Youth-to-Youth Session, Transition Meeting, Family Doctor Contact, and Navigation Guide, and parents are asked to

complete at least two entries, one after completing the Parent-to-Parent Session and Navigation Guide each. The purpose of the reflections is to allow participants to describe their perceptions of the feasibility (Study Outcome #1) and their experiences completing each intervention component (Study Outcome #4) soon after their exposure or involvement in it. All reflections were exported into individual Microsoft Word documents and were uploaded to NVivo in preparation for analysis.

Adolescents and parents are also each invited to participate in an individual, semi-structured interview at post-intervention virtually through Zoom for Healthcare. Interview guides were developed in collaboration between MN and JC: the Adolescent Post-Intervention Interview Guide or the Parent Post-Intervention Interview Guide (see *Appendix D* to see the interview guides). These guides prompted respondents to describe their perceptions of the entire intervention feasibility (Study Outcome #1), feasibility of the research processes and measures (Study Outcome #2), elaborate upon their intended transition plan and destination program or treatment and whether they have successfully transitioned to this set of supports (Study Outcome #3), and their perspectives and experiences of the intervention (Study Outcome #4). The resultant recorded audio files of these interviews are transcribed verbatim by MN using Microsoft Word.

*Data Analysis.* All interview transcripts and reflections were imported into NVivo—a qualitative data management software—for analysis. Content analysis is a systematic coding and categorizing approach that is used to unobtrusively explore trends, frequency, and relationships between words in large amounts of text with the purpose of describing participant experiences, rather than interpreting them (Vaismoradi et al., 2013). This approach was chosen for this study because it aligns with the purpose of reporting these data—to *describe* participant perceptions

and experiences. Additionally, content analysis is believed to align well with the QD design, as it involves minimal interpretation of the data and provides a “straight description” of participant’s responses (Bradshaw et al., 2017; Sandelowski, 2000). Specifically, two distinct types of content analysis—conventional and summative—were blended to analyze and report the qualitative data for the present study (Hsieh & Shannon, 2005).

Conventional content analysis is often used when the purpose of the study is to describe a novel or not yet well-researched phenomenon of interest (Hsieh & Shannon, 2005), such as in the present study where there are a lack of existing theories or frameworks to guide the assessment of feasibility for the ED transition intervention being studied. Conventional content analysis is considered an inductive approach, as codes are derived through multiple readings of the data, rather than a deductive approach, where a coding scheme based on relevant theories or research is prepared prior to analysis (Armat et al., 2018; Hsieh & Shannon, 2005). Following conventional content analysis procedures, MN started by reading all of the transcripts and reflections to achieve immersion of the data (Hsieh & Shannon, 2005). Initial codes were derived by highlighting the exact words used by participants, and were later sorted or collapsed into categories based on the outcome of interest (e.g., feasibility of intervention, desired destination program, group experience).

Summative content analysis involves counting and comparisons of keywords or content (Hsieh & Shannon, 2005). Rather than interpreting the meaning behind code frequencies as usually done when using this approach, summative content analysis was employed in the present study for the purpose of reporting (1) the number of participants that expressed each idea, perspective, or opinion and (2) the number of times each perspective was mentioned. Thus, summative content analysis took on a supportive role to provide an indication of how often



participants stated each code or category identified by the main form of content analysis—conventional. Representative quotes were used to support and contextualize some of the more frequently stated perspectives and opinions in the reporting of this data.

Also characteristic of the QD design, the qualitative data collection and analysis occurred simultaneously using the constant comparison method (Sandelowski, 2000); unexpected topics or themes that arose from interviews earlier in the study were explored in subsequent interviews to accommodate for these new insights.

*Data Reporting.* The findings from this analysis were presented in a written format, supported using tables depicting the frequencies of participant perspectives and illustrative quotes. Integration of qualitative data pertaining to the three mixed methods study outcomes will be compared against the relevant quantitative findings in the discussion to yield a commentary about similarities and discrepancies between data gathered via the two approaches.

*Efforts to Enhance Qualitative Rigour.* Lincoln and Guba's four principles of trustworthiness were followed and integrated into the study to ensure rigour of the qualitative design as well as data collection, analysis, and reporting (Lincoln & Guba, 1985): credibility, similar to internal validity from the quantitative realm, ensures that the results accurately represent what was studied; transferability, like generalizability or external validity, requires researchers to provide detailed explanations and information so that those reading can decide if findings are applicable to their context; dependability, like reliability, necessitates methods, reasoning, and results to be sound, clear, and consistent for others to be able to replicate the work, if needed; and confirmability, akin to objectivity, asks researchers to consider and communicate their biases and positionality that has the potential to bias the research or the interpretation of results (Johnson et al., 2020; Krefling, 1991; Lincoln & Guba, 1985).

The following strategies were used to meet one or more of these principles. To address the credibility of the research, two types of member-checking were used. Member-checking refers any technique that helps to confirm the data or interpretations with participants (Krefting, 1991; Lincoln & Guba, 1985). This was first employed live during interviews by prompting participants about topics brought up by adolescents and parents interviewed earlier in the study. Additionally, some details—such as an adolescent’s transition status or areas of the transcript that were incoherent—were clarified or confirmed with participants via e-mail, such as clarifying one’s transition status, after the study. It is important to note that member checks completed post-data collection were only done when necessary, to minimize the chance that interviewees changed their opinion after they internalize their previous responses (Krefting, 1991); by the end of the study, four member checks were conducted to either confirm transition status with participants at one month post-transition or to clarify demographic information.

Using method and data source triangulation, multiple data sources (i.e., reflections, interviews) that addressed the same constructs (e.g., perceptions of feasibility of each intervention component) were gathered from both types of participants (i.e., adolescents and parents). This was done with the purpose of converging and corroborating the findings to optimize their accuracy and to avoid bias, thus influencing the credibility and dependability of the results (Johnson et al., 2020; Krefting, 1991).

In this project, there was prolonged engagement with participants, as the researcher interacted with the participants over several months due to the longitudinal nature of the study. Prolonged engagement is a strategy that enhances the credibility of the data because it allows participants to grow accustomed and trust the researcher with their responses and allows the

researcher to grow familiar and understand the context and factors that may influence the phenomenon being studied (Johnson et al., 2020; Krefting, 1991).

Also important to ensure credibility, efforts were made to ensure that the interviews were accurately transcribed through a double re-reading of transcriptions while listening to the audio file, shortly after interviews occurred to enable the consideration of relevant nonverbal communication such as laughing, crying, or pauses (Milne & Oberle, 2005).

Some of these strategies, such as ensuring accurate transcription or prolonged engagement, have the potential to introduce unintended bias from the researcher, not allowing them to remain neutral as possible especially when interpreting data. When using a qualitative approach, it is impossible to separate the researcher from the research itself (Krefting, 1991). Since MN was the main individual designing, collecting, and analyzing this data, it is important to engage in reflexivity to address the researcher's inherent biases and position in relation to the participants which could potentially influence the findings and address the confirmability principle (Johnson et al., 2020; Krefting, 1991; Milne & Oberle, 2005). MN is a graduate student with over six years of research experience in mental health and health-related research fields, and two of those years were spent conducting pediatric ED research. Aside from this thesis, she has been involved in other research projects where she has been exposed to the nature of the disorder as well as the perils of transition, as expressed by participants and clinicians in other studies. This familiarity with the topic may have enhanced the researcher's ability to probe further, when needed. Given that MN is not also a clinician in this field, this may have impacted her understanding of the participants' exposure to the clinical setting or influenced how she was received by adolescents and parents in the study. The identity of MN and her life experiences as

a graduate-trained, Caucasian, physically able woman living in Hamilton, Ontario also had the potential to influence her interpretation of the data or how participants interacted with her.

Lastly, auditing is an important part of ensuring the principles of transferability and dependability (Johnson et al., 2020; Krefting, 1991; Lincoln & Guba, 1985). Detailed records of how the study was led—in the methods section of this thesis and in offline documents—were written for this thesis and are vital to ensure that a comprehensive and accurate account of how the study was led is captured, in case readers are interested to reflect upon the process or would like to re-create it.

### 2.10.3 Integration of Quantitative and Qualitative Data

The integration of the qualitative and quantitative data occurred at the data interpretation stage and is reflected in the discussion section of the present report. To aid interpretation, congruence and discordance between qualitative and quantitative data was evaluated and synthesized using a concept-by-concept weaving narrative integration approach (Fetters et al., 2013). For instance, results from the quantitative feasibility indicators (e.g., completion rates and duration to complete) will be compared to the qualitative themes regarding intervention feasibility to depict a comprehensive picture of the feasibility of the intervention. Additionally, feasibility metrics regarding the measures used in the study (e.g., proportion of missing data at the item and scale level) will be integrated with participant experiences to reflect this construct using the strength of both quantitative and qualitative approaches, respectively. Since the remaining secondary research questions are either quantitative or qualitative, these data will not be integrated with one another or with data pertaining to the mixed methods questions.

## **2.11 Ethical Considerations**

This thesis project was approved by the Hamilton Integrated Research Ethics Board (Review Reference: 2021-13303-GRA). The three core principles of the Tri-Council Policy Statement (TCPS 2) in Canada were considered in the present study: Respect for Persons, Concern for Welfare, and Justice. The autonomy of participants was respected through the informed consent process of the study. MN provided prospective participants a digital copy of the appropriate letter of information and consent form prior to the orientation meeting, in order to read the document and prepare questions before signing. This document, written in lay language, outlined the purposed of the study, what is expected of them, the risks and benefits involved, and the contact information of the research team, in case of withdrawal. During the orientation meeting, MN walked the adolescent and parent through the consent form, offered participants a space to ask questions, and provided them with sufficient time to make an informed decision about their recruitment into the study. Participants are made aware that they are provided with a gift-card after completing the post-intervention interview. Although monetary incentives such as these can be considered coercive depending on the situation, the benefit offered by this gift-card to strengthen the internal validity of this study by minimizing the change of loss to follow-up outweighs the minimal risk it presents for participants.

Concern for Welfare was addressed by anticipating and mitigating the risks involved in the research. The first potential risk to participants in this study are the potential for difficult emotions to arise while participating in intervention components or while completing data collection measures (e.g., interview). To mitigate this risk, participants are provided with a resource list at the end of the orientation meeting that they can access in case they are in distress at any point in the study. If MN learns that a participant is in distress, the supervisor—who is

also a mental health professional—will be contacted immediately. If the distress occurs while interacting with MN, they will conclude the research activity being completed (e.g., interview) and will remain on the call or meeting until the person is comfortable or have access crisis resources. Given that this study was conducted virtually, the second risk posed onto participants regards the potential for a breach in their confidentiality or privacy. To minimize the chance that participants are identified in the study, confidentiality was maintained by adhering to secure practices when using online platforms and using the most secure versions of the programs used in the study (e.g., Zoom Healthcare). As soon as participants are consented to the study, each adolescent and parent was given a Study ID and any identifying information is saved on a Study Key that is password-protected and saved on MacDrive—a secure, encrypted cloud-based server provided by McMaster University. All subsequent data files will refer to participants only by their Study ID. E-mail and telephone communication with participants will occur in a space to which others cannot access, and any potential identifiers in quotes used in the following report will be adjusted (e.g., changing any gendered subject pronouns to be gender neutral, anonymizing names of programs, cities, and people).

Lastly, the principle of Justice was upheld by maximizing representation of the target population and ensuring that all adolescents who met eligibility criteria (e.g., 17-years-old, MCH PED Program) were provided with an equal opportunity to participate in the study. The tenet of Justice also considers the fair and equitable treatment of vulnerable persons. Historically, children—including adolescents, given that they are under the age of 18—have been at risk for being marginalized in research due to belief that they have reduced capacity to provide informed consent and because existing research methods have not been properly adapted to meet the cognitive and developmental needs of children (Einarsdóttir, 2007; Fargas-Malet et al., 2010).

However, the Government of Canada considers 17-year-olds to be “mature minors” and to have the capacity to make informed decisions on their own (Government of Canada, 2019). For this, no extra precautions were required when preparing the letter of information and consent form for the adolescents in the study.

## CHAPTER 3: RESULTS

### 3.1 Participants

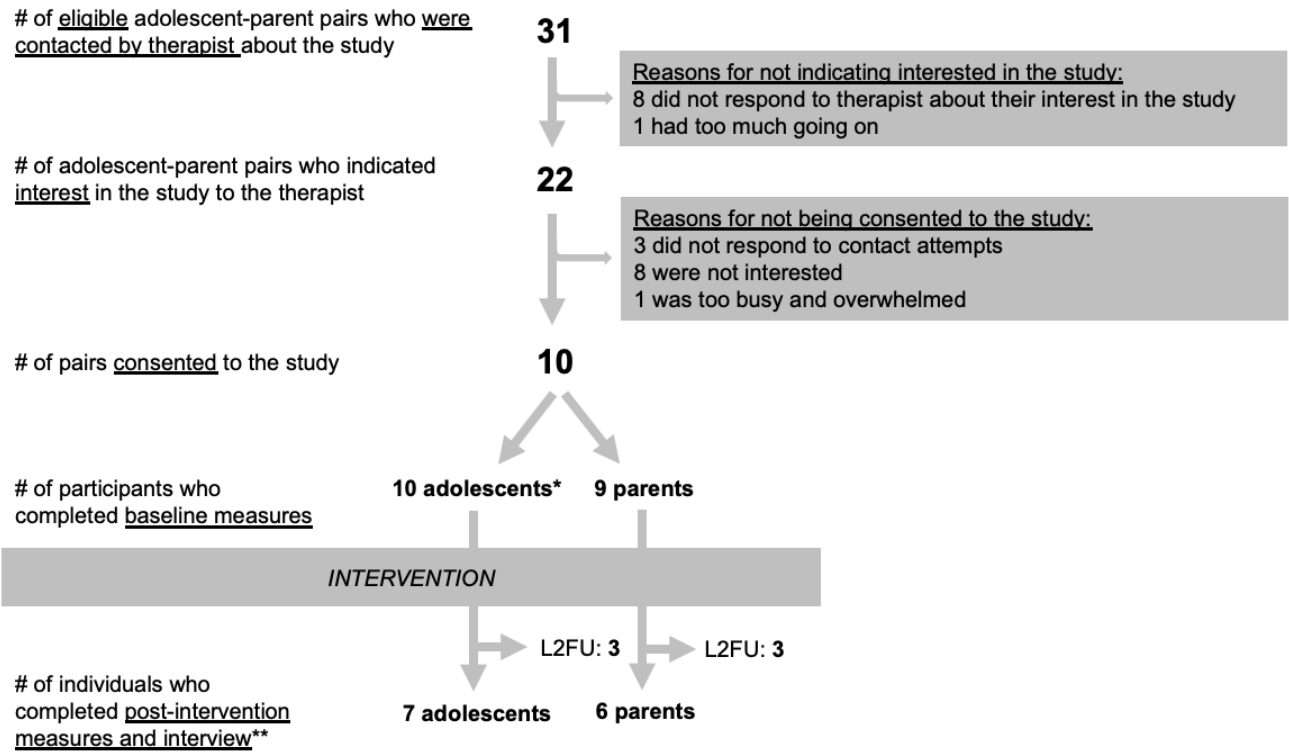
Thirty-one patients and their parents were invited by their pediatric therapist to participate in the study. Of the 22 pairs that voiced an interest in the study, nine adolescent-parent pairs and one adolescent participating individually—a total of 19 individuals—were consented into the study (see Figure 1). Five adolescent-parent pairs, two adolescents, and one parent—thirteen participants in total—completed the intervention and all required measures.

#### 3.1.1 Demographics

*Adolescents.* At baseline, all ten adolescents in the study were 17 years old (100%), and the majority self-identified as female (80%), were in Grade 12 (90%), had a diagnosis of AN (80%), and were Caucasian (80%). Participants reported receiving a variety of eating disorder treatments, including FBT, CBT, DBT, therapy (unspecified type), and medication as well as being hospitalized in the in-patient unit or at day hospital; on average, the sample received 2.90 types of treatment [Standard Deviation (SD) = 0.99, Range = 2 – 5]. The average weight and height of the sample was 56.18 kg (SD = 4.99, Range = 51.26 – 65.00) and 166.61 cm (SD = 7.86, Range = 157.48 – 186.42), respectively. The adolescents in this sample started showing symptoms for an average of 3.25 years (SD = 1.77, Range = 1.29 – 5.96) and received an eating disorder diagnosis an average of 2.38 years (SD = 2.08, Range = 0.21 – 5.66) prior to the study. Participants were consented to the study an average of 3.80 months away from their 18<sup>th</sup> birthday (SD = 2.48, Range = 0.56 – 8.30). See Tables 4 and 5 for summaries of the demographic variables pertaining to the adolescent sample.



**Figure 1.** Participant Flow Chart



L2FU = Lost-to-follow-up.

\*One adolescent participated in the study without their parent.

\*\* Study completion was determined by a completion of the baseline measures, at least one intervention component (and reflection), post-intervention measures, and the post-intervention interview.

**Table 4.** Demographic Summary of Categorical Variables at Start of Intervention

	Adolescents (N=10) n, (%)	Parents (N=9) n, (%)
<b>Sex</b>		
Female	9 (90%)	8 (89%)
Male	1 (10%)	1 (11%)
<b>Gender</b>		
Female	8 (80%)	8 (89%)
Male	1 (10%)	1 (11%)
Gender Non-Conforming	1 (10%)	0 (0%)
<b>Ethnicity</b>		
Caucasian	8 (80%)	8 (89%)
Hispanic and European	1 (10%)	0 (0%)
Don't know	1 (10%)	0 (0%)
Missing	0 (0%)	1 (11%)
<b>Grade</b>		
12	9 (90%)	
12+	1 (10%)	
<b>Type of Eating Disorder</b>		
Anorexia Nervosa (AN)	8 (80%)	
Bulimia Nervosa (BN)	1 (10%)	
Avoidant/Restrictive Food Intake Disorder (ARFID)	1 (10%)	
<b>Types of ED treatment received*</b>		
Family-Based Treatment (FBT)	7 (70%)	
Cognitive Behavioural Therapy (CBT)	7 (70%)	
Dialectical Behaviour Therapy (DBT)	3 (30%)	
Therapy (unspecified type)	3 (30%)	
In-patient hospitalization	4 (40%)	
Day Hospital	2 (20%)	
Medication	5 (50%)	
<b>Relationship to Child</b>		
Mother		8 (89%)
Father		1 (11%)
<b>Marital Status</b>		
Married/Common-law		5 (56%)
Divorced/separated, not remarried		4 (44%)
<b>Highest Education Level</b>		
Secondary or High School Certificate		1 (11%)
Trade Certificate from Vocational School		1 (11%)
Non-University or College Certificate		2 (22%)
Bachelor's Degree		2 (22%)
University degree above Bachelor's Degree (e.g., MSc, MD)		3 (33%)
<b>Household Income</b>		
Less than \$25,000		1 (11%)
\$35,000-\$49,999		1 (11%)
\$50,000-\$99,999		0 (0%)
\$100,000-\$149,999		2 (22%)
\$150,000-\$199,999		4 (44%)
\$200,000 or more		1 (11%)

\*Corroborated using interview data.

**Table 5.** Demographic Summary of Continuous Variables at Start of Intervention

<b>Adolescents</b>	<b>n</b>	<b>Mean</b>	<b>St. Dev.</b>	<b>Range</b>
Age (years)	10	17	0	N/A
Height (cm) *	10	166.91	7.86	157.48 – 186.42
Weight (kg) *	10	58.18	4.99	51.26 – 65.00
Time between start of intervention and 18 <sup>th</sup> birthday (months)	10	3.80	2.48	0.56 – 8.30
Time between start of intervention and start of symptoms (years)	10	3.25	1.77	1.29 – 5.96
Time between start of intervention and date of diagnosis (years)	10	2.38	2.08	0.21 – 5.66
Number of Treatment Types Received	10	3.10	0.99	2 – 5
<b>Parents</b>	<b>n</b>	<b>Mean</b>	<b>St. Dev.</b>	<b>Range</b>
Age (years)	8	50.40	4.11	43 - 57
Number of Children	9	2.00	0.87	1 – 3

St. Dev. = Standard Deviation.

\*Self-reported data from EDE-Q.

*Parents.* Of the nine parents recruited, most were female (89%), and thus mothers (88.9%), and identified as Caucasian (89%). The average age among this sample was 49.91 (SD = 4.70, Range = 43 – 57) and who were parents to a mean of 2 children (SD = 0.87, Range = 1 – 3). Five parents were married or common-law (56%), while four were divorced or separated (44%). Education level was evenly distributed among parents, while most parents (78%) lived in a household with a yearly income of over \$100,000. One parent in the study had another child with an ED and another parent had previously lived with ED symptoms themselves. See Tables 4 and 5 for demographic summaries for the parents in the study.

### **3.2 Feasibility of Intervention**

#### **3.2.1 Quantitative**

*Completion Rates of Intervention Components and Entire Intervention.* Adolescents were asked to complete their expected number of four intervention components during the study. As determined by the submitted reflections, the completion rate for each intervention component among adolescents were as follows: nine attended the Youth-to-Youth session (90%), all ten completed the Transition Meeting (100%), four contacted their family doctor (40%), and six read the Navigation Guide (60%). Given that 29 individual components were completed by the 10 adolescents in the sample, the completion rate of all expected intervention components is 73%. Parents were expected to complete two intervention components; all nine completed the Parent-to-Parent Session (100%) and five read the Navigation Guide (56%). Therefore, the completion rate of all expected components among parents was 78%, given that 14 individual components were completed. Of note, one parent (11%) joined their adolescent in the Family Doctor Contact,

and two parents (22%) took part in the Transition Meeting with the adolescent. See Table 6 for a visual depiction of these results.

*Duration to Complete Intervention Components and Entire Intervention.* The duration to complete each intervention component from their starting date in the study ranged from an average of 37.44 days for the nine parents who completed Parent-to-Parent Session (SD = 21.33, Range = 1 – 67) to a mean of 52.08 days for all adolescents and the two parents who attended the Transition Meeting (SD = 29.75, Range = 3 – 85). Information pertaining to duration to complete each component is included in Table 7. Lastly, it took the 13 participants who reached the end of the study an average of 36.46 days to complete their intervention components (SD = 29.58, Range = 0 – 78).

**Table 6.** Proportion and Percentage of Completion of Intervention Components

	Y2Y/P2P	TM	FDC	NG	Expected Components
Adolescent	9/10 (90%)	10/10 (100%)	4/10 (40%)	6/10 (60%)	<b>29/40</b> <b>(73%)</b>
Parent	9/9 (100%)	2/9* (22%)	1/9* (11%)	5/9 (56%)	<b>14/18</b> <b>(78%)</b>

Y2Y = Youth-to-Youth Session; P2P = Parent-to-Parent Session; TM = Transition Meeting; FDC = Family Doctor Contact; NG = Navigation Guide.

\*Completion of this component is not required for parents, as they must be invited by the adolescent.

**Table 7.** Duration to complete each intervention component and entire intervention, from each participant’s intervention start date

	N	Mean (days)	St. Dev. (days)	Range (days)
Youth-to-Youth Session	9A	<b>38.44</b>	23.30	14 - 78
Parent-to-Parent Session	9P	<b>37.44</b>	21.33	1 - 67
Transition Meeting	10A, 2P	<b>52.08</b>	29.75	3 – 85
Family Doctor Contact	4A, 1P	<b>46.20</b>	22.48	7 - 61
Navigation Guide	6A, 5P	<b>51.27</b>	30.03	7 – 98
<b>Entire Intervention</b>	<b>7A, 6P*</b>	<b>36.46</b>	29.58	0 – 78

A = Adolescent; P = Parent; St. Dev. = Standard Deviation.

\*This was only calculated for participants who completed the intervention and study.

### 3.2.2 Qualitative

*Overall.* Visit *Appendix E* for the qualitative analysis of participants' perceptions of intervention feasibility. Most participants in the study found it easy to participate in and convenient to access or attend components of this intervention. Specifically, the 3-month timeframe to complete the intervention was considered by most participants to be appropriate; one adolescent stated three months as “plenty of time to get everything done without being rushed” (A10). Some participants elaborated on the convenience of the intervention: an adolescent stated that the “resources were right there for me”, another felt that the virtual nature allowed them the freedom to complete components “if I had some downtime”, and a third adolescent reported that “there were a good number of components to do” and that “it wasn't too much or too little.” Only one adolescent mentioned that a few personal obstacles got in the way of them completing components sooner.

*Youth-to-Youth Session.* A total of five Youth-to-Youth Sessions were led over an eight-month period, with one to two adolescents in attendance at each one. Most of the nine adolescents who attended, found the Youth-to-Youth Session to be convenient. Specifically, one adolescent felt that the content was relatable, a different participant reported that “being on Zoom made it very easy to participate” (A1), and another noted that the small group allowed their voice to be heard. Conversely, one adolescent mentioned feeling “nervous about seeing people I didn't know though” (A2) and another had a “hard time finding a good time for it” (A8) due to their schedule.

*Parent-to-Parent Session.* Over the course of seven months, three Parent-to-Parent Sessions were held virtually and two to four parent participants attended each session. This session was reportedly convenient among the nine participants who participated, with two

participants crediting the virtual format as the reason for this convenience. In their interview, one parent (P4) shared that this session “was not so easy cause I’m not really open to discussing a lot”; this parent stated the same sentiment in their reflection but elaborated further to report that “hearing other stories made it a little easier.”

*Transition Meeting.* Four adolescents completed the meeting with their therapist, while the remaining two completed it with their therapist and parent present. The Transition Meeting was found by both adolescents and parents to be convenient; of note, two adolescents and one parent credited this to it taking place during an already-occurring therapy session. Adolescents who elaborated further found the meeting a “safe space to discuss [their] worries and concerns” (A1), that it was “easy to talk to therapist and video was easy to watch” (A7), and that everything they wanted to say was heard. A10’s experience changed throughout the meeting, stating that “it was stressful at the start just because I am nervous to get closer to leaving [MCH PED Program]. But after hearing all the information I was feeling a lot better and I very glad I participated in it.”

*Family Doctor Contact.* Four adolescents and one parent completed this component. Two adolescents completed this component alone—one in-person and one over the phone—while the other two completed this component with their parent present (one of whom is recruited to the study)—once again, one pair did this over the phone while the other did it in person. Most adolescents and the sole parent who participated in the Family Doctor Contact described this component as convenient. One adolescent mentioned that “they had to go in anyways” (A1), while another youth stated, “it was just one-on-one so I could talk freely” (A9). Two adolescents found this component less convenient; one attributed this to “anxiety making appointments” (A7), while both reported this was due to difficulty accessing their doctor—whether it was because they had to commute to the office or it was hard to book an appointment.

*Navigation Guide.* All six adolescents and five parents who completed this component read the guide on their own; eight participants read it one sitting, while three referred to it more than once. The Navigation Guide was found to be convenient by participants who read it. Participants from both groups highlighted the role that the headings played in making it easy to navigate. Adolescents described the guide as “straightforward” (A4) and “relevant” (A10), while parents reported it convenient to read on their device. One adolescent commented that the guide was “a bit lengthy” (A7).

*Reasons for not completing intervention components.* In the qualitative interviews, participants were asked to provide a reason for not completing intervention components. An adolescent shared that they were too stressed and hesitant to share about themselves to attend the Youth-to-Youth Session. In a separate interview, their parent stated that this adolescent also finds it hard to engage with groups virtually: “Like even, like the youth session, I don’t know. Like just being online too I think is, it’s gotten hard for [them]” (P10). Adolescents shared different reasons for not completing the Family Doctor Contact including experiencing anxiety when calling their doctor, not wanting them to be part of their care, and finding parking at their doctor’s office inconvenient. Four participants reported not completing the Navigation Guide because they “forgot about it” (A5), they missed it in the e-mail, or they did not think it would be useful. Even though parents were not required to complete the Transition Meeting or the Family Doctor Contact, one parent stated this is because they “presumed those things I wasn’t to attend. [They were] to do those two things on [their] own. Because, to be honest, now [they’re] 18. [They] should be handling [their] doctor on [their] own, seeing a doctor on [their] own, you know, taking ownership for that sort of thing” (P1). The other parent reported not being invited by their adolescent to partake in these components with them.



*Suggestions for Increased Convenience.* Three participants offered their feedback on what changes could be made to make these intervention components more convenient. Firstly, one adolescent suggested that shortening the transition video may make it easier for participants to watch. When speaking about the timing of the Parent-to-Parent Session, one parent (P4) offered that it would have been “preferable to be in the evening” to their work schedule. Lastly, one adolescent and one parent recommended making the group sessions one-on-one to make it more comfortable.

### **3.3 Feasibility of Research Processes and Measures**

#### **3.3.1 Quantitative**

*Recruitment and Retention Rates.* This study had a recruitment rate of 45% as 10 pairs were consented of the 22 pairs that showed interest in the study. Similarly, 13 of the 19 participants completed the intervention and all required measures, which resulted in a retention rate of 68%. The six participants who did not complete the study were lost-to-follow-up after multiple contact attempts; none withdrew from the study.

*Proportion of Missing Data.* As shown in Table 8, the proportion of missing data at the item and scale level were less than 8% for two adolescent outcome measures—the EDE-Q and the TRAQ—at baseline. Three of the four parent outcome measures (EDSIS, CaNAM, and PACCS-C) had a proportion of missing data at the item level of 1% or less. The remaining adolescent and parent outcomes measures at baseline and all post-intervention measures had no missing items.

*Completion of Measures.* All participants completed the baseline measures. Although the completion of reflections ranged from 60 to 100% depending on the component among

adolescents, parents completed all reflections for each component of the study they completed. By the end of the study, only 70% of adolescents and 67% of parents completed the post-intervention measures and the interview; this loss-to-follow-up is captured in Figure 1 as well. See Table 9 to see a summary of the completion of measures in the study.

*Duration to Complete Measures and Entire Study.* The duration to complete the measure packages ranged from an average of 10.29 (for the Adolescent Post-Intervention Measure Package;  $N = 6$ ,  $SD = 2.87$ ) to 27.71 minutes (for the Parent Baseline Measure Package;  $N = 7$ ,  $SD = 11.24$ ). A total of four outliers were extracted from the data pertaining to the duration to complete measure packages. Participants spent more time, on average, on the baseline measure packages than on the post-intervention measure packages. Reflections took participants less time to complete, ranging from an average of 7.86 minutes (for the Youth-to-Youth reflection;  $N = 6$ ,  $SD = 2.58$ ) to an average of 12.75 minutes (for the Navigation Guide;  $N = 11$ ,  $SD = 5.57$ ). Two outliers were extracted from the data pertaining to the duration to complete reflections. See Table 10 for more details regarding the duration to complete each data collection measures in this sample. Lastly, among the 13 participants who completed all necessary data collection measures, it took an average of 92.54 days to complete the study ( $SD = 33.45$ ,  $Range = 57-157$ ), determined by the dates that participants completed their Baseline Measure Package and their Post-Intervention Interview.

**Table 8.** Proportion of Missing Data at the Item and Scale Level for Quantitative Measures

		Baseline		Post-Intervention	
Level		Item *	Scale**	Item*	Scale**
A	<b>EDE-Q</b>	1/[(28)(10)] = 0.004	None missing	None missing	None missing
	<b>TRAQ</b>	17/[(20)(10)] = 0.085	4/[(5)(10)] = 0.080	None missing	None missing
	<b>SMSAG-Y</b>	None missing	None missing	None missing	None missing
	<b>ED-RR</b>	None missing	None missing	None missing	None missing
P	<b>EDSIS</b>	1/[(24)(9)] = 0.005	None missing	None missing	None missing
	<b>CaNAM</b>	1/[(32)(9)] = 0.004	None missing	None missing	None missing
	<b>PACCS-C</b>	3/[(33)(9)] = 0.010	None missing	None missing	None missing
	<b>SMSAG-P</b>	None missing	None missing	None missing	None missing

A = Adolescent; P = Parent.

\*Formula for determining number of missing items:  $\# \text{ of items missing} / [(\# \text{ of items in measure})(\# \text{ of respondents})]$

\*\*Formula for determining number of missing scales:  $\# \text{ of scales missing} / [(\# \text{ of scales in measures})(\# \text{ of respondents})]$

**Table 9.** Proportion and Percentage of Completion of Measures

	Measure Packages		Reflections				Post-Intervention Interview
	Baseline	Post-Intervention	Y2Y/P2P	TM	FDC	NG	
A	10/10 (100%)	7/10 (70%)	6/9 (67%)	6/10 (60%)	4/5 (80%)	6/6 (100%)	7/10 (70%)
P	9/9 (100%)	6/9 (67%)	9/9 (100%)	2/2 (100%)	1/1 (100%)	5/5 (100%)	6/9 (67%)

A = Adolescent; P = Parent.

Y2Y = Youth-to-Youth Session; P2P = Parent-to-Parent Session; TM = Transition Meeting; FDC = Family Doctor Contact; NG = Navigation Guide.

Note: The denominator of each reflection column is based upon the number of participants who completed that intervention component.

**Table 10.** Time to Complete Data Collection Measures

	<b>N of Outliers</b>	<b>N of Valid Responses</b>	<b>Mean (min)</b>	<b>St. Dev. (min)</b>	<b>Range</b>
<b>Measure Packages</b>					
Adolescent Baseline	1	9	19.55	9.16	10.40 – 39.13
Adolescent Post-Intervention	1	6	10.29	2.87	5.47 – 13.03
Parent Baseline	2	7	27.71	11.24	17.78 – 44.58
Parent Post-Intervention	0	6	17.95	5.71	11.05 – 27.17
<b>Reflections</b>					
Youth-to-Youth Session	0	6A	7.86	2.58	4.00 – 10.90
Parent-to-Parent Session	1P	8P	9.14	3.64	5.05 – 16.92
Transition Meeting	0	6A, 2P	10.38	5.84	3.92 – 20.97
Family Doctor Contact	1A	3A, 1P	8.47	3.18	4.60 – 11.12
Navigation Guide	0	6A, 5P	12.75	5.57	4.87 – 22.45
<b>Interview</b>					
Adolescent	0	7	27.81	6.40	18.70 – 39.98
Parent	0	6	33.11	14.95	13.15 – 52.27
		<b>N</b>	<b>Mean (days)</b>	<b>St. Dev. (days)</b>	<b>Range (days)</b>
<b>Entire Study</b> (from Baseline Measure Package to Interview)		7A, 6P	<b>92.54</b>	33.47	57 - 157

A = Adolescent; P = Parent.

### 3.3.2 Qualitative

*Study Communication and Access to Materials.* For a summary of the qualitative content analysis regarding the feasibility of the research processes and methods, see *Appendix F*.

Participants were satisfied and found the communication and access to intervention materials to be convenient. Of note, adolescents and parents appreciated having multiple options for dates and times provided to them for the Youth-to-Youth and Parent-to-Parent Sessions. The regular communication and the e-mail reminders about incomplete intervention components or data collection measures were also appreciated by parents.

*Baseline and Post-Intervention Measures.* Generally, participants found the measure packages to be satisfactory and a suitable length. Some adolescents and parents commented upon the relevancy of the measures; one adolescent said: “all the questions were directed towards what

we were dealing with, like there was none that were really, that didn't really need to be there” (A4). Conversely, many of the adolescents reported that items in the EDE-Q were not relevant to their situation—particularly the items regarding symptoms they were not experiencing. Select participants noted that although some items may not be relevant to them, they figured the goal of the questionnaire was to address a broad sample's experience. One parent stated that “some things didn't exactly apply, but I answered to the best of my ability. Everybody's story's different, right? So, I think you're just trying to cover all your bases to just make sure you get the most facts possible” (P4). Lastly, although most participants found the measures easy to comprehend, two parents found it difficult to answer or understand some of the questions on the EDSIS measure, specifically.

*Reflections.* Adolescents and parents were satisfied with the written reflections and valued the opportunity to reflect on their experience of each intervention component directly afterwards. One adolescent stated that “it's helpful doing it right after cause it's fresh in your mind” (A1). Participants from both groups found the reflections easy to understand, with one adolescent noting that sometimes the reflections were slightly repetitive and could have been condensed. Some participants found the reflections to be a satisfactory length, while others found it to be slightly too long.

*Interview.* Similar to the reflections, participants found the interview easy to understand, relevant, and enjoyable. Specifically, adolescents found the interview helpful to wrap up and reflect on their time in the study. An adolescent (A4) expands on this: “I think it's a good summary of everything we've done and, um, it kind of jogs my memory of what I've done over the last few months with this study.”

*Suggestions for Research Methods.* When asked what would make the data collection process better, participants suggested that more reminders are sent to notify participants of remaining tasks to complete. One parent (P8) suggested that the researcher adds phrases such as “Friendly Reminder” or “Task Due” to the e-mails. Another parent reported liking interview formats of data collection more than questionnaires. In contrast, two adolescents shared the same perspective of preferring close-ended or multiple-choice questions over the open-ended questions offered in the reflections.

The suggestion of an online portal to manage study communication and the intervention components arose during an interview early on in the study; thereafter, participants were asked of their opinion such an online portal that would be used to organize this intervention and study. In interviews with subsequent participants, this online portal was proposed to have a visual checklist or tracker for all the components they have or have not yet completed, direct access the materials and links for the data measures, and participants would receive reminders from this portal to complete each task. Three adolescents reported that the study communication via e-mail, Qualtrics, and Zoom was sufficient or felt neutral about this alternative, with one participant stating, “it’s pretty good the way it, like it was” (A8). However, three adolescents and three parents shared their enthusiasm for this possibility because they would not have to search through e-mails to find what they were looking for and because “I do like visually seeing where I’m at or the progress or like what I have to get done” (A10).

### **3.4 Nature of Intended and Actual Transition**

As shown in Table 11, the transition plans stated (at post-intervention) and status (at one-month post-transition) were captured for seven of the ten adolescents in the study. Among these seven, five adolescents had established a plan, while two (A8 & A10) were still considering care options. Six adolescents had entered their names onto a waitlist with the help of their pediatric therapist, either for a local, outpatient adult ED or anxiety treatment program; five of these six planned to use alternative supports in the interim, such as their family doctor, a private therapist, or a combination of the two. The only participant not planning to eventually transition to the local adult ED program (A9) planned for a permanent transition to their family healthcare team or, if needed, counselling supports offered at their future post-secondary institution.

The one-month post-transition timepoint for two of the seven adolescents who shared their transition plans (A9 & A10) were not captured in this thesis given that this will take place after the study has ended. Of the remaining five: one (A8) reported that they have transitioned to a mental health care organization that provides care across the lifespan, with whom they worked with in the past; two (A1 & A5) have successfully transitioned to their interim supports; and, the remaining two (A4 & A7) do not consider themselves transitioned. Aside from A8, none of the other adolescents who planned a transition to an adult ED or anxiety treatment program was relieved off the waitlist at one-month post-transition.

**Table 11.** Transition Plans and Status of Adolescents in Study Captured at End of Study

	<b>Transition Plan</b> <i>(data from qualitative interview)</i>	Time from transition that plan was stated	<b>Has the adolescent transitioned to their planned form of adult care at 1-month post-transition?</b> <i>(data from qualitative interview or e-mail check-in)</i>
A1	Private Therapist and Family Doctor while on waitlist for adult ED program	1 month post-transition	Yes – to Private Therapist and Family Doctor
A2	Unknown – L2FU	N/A	Unknown – L2FU
A3	Unknown – L2FU	N/A	Unknown – L2FU
A4	On waitlist for adult anxiety program	3 months post-transition	No
A5	Private Therapist and Family Doctor while on waitlist for adult anxiety program	2 months post-transition	Yes – to Private Therapist and Family Doctor
A6	Unknown – L2FU	N/A	Unknown – L2FU
A7	Family Doctor while on waitlist for adult ED program	1 month pre-transition	No
A8	<i>Not yet certain</i> - possibly surveillance from doctor, therapist, and dietician, while on waitlist for CBT/adult ED program	1.5 months pre-transition	Yes – to a mental health program provided by an organization that offers treatment across the lifespan
A9	Family doctor and therapist from family health team, and switch to counselling services at future post-secondary institution, if necessary	3 months pre-transition	E-mail check is past end of study
A10	<i>Not yet certain</i> - possibly surveillance from family doctor and a private therapist, while on waitlist for adult ED program	4 months pre-transition	E-mail check is past end of study



### **3.5 Participant Perspectives and Experience of the Intervention**

#### **3.5.1 Entire Intervention**

See *Appendix G* for a summary of participants' perspectives and experiences of the entire intervention, as captured by qualitative data. Many participants reported that they enjoyed the intervention or found it helpful. Specifically, three adolescents described the intervention as informative, supported by one participant's statement: "I think it was pretty informative and I learned a lot" (A1). Adolescents learned about adult care options available to them and, for one adolescent, the study helped to validate their choice to commit to anxiety treatment as an adult over ED-specific care: "... it helped clarify that, for me, eating disorder treatment isn't something I specifically need going forward" (A9). These intervention components made some participants feel less anxious, with A7 reporting that "it's a bit less nerve-wracking." Meanwhile, one participant (A1) felt uncertain of what to do now that they have completed the intervention while waiting to hear back from their future adult ED treatment centre. One adolescent said they thought it may have not been the best fit for them "because I kind of already knew what I was doing..." (A5).

Although adolescents and parents shared their preferred order of intervention components, two ideas were supported by multiple participants. Firstly, many indicated that the Navigation Guide should be completed before the other components, with one adolescent's reasons being "that was kinda would have been a good starter kinda thing to do" (A9). Secondly, two participants reported that the peer sessions should not be completed first, because it "might be too overwhelming for some people without having some idea of what a transition is", as stated by a parent (P9) when reflecting on the Parent-to-Parent Session.

The interviewer proposed various solutions that were brought up in earlier interviews or were inspired from the literature but could not be integrated in the present intervention.

Participants agreed that various additional policies or supports would benefit the transition experience, including earlier transition planning, a period of parallel care, or receiving updates on wait-times from the adult ED program. The suggestion of a transition coordinator received a split response; some supported this idea fully—with one parent stating that “it would be good to have a point of contact” (P1)—while others were satisfied with the coordination conducted by MN. Lastly, some suggestions participants proposed to improve the intervention included the provision of a list of providers (from private care or that were region-specific), earlier formal conversations about transition, making parents aware of the waitlist lengths, clearer guidance from the pediatric therapist, a meeting between the adolescent and the future therapist, and supports specific to other psychiatric symptoms that adolescents may have.

### 3.5.2 Youth-to-Youth Session

*Appendix H* shows the qualitative content analysis of summary of adolescents’ perspectives and experiences of Youth-to-Youth Session, as captured by qualitative data. This intervention component was found to be helpful and enjoyable by adolescents who attended it; five participants reported the Youth-to-Youth Session as their favourite part of the intervention. Notably, participants liked hearing the perspective of a young person with lived experience of this transition, because “it’s different than seeing a therapist, like it’s someone that actually went through it yourself [sic]”, as stated by A7, and “even though our stories aren’t exactly the same, I can kind of sympathize with them, I knew what [they were] going through and things like that, like the struggles” (A5). Adolescents who partook in this session appreciated the information and

resources provided, the group discussion, and the overall message of the session. Participants identified multiple lessons from this session, including learning of the existence, and associated details, of the local adult ED program, other treatment options, what transition will look like, and the awareness they can advocate for their care or specific needs post-transition. Two adolescents mentioned how this session influenced their transition plan. Hearing the presenter's story validated A9's decision to pursue anxiety treatment rather than ED-specific adult care by realizing "I'm past that point, like I'm not in the same mindset or anything." For another participant who had also been only considering anxiety treatment post-transition, this session gave them an opportunity to redirect their focus to their ED, saying "that's why I've been focusing on the anxiety, but it also, but it helped me to think about my eating disorder more" (A5).

Most adolescents reported feeling comforted or less nervous after the session, with one participant (A8) stating "it was kind of almost comforting to know that there is still treatment out there and that it's worked for someone." On the other hand, one participant reported feeling more nervous due to the wait time between programs and elaborated that "I now know of some other supports, like Body Brave, but am still worried about being more vulnerable during that transition and relapsing" (A2). The session allowed some to feel more confident and prepared, as exemplified by A9: "it made me feel more confident that I will be able to successfully transition my care and know other people went through the exact same thing as me and got the care they needed." Lastly, some participants felt less alone having heard of someone else go through the transition process—"it's not just me, I'm not alone in this" (A5).

A few less helpful parts of the session were identified by participants. A4, found the content from this session to be less memorable than other components, through their report "...

the meetings, I like them, but I don't necessarily remember them", A7 did not feel comfortable sharing as much as they would have liked to as they did not want to trigger the other adolescent present, and A1 found the session to be "a bit long and repetitive." To improve this session, adolescents suggested that various efforts are made to facilitate or improve the interaction between participants and the presenter, such as by "having check points during the presentation where we could ask questions and interact rather than waiting until the very end for the interactive piece" (A9) or by "having more people in a meeting at once with cameras and [microphones] on or in person so it may cause more conversation" (A8). The other recommendation made was for the content covered in the session to also include the experience or potential resources for adolescents living with other psychiatric symptoms or are considering non-ED treatment.

### 3.5.3 Parent-to-Parent Session

The qualitative content analysis of parents' perspectives of the Parent-to-Parent Session can be found in *Appendix I*. Parents found it helpful to hear from other parents whose children have undergone this transition during the session, with one parent (P6) finding it helpful "to learn how others [sic] families have coped with their children's situations and supported them as they move on to university and living more independently." Others identified the information and resources provided, the discussion among parents, and the preparation it offered as helpful aspects of the session. One parent (P6) was grateful that "the idea of transitioning has been introduced early, in my case, 6 to 7 months before my [child's] 18th birthday." From this session, parents learned about various resources or programs available, the long, enduring nature of EDs, that they will now need permission from their child to be involved in their care or that

their child will need to take responsibility of their health, and the reality of long waitlists for treatment programs. One parent reported learning that “it is okay to move away from always being in red-alert mode and that it is important that we do” (P8). This session contributed to parents’ thoughts regarding treatment options, as exemplified by one parent (P9) who reported that “it got me thinking and then saying “okay, I need to do this” and gave me some tips”, as well as parents can adapt to their and their child’s changing roles, with another parent (P5) who began “thinking about also how to support my child now that they are an adult.”

The Parent-to-Parent Session allowed attendees to feel less alone, hopeful, good, and confident. One parent’s (P5) opportunity to be emotional with the group “gave [them] an outlet to feel okay sharing the stress and pressure I have been feeling.” Three parents experienced a simultaneous mixture of concern or worry as well as reassurance and preparation, while two other parents reportedly only felt concern regarding the long waitlists or “a little overwhelmed” (P4). Some participants found it difficult to share because “there’s a lot of people watching and talking... I’m not used to that” (P4) or because they did not know what they could share without shocking parents with their experience (P8). Other less helpful parts of the session included feeling rushed during the short amount of time left for discussion as well as having to now notify their child of the long waitlist they learned about during the session. Parents offered some recommendations for the session: hearing the adolescent perspective of transition as “it would be really helpful to connect and hear from and speak with survivors of such things” (P8), delivering it in-person because “it’s not as personable as if you were there, sharing stories, in person” (P4), leaving more time for discussion, and providing parents with a list of private providers.

#### 3.5.4 Transition Meeting

Refer to *Appendix J* for the content analysis of participants' perspectives and experiences of the Transition Meeting, captured using qualitative data. This component was found to be helpful and enjoyable, with one parent reporting it to be one of the most helpful from the intervention. Participants found this meeting to be informative, and adolescents also found it comfortable and valuable to speak to their therapist and have their questions answered. The video about the local adult ED program was also found to be helpful, “informative” (A9), and “thorough in the explanation about what happens when you go” (P10). Although this meeting did not influence the care plan for one adolescent, it offered ideas for three others—one of whom stated that “having this meeting will help the planning” (A10)—and it directly influenced the transition plan for two adolescents, where A9 shared that they “made a game plan until and after I turn 18.” Similarly, three adolescents reported learning nothing novel during the session; meanwhile, others gained knowing about the local adult ED program, were informed of treatment options available and what to expect from adult treatment, and were reminded consent is required for parents to be involved in the adolescent's future care.

Participants identified feeling a variety of things after this meeting, including comfort and reassurance; A7 reflected this sentiment by saying that “a weight was lifted off my shoulders [because] I knew what I needed to do moving forward.” Additionally, various parents and adolescents reported feeling less stressed, more prepared, supported, and less alone for their upcoming transition, with one adolescent acknowledging that “both my parents and therapist are on my team and will do everything they can to make this transition as easy as possible” (A9). Meanwhile, this meeting led others to experience some feelings of increased nervousness or

loneliness, uncertainty. One participant said that the Transition Meeting was when they realized that “I’m going to be 18 soon and will have to lose the wonderful team I have now” (A9).

In terms of non-helpful aspects of the Transition Meeting, one adolescent (A8) did not enjoy their experience with the particular therapist they had, and a different adolescent did not find it memorable, reporting that this meeting as well as the Youth-to-Youth Session “almost completely left my mind...” (A4). The content of the video was not relevant for some youth and their parents because they were not pursuing ED treatment post-transition. Adolescents also reported that the video “a bit lengthy” (A7), “it’s just a lot of information at once” (A7), “felt kind of repetitive” and that the video format was harder to reference. Two adolescents suggested that the Transition Meeting incorporated information “about other mental health services, not just eating disorders, because although my eating disorder is part of the transition, it is not the only component” (A9), while A8 felt that “it would have been better had I had a different therapist.” Additionally, A7 recommended “making videos shorter and more straight to the point” and that more “more visuals will probably better than them just talking the whole time.”

### 3.5.5 Family Doctor Contact

For a summary of the qualitative analysis conducted on qualitatively-captured adolescent and parent perspectives on the Family Doctor Contact component of the intervention, see *Appendix K*. Participants described this component as helpful, as it played a role in their transition plan. A10 expressed that “it was an opportunity to talk about the future for my treatments and how she can be involved going forward.” Two adolescents found the Family Doctor Contact to be the most helpful aspect of the study. For some, this meeting or call directly influenced the involvement of their family doctor as part of their transition, with A5 reporting

that “now, I’ll start doing monthly check-ups with them” and A10 stating that they “discussed how [they] will monitor me and the medication I’m on and [they are] there to refer me to any adult programs if I feel that is necessary.” For others, this component did not change their transition plan; one adolescent from this group (A8) reported “think we just decided that they wouldn’t really be involved because there was one point in my treatment where I had to... stop in with her and she doesn’t really specialize with eating disorders and stuff?”

Participants reported feeling reassured—such as A9, who “felt really good knowing I will have the support system I need when I turn 18”—and comforted—such as P10, who knows that their child “will be in good hands with [them].” Others reported feeling “fine” (A1), supported, and “valued as a patient and person” (A9) after this contact with their doctor. This intervention component was found to be less helpful for two adolescents who are choosing to not involve their family doctor as part of their care. A participant (A10) who still had four months before their 18<sup>th</sup> birthday reported that they may have gained more from this contact had they talked “to them closer”, when they have “everything sorted out.”

### 3.5.6 Navigation Guide

Visit *Appendix L* for the qualitative content analysis for the final intervention component—the Navigation Guide. Participants enjoyed reading the guide, and two participants stated it was most helpful component. Its helpfulness was credited to the information and resources outlined in the document by multiple participants, with an adolescent (A1) describing that “it contained a lot of important information about adult care and what additional resources are available if needed.” Participants appreciated the organized and straightforward format of the Navigation Guide, and found it helpful to have a document to refer back to. Two participants did



report revisiting the guide, six participants had not yet referenced it again but did plan to do so “closer to my 18<sup>th</sup> birthday” (A7) or “in the future” (A9), and three did not and did not feel the need to read it again, with one participant noting that they “mostly knew all of the information that was covered in this guide already” (A1). Although some learned nothing new, most participants described acquiring knowledge by reading this guide: the fact that adult treatment programs for EDs existed, “various programs for different regions” (A4), “how the transition worked” (P1), tips for a successful transition, expected responsibilities for adolescents entering adult care—“such as arranging my own appointments and ‘speaking up’ for myself” (A10), differences between the pediatric and adult care setting, details regarding a healthcare platform used at the local adult ED program, as well as the nature of parental involvement post-transition.

Adolescents and parents felt less anxious and alone after reading the guide; this is evidenced by A9 who stated that “I don’t feel alone going through this journey because there are services and professionals to help me” and P1 who reported feeling relieved “as [their child] will have a similar team to what [they have] at [MCH PED Program] supporting [them].” Transition readiness was expressed by some adolescents, such as A9 who noted that they “feel ready to transition to adult care because I will have the support I need to get me through it.” One parent (P1) reported feeling “more confident that when [Name of Adolescent] leaves [MCH PED Program], [they] will get the care [they need] at [Local Adult ED Program].” Other parents reported feeling informed, yet nervous, about the upcoming transition, with one parent (P9) sharing that they were “still nervous about transition but glad to see what support is available.”

Some less helpful aspects of Navigation Guide identified by adolescents included that there “a lot of text” (A1) and that it “felt like a lot of reading” (A7). In response to these drawbacks regarding the format of the guide, participants recommended adding more visuals “to

help make the guide more engaging (A1), shortening it, presenting it using “more bullet points” (A7), and possibly to present this information verbally rather than through written text.

Additionally, two participants did not appreciate some of the content, but understood its purpose; for instance, P6 reported that “I don't enjoy being told that I will be losing control over my [child's] healthcare and treatment; however, I appreciate the necessity of making this age group more independent and responsible for their future health needs.” Other suggestions from participants to improve this component of the intervention were to include “more parts about mental health services beside at the bottom because I feel many people have other mental health issues besides an eating disorder that have to be acknowledged” (A9) and to include “specific names for potential therapists” (P6).

### **3.6 Change in Adolescent Outcomes**

Seven adolescents completed both the baseline and post-intervention measure packages. No significant differences were found between the mean subscale and total scores of any measures completed by this group from baseline to post-intervention; see Table 12 for a detailed summary of the mean differences between timepoints for each measure and the corresponding repeated measures analysis. According to EDE-Q subscale and total scores, the self-reported presence, frequency, and severity of ED symptoms in the adolescent sample increased insignificantly over time. Transition readiness and self-management skills, as measured the TRAQ and SMSAG-Y questionnaires, increased insignificantly or remained unchanged among the sample. Participant's readiness to change ED-related attitudes and behaviours, as indicated by the change in the Readiness to Change subscale of the ED-RR, decreased to an insignificant degree. As evidenced by the Controlled and Autonomous Motivation subscale scores of the ED-

RR, the adolescent sample's motivation to change for oneself decreased, while their motivation to change for others increased—both to an insignificant degree.

### **3.7 Change in Parent Outcomes**

Six of the nine parents originally recruited to the study completed the baseline and post-intervention measure packages. For a detailed summary of the changes in parent outcomes throughout the study and the associated repeated measures analyses, see Table 13. The results of the EDSIS measure indicate that caregiver burden related to their child's eating disorder did not significantly change over time; specifically, nutrition-related caregiver burden remained unchanged, burden related to their child's dysregulated behaviour increased, and self-reported burden with regards to social isolation as well as overall caregiver burden both decreased. However, there was a significant decrease in the guilt subscale of this measure ( $Z = -2.023, p = 0.043$ ), indicating that the parents in the sample experienced less guilt at the end of the study compared to baseline. Subscale and total scores of the CaNAM indicate that parents experienced an increase in number of met informational and support needs from baseline to post-intervention. However, none of these increases were considered significant. Lastly, parent's confidence to manage their child's ED and their perceptions of their adolescents' transition readiness both increased, according to the PACCS-C and SMSAG-P scores respectively, but not to a significant degree.

**Table 12.** Change in Adolescent Outcomes from Baseline and Post-Intervention Measures (n=7)

		Number of items	Possible Score Range	Baseline Mean (SD)	Post-Intervention Mean (SD)	Normality*	Mean Difference (SD)	95% CI	Paired <i>t</i> -test (df=6) <i>t</i> score, <i>p</i> **	Wilcoxon Signed-Rank Test <i>Z</i> score, <i>p</i> ***
<b>EDE-Q</b>	Restraint	5	0-6 <sup>a</sup>	1.77 (1.63)	2.06 (1.52)	Normal	-0.29 (1.50)	-1.67, 1.10	-0.505 (0.631)	
	Eating Concerns	8	0-6 <sup>a</sup>	1.66 (1.55)	2.09 (1.40)	Normal	-0.43 (1.80)	-2.09, 1.24	-0.629 (0.552)	
	Shape Concerns	5	0-6 <sup>a</sup>	3.15 (1.78)	3.57 (1.88)	Non-normal				-0.524 (0.600)
	Weight Concerns	5	0-6 <sup>a</sup>	2.31 (1.59)	3.09 (1.90)	Non-normal				-1.022 (0.307)
	Global	22 <sup>****</sup>	0-6 <sup>a</sup>	2.34 (1.57)	2.81 (1.44)	Non-normal				-0.847 (0.397)
<b>TRAQ</b>	Managing Medications	4	1-5 <sup>b</sup>	3.68 (0.76)	3.79 (0.82)	Normal	-0.11 (0.96)	-0.99, 0.78	-0.297 (0.777)	
	Appointment Keeping	7	1-5 <sup>b</sup>	2.82 (0.54)	2.79 (0.64)	Normal	0.02 (0.72)	-0.65, 0.69	0.078 (0.940)	
	Tracking Health Issues	4	1-5 <sup>b</sup>	3.21 (0.64)	3.04 (0.81)	Normal	0.18 (0.57)	-0.35, 0.71	0.826 (0.441)	
	Talking with Providers	2	1-5 <sup>b</sup>	4.43 (0.73)	4.36 (0.63)	Non-normal				-0.272 (0.785)
	Managing Daily Activities	3	1-5 <sup>b</sup>	4.24 (0.98)	4.38 (0.45)	Normal	-0.14 (0.74)	-0.83, 0.54	-0.513 (0.626)	
	Total	20	1-5 <sup>b</sup>	3.44 (0.37)	3.44 (0.50)	Normal	0.01 (0.30)	-0.27, 0.29	0.062 (0.952)	
<b>SMSAG-Y</b>	Total	21	1-5 <sup>c</sup>	3.69 (0.68)	3.70 (0.60)	Normal	-0.01 (0.28)	-0.27, 0.25	-0.108 (0.918)	
<b>ED-RR</b>	Readiness to Change	9	0-9 <sup>d</sup>	6.11 (1.96)	5.61 (2.34)	Normal	0.50 (3.10)	-2.37, 3.37	0.427 (0.684)	
	Controlled Motivation	9	0-9 <sup>e</sup>	2.00 (1.83)	2.57 (1.72)	Normal	-0.57 (2.37)	-2.76, 1.62	-0.638 (0.547)	
	Autonomous Motivation	9	0-9 <sup>f</sup>	1.43 (1.13)	0.57 (0.79)	Non-normal				-1.857 (0.063)

\*Normality was determined by the Shapiro-Wilk test. \*\*P-value is two-tailed. \*\*\*P-value is asymptotic two-tailed.

\*\*\*\*The number of items in the EDE-Q subscales do not add up to the number of items in the Global EDE-Q score because one item is in both the Shape and Weight Concerns Subscales.

\*\*\*\* Significant  $p$ -value ( $< 0.05$ ).

SD = standard deviation; CI = confidence interval.

<sup>a</sup> Higher subscale and global scores on the EDE-Q indicate increased ED symptomology.

<sup>b</sup> Higher subscale and total scores on the TRAQ indicate greater healthcare management skills.

<sup>c</sup> Higher total SMSAG-Y scores indicate greater self-management skills.

<sup>d</sup> Higher Readiness to Change subscale scores on the ED-RR indicate increased readiness to change.

<sup>e</sup> Higher Controlled Motivation subscale scores on the ED-RR indicate that the adolescent is motivated to change for others.

<sup>f</sup> Higher Autonomous Motivation subscale scores on the ED-RR indicate that the adolescent is motivated to change for themselves.

**Table 13.** Change in Parent Outcomes from Baseline and Post-Intervention Measures (n=6)

		Number of items	Possible Score Range	Baseline Mean (SD)	Post-Intervention Mean (SD)	Normality*	Mean Difference (SD)	95% CI	Paired <i>t</i> -test (df=5) <i>t</i> score, <i>p</i> **	Wilcoxon Signed-Rank Test <i>Z</i> score, <i>p</i> ***
<b>EDSIS</b>	Nutrition	8	0-32 <sup>a</sup>	12.44 (3.63)	12.33 (5.61)	Normal	0.11 (4.74)	-4.86, 5.07	0.054 (0.959)	
	Guilt	5	0-20 <sup>a</sup>	12.83 (2.79)	9.00 (4.98)	Non-normal				-2.023 (0.043****)
	Dysregulated Behaviour	7	0-28 <sup>a</sup>	3.00 (2.68)	3.17 (2.79)	Normal	-0.17 (0.98)	-1.20, 0.87	-0.415 (0.695)	
	Social Isolation	4	0-16 <sup>a</sup>	5.83 (4.31)	5.00 (4.15)	Normal	0.83 (1.60)	-0.85, 2.51	1.274 (0.259)	
	Total	24	0-96 <sup>a</sup>	34.11 (10.83)	29.50 (14.20)	Normal	4.61 (7.02)	-2.76, 11.98	1.607 (0.169)	
<b>CaNAM</b>	Information about Eating Disorders	14	0-14 <sup>b</sup>	3.67 (3.20)	6.67 (4.89)	Non-normal				-1.625 (0.104)
	Support from Other People or Organizations	13	0-13 <sup>b</sup>	5.00 (4.15)	5.50 (3.78)	Normal	-0.50 (2.07)	-2.68, 1.68	-0.591 (0.580)	
	Support for yourself	5	0-5 <sup>b</sup>	1.00 (1.27)	2.17 (1.60)	Normal	-1.17 (1.17)	-2.39, 0.06	-2.445 (0.058)	
	Total	32	0-32 <sup>b</sup>	9.67 (7.50)	14.33 (9.25)	Normal	-4.67 (5.13)	-10.05, 0.71	-2.230 (0.076)	
<b>PACCS-C</b>	Total	33	0-100 <sup>c</sup>	72.05 (20.35)	80.71 (16.62)	Normal	-8.66 (12.02)	-21.27, 3.96	-1.764 (0.138)	
<b>SMSAG-P</b>	Total	21	1-3 <sup>d</sup>	2.35 (0.29)	2.50 (0.33)	Non-normal				-0.946 (0.344)

\*Normality was determined by the Shapiro-Wilk test. \*\*Paired *t*-test *p*-value is two-tailed. \*\*\*Wilcoxon Signed Rank Test *p*-value is asymptotic two-tailed.

\*\*\*\* Significant *p*-value (< 0.05).

SD = standard deviation; CI = confidence interval.

<sup>a</sup> Higher subscale and total scores on the EDSIS indicate increased carer burden.

<sup>b</sup> Higher subscale and total scores on the CaNAM indicate increased amount of met informational and support needs.

<sup>c</sup> Higher total PACCS-C scores indicate increased confidence in managing their child's eating disorder.

<sup>d</sup> Higher total SMSAG-P scores indicate increased self-management skills of the adolescent, reported by the parent.

## CHAPTER 4: DISCUSSION

### 4.1 Interpretation and Integration of Findings

To our knowledge, this is the first report to explore the feasibility, among other outcomes, of an intervention designed to support adolescents and their parents as they prepare for a transition out of pediatric ED services. Nineteen participants were consented to the study—ten adolescents and nine parents. Although a pre-established study eligibility criterion required that each adolescent have a willing parent to participate in the study and vice versa (see Table 1), an exception was made for one adolescent whose parent was too busy for the study.

*Demographic Considerations.* The demographic composition of the sample is important to consider in the interpretation of the results and when making comparisons to the samples and findings in existing research. To start, most adolescents identified as female (80%) with the exception of one male (10%) and one gender non-confirming individual (10%), which is not surprising considering that ED prevalence rates are higher among females (Ackard et al., 2007; Bhattacharya et al., 2020; Flament et al., 2015; Galmiche et al., 2019; Udo & Grilo, 2018). Men are less likely to seek for help for their ED in general—not only during transition (Bhattacharya et al., 2020; Coffino et al., 2019; Grillot & Keel, 2018). This pattern has been attributed to increased stigma and shame among men about EDs (e.g., concern about being labelled as homosexual by acknowledging an ED) and providers' under-recognition of ED symptoms in men due to the assumption that they are predominantly a “female disorder”, both of which pose as barriers to treatment utilization (Coffino et al., 2019; Grillot & Keel, 2018; Thapliyal & Hay, 2014). Transgender and gender-diverse individuals have also reported having negative experiences with clinicians during ED treatment after disclosing their gender identity (Duffy et

al., 2016; Hartman-Munick et al., 2021). Hesitancy regarding ED treatment or engaging with providers among males and gender minorities may explain the low rates of their involvement in this study; however, it is difficult to ascertain the ultimate cause given the small sample of 10 adolescents. Special attention should be placed upon gender-related treatment-seeking hesitancies when studying or implementing this intervention to ensure that gender-specific needs of youth are met in their destination mental health adult program.

Most participants were Caucasian (84%), which is slightly higher than the proportion of Caucasian people in Ontario of 71% based on the 2016 Canadian Census (Statistics Canada, 2016). This proportion is not dissimilar from existing ED research, where racial and ethnic representation is limited (Egbert et al., 2022); specifically, non-White or Hispanic participants make up less than 5% of ED research reporting on race and ethnicity data. However, ethnic and racial minorities (Hispanics and non-Hispanic Blacks) are less likely to seek treatment for their ED symptoms than their non-Hispanic White counterparts (Coffino et al., 2019). Contributing factors include financial difficulties experienced by ethnic minorities, differences in clinical presentations among individuals from diverse groups, and biased or inadequate ED screening by healthcare providers (Acle et al., 2021; Cachelin et al., 2001; Coffino et al., 2019). An adolescent's race and ethnicity should be considered in future studies and implementation of this intervention (1) by reporting race and ethnicity data, to facilitate an understanding of where improvements are needed, and (2) by linking ethnic minority youth with adult mental health or ED care providers that are informed of the fears, beliefs, and previous treatment experiences unique to these individuals.

Participants also ranged in the duration of time they have lived with their ED, from less than three months to over five years, as well as the number of ED treatment types experienced—



two to five. It is possible that the number or nature of previous ED treatment experiences influenced adolescents' desire to partake in the intervention—for those in the study and those asked, but whom were ultimately not consented. Existing evidence shows that previous positive experiences led youth with EDs to have positive attitudes towards counselling, while negative treatment experiences fostered unfavourable attitudes towards counselling (Akey et al., 2013; Dotson et al., 2011; Nicula et al., 2022; Schoen et al., 2012). However, youth who are not aware of the well-established differences between pediatric and adult ED treatment—a concept discussed in this intervention—may not realize that adult care may be a better fit if their negative treatment experience had to do with feeling patronized in the pediatric setting, as has been reported by a sample of youth adults with chronic illness (van Staa et al., 2011), for instance.

Eighty percent of the adolescent sample had a primary ED diagnosis of AN; although AN is often the disorder emphasized in ED research, it is not the most common ED, as prevalence rates of OSFED, BN and BED are higher (Galmiche et al., 2019). Additionally, 78% of parents reported having a household income of over \$100,000 which is significantly higher than the median after-tax income of families in Canada of \$66,800 in 2020 (Statistics Canada, 2020).

Reflecting upon the demographic distribution of the study sample, and its implications on the findings, is good practice. However, the sample used in this study was too small and took place in a singular context and program. To allow for appropriate comparison to other members from the same target population, future research on this intervention should employ sampling approaches that are designed to capture a larger, diverse, and more representative sample—with regards to gender, ED type and duration, treatment history, race and ethnicity, geographical area—to ensure that the results are similarly applicable to anyone in need of such an intervention. Using this larger sample, subgroup analyses can be led to explore differences in the

transition experience held by youth and parents based on these demographic differences. Such an exploration may shed light upon the groups that require special attention or a dedicated effort to ensure they receive a strong transition to adult care.

*Feasibility of Intervention.* On average, participants in the study completed approximately three quarters of the intervention components they were expected to complete in . This finding was corroborated by participants' qualitative reports that the intervention was convenient and easy to complete. Quantitative completion rates of individual intervention components were also supported by qualitative reports about their feasibility. For instance, the Youth-to-Youth and Parent-to-Parent Sessions—components with some of the highest completion rates (90% and 100%, respectively)—were reported to be convenient due to their virtual nature and because they provided an opportunity to ask questions in a small group. The Transition Meeting, with an 100% completion rate among adolescents, was easy to participate in because it took place during a pre-scheduled session and offered a safe, comfortable space to ask questions and be heard, according to participants. The low completion rate of the Family Doctor Contact among adolescents (40%) was explained by anxiety making the initial call or inconvenience of driving to the office. Similarly, participants reported finding the Navigation Guide—with a completion rate of 56-60%—too lengthy, forgetting to do it, missing it in the e-mail, or not thinking it would be useful. Together, the quantitative and qualitative findings indicate that participants were more likely to complete components that involved other people and one's schedule (e.g., Youth-to-Youth and Parent-to-Parent Session) or were initiated by a clinician (e.g., Transition Meeting) over self-directed intervention components (e.g., Family Doctor Contact, Navigation Guide) or components that were not officially expected to complete (e.g., Family Doctor Contact or Transition Meeting among parents).

Since participants were given three months to complete the intervention and, on average, they completed it just over a third of that time (36.46 days;  $SD = 29.58$ ), it is understandable that almost all participants in the final interview reported the three-month prescribed for the intervention as sufficient. Although it is tempting to shorten the time dedicated for this intervention in future studies, keeping it the same may make it more feasible for participants who need more time, such as the adolescent who needed 78 days to complete all four components.

The integration of the quantitative indicators and participants' associated qualitative reports suggests that the intervention was acceptable, feasible, convenient, and easy to complete. Intervention feasibility was chosen as the primary outcome of this study because the many life changes that take place at the age of 18 (e.g., secondary school graduation, independence from family), combined with the egosyntonic nature of the EDs (Gregertsen et al., 2017), have the potential to distract adolescents with EDs from forming transition plans. One consideration for implementing a transition intervention for adolescents with EDs from Nadarajah and colleagues was applied in this study: to offer choices of various interventions to adolescents and families to choose those most suitable for their circumstances (Nadarajah et al., 2021). Although this may have contributed to the feasibility and acceptability of the intervention, as they were able to complete the components relevant to their needs in the order they desired, a larger-scale study following a more rigorous design is required to establish this causation. Participants are more likely to adhere to treatment recommendations or experience improved clinical outcomes when an intervention is acceptable and feasible (Sekhon et al., 2017); this applies to what was achieved in the present, small-scale study. The demonstration of acceptability and feasibility for this intervention suggests that adolescents and parents are more likely to gain information, grow

aware of care options, and prepare themselves with enough time to make a successful, tailored transition.

*Feasibility of Research Processes and Measures.* Of the 31 adolescents or parents approached about the study, 22 voiced some level of interest to hear more and 10 adolescents were consented—resulting in a rather low recruitment rate of 45%. Some patient- or therapist-reported qualitative accounts that explain this rate were captured via e-mail or telephone communication with MN throughout the recruitment process; these include a lack of interest in the study, no response to recruitment efforts, or being too busy or stressed with other aspects of life. One eligibility criterion that may have particularly influenced the recruitment rate was the requirement for the adolescent to be preparing for a healthcare transition to future mental health care; this requires the adolescent to want to continue ED treatment. The egosyntonic nature of EDs may cause patients to be reluctant to continue pursuing treatment for their disorder, as has been reported by other mental health professionals working with AN youth during healthcare transition (Lockertsen et al., 2020b). Hesitancy to transition is also evident among youth with other psychiatric illnesses. In one study, 56% of patients in pediatric treatment with the potential to transfer to adult treatment dropped out of pediatric treatment directly before transition age (Reneses et al., 2022). Additionally, it is also possible that disruptions in treatment and or changes in service delivery faced by Canadian pediatric patients with EDs as a result of the COVID-19 pandemic (Spettigue et al., 2021; Spigel et al., 2021; Weissman & Hay, 2022) affected the eligible participant pool. Furthermore, a review of CBT studies found higher rates of treatment dropout among ED patients when delivered virtually rather than in-person (Linardon et al., 2018). The move to virtual care due to the pandemic may have led more patients to not attend their therapy sessions, which is where they would learn about this study.

As for the retention rate, 68% or 13 out of the 19 consented participants completed the intervention and all required measures of the study; all six participants who did not complete the study never responded after multiple contact attempts and were thus considered lost-to-follow-up. No qualitative reports exist to suggest why these participants were lost-to-follow-up given that they did not complete the final interview.

While there was no missing data at the item or scale level for any measures included in participants' post-intervention packages, some adolescents and parents did not provide a response to a few items on various baseline measures. The proportions of missing data for baseline measures that fell under this category were almost all below 0.05 or 5%—which is considered to be an inconsequential amount of missing data by experts (Dong & Peng, 2013; Schafer, 1999). The TRAQ measure at baseline was the only exception to this, as it was missing approximately 8% of responses at baseline; this was due to one adolescent who did not provide a response to 17 items, comprising four of the five scales, included in this measure. Interestingly, this was not the measure that received the most feedback in the interview regarding its relevancy, which may have explained this missing data. Instead, some adolescents commented on items on the EDE-Q that asked about a variety of ED behaviours—such as overexercising, use of laxatives, or vomiting—as being irrelevant for them. Similarly, two parents reported that they struggled at post-intervention to respond to items on the EDSIS; some questions assumed their child still lived at home, but one parent's adolescent had since moved out, and the other parent found it unclear whether the questions were meant to be answered by the adolescent or parent. Participants were otherwise generally satisfied with the baseline and post-intervention measure packages and described them as easy to understand, for the most part, and those who did not report issues with items inapplicable to them reported them as relevant. One explanation for the

low rates of missing data, particularly for the adolescents in the sample, is that individuals with EDs exhibit perfectionistic behaviours, which can include ensuring that all questions are answered (Wade et al., 2016). However, the high rates of measure completion at the item and scale level may also indicate that the measures chosen for this study were feasible to complete, which was reiterated by the qualitative data.

Participants all spent a reasonable, predictable amount of time to complete each data collection measure, even though pre-determined criteria were not set prior to analysis. Specifically, it took participants the shortest amount of time to complete the reflections compared to other measures. There were six outliers in the data regarding duration, likely due to participants leaving the questionnaire open on their Internet browser and revisiting it later; these were excluded from the descriptive summary of the duration to complete each measure in Table 10. To avoid this in the future, participants will be instructed to complete measures in the same sitting to capture this metric accurately. Although no concerns were brought up by participants regarding the length of measure packages or the interview, the reflections received a mixed response; five participants were satisfied with their length and two adolescents found some to be repetitive or longer than desirable.

Some aspects related to the feasibility of the research methods and processes not captured by the quantitative indicators were participants' perceptions of the study communication and access to materials. Participants were pleased with the communication and materials provided to them throughout the study. Specifically, e-mail reminders were appreciated, with some suggesting more reminders are sent to prompt participants to complete intervention components, reflections, or measure packages. This is supported by existing literature, as e-mail and text reminders were found to increase the rate of patient-reported outcome measure completion

among participants in at least two studies to date (Roberts et al., 2014; Triplet et al., 2017). In addition, participants found it helpful to reflect on each intervention component using the reflection while “it’s fresh in your mind” (A1). This offers support for reflections as method of collecting qualitative data during an intervention rather than only doing a traditional post-interview. However, the interview was still reported by adolescents to be “helpful to wrap everything up”, easy to understand, relevant, and enjoyable. The opportunity for participants to self-reflect during a qualitative interview has previously been reported as a benefit of this data collection method (Wolgemuth et al., 2015). Lastly, the idea of a virtual portal was proposed to participants as an alternative to the use of multiple platforms to conduct the study. Participants were either pleased with how the study was led or felt enthusiastic about this idea. To expand on existing research on digital transition supports (Shi et al., 2021), it may be helpful to explore the implementation of this or similar intervention using a portal as described to participants.

*Nature of Intended and Actual Transition.* Transition plans were gathered for seven of the adolescents in the study, given that three were lost-to-follow-up. Most adolescents who communicated their plan during the final interview arranged to receive care from a private therapist, their family doctor, or both, while waiting to hear back from specialized adult ED or anxiety treatment programs. The exceptions to this pattern were one adolescent who planned to wait on the waitlist to the local adult treatment program and another adolescent who planned to transition their care to their family health team or transfer to counselling services at their future post-secondary school, if needed.

One-month post-transition status is only known for five of the seven adolescents. (This information is unknown for two adolescents as their 18<sup>th</sup> birthday will take place after the study is over. This occurred due to the relaxation of the study eligibility criteria to allow adolescents to

partake in the intervention who are more than six months from their 18<sup>th</sup> birthday to partake in the study to meet the desired sample size.) One adolescent considered themselves to be “fully transitioned” to an organization that provided mental health and ED care across the lifespan, after they left the MCH PED Program. This case highlights the potential benefits of investing in ED services that provide continuous mental health treatment across the lifespan. If tertiary specialized ED treatment was not dependent on stage of life, transition-related discontinuity of care would be less of a problem. However, such a change would require time, money, and a fundamental shift in the Canadian healthcare system and training of mental health professionals. Furthermore, it may be difficult to implement such a change given the differences in treatment philosophies between pediatric and adult ED settings (Dimitropoulos et al., 2013; Lockertsen et al., 2020b; Winston et al., 2012). One recommendation to address the dissonance in treatment philosophy between pediatric and adult ED treatment programs is to develop, implement, and evaluate efforts designed to educate or debunk on well-entrenched assumptions held by providers from each domain [e.g., that pediatric care providers “mother” their patients (Lockertsen et al., 2020b)] and to strengthen relationships and collaborations between providers from both settings. By extinguishing assumptions and biases held by providers, these interventions have the potential of improving the chances and speed of referral from pediatric to adult ED treatment or mental health programs and increasing the willingness of youth with EDs to continue into adult care, as pediatric care providers would promote these programs more positively.

Next, two adolescents self-reported a “successful transition” to the care of their family doctor and/or private therapist, while still waiting to enter their respective specialized adult treatment programs. Participants with EDs from a Canadian qualitative study also transitioned to family doctors after leaving pediatric care (Dimitropoulos et al., 2015). It is important to note



that these two individuals were self-reportedly close with their family doctor, discussed transition with them during the study, and found the Family Doctor Contact component to be helpful. It is possible that arranging support from primary care during or after one's transition is dependent on the doctor's existing relationship with the adolescent, level of involvement in the adolescent's ED care to date, and knowledge about EDs. The potential for family doctors to support adolescents during this transition period should be harnessed or considered as a valid post-pediatric care option—whether it is a permanent shift or temporary, prior to graduating to their destination specialist program. It would be helpful to dedicate a multi-phase research program that starts by determining the current eating disorder-related mental health literacy among primary care providers in Ontario. Next, the tenets of an education intervention for primary care providers should be developed, with the help of adolescents and parents with EDs, on how to diagnose, manage, refer, and transition individuals with EDs. The last step would be to pilot and evaluate the effectiveness of this intervention by, for instance, measuring changes in eating disorder-related mental health literacy or reporting the number of transition-age youth who transition their care to their primary care provider or to specialized services with the help of their primary care provider.

The remaining two that have not yet transitioned remain on the waitlist with no additional mental health-related adult care one month after turning 18. This discontinuity in care may pose an increased risk of relapse and disengagement from adult mental health services, as reported in other ED transition research (Dimitropoulos et al., 2015; Lockertsen et al., 2021). Patients undergoing a transition for mental health needs who had no family doctor or primary care were more likely to experience a mental health-related hospitalization in their young adulthood (Toulany et al., 2019). This research combined with the reality of transition among this study's

adolescent sample underlines the importance of integrating family doctors or other supports into one's transition plan. This is especially critical with unprecedented changes in care pathways, such as the long waitlists experienced by the local adult ED program due to COVID.

Additionally, a regression analysis using data from a national American survey from 2000-2001, disease complexity was identified as a factor that influenced transition success among youth with special needs (Scal & Ireland, 2005). Specifically, those with more complex needs or increased disease severity were more likely to experience an adequate healthcare transition, given that this was given more attention and seen as a higher priority by healthcare providers. This is relevant to this study as it is possible that therapists from MCH PED Program who helped with recruitment were more likely to show the flyer or introduce the study to adolescents with increased ED symptom severity or caused greater concern. This highlights the importance of providing equal opportunities for transition support to all 17-year-olds graduating from a pediatric program so that no adolescent is left behind. It is vital that transition practices are incorporated when working in ED settings, given that the egosyntonic nature of the disorders may enable adolescents to hide their desire to discontinue treatment behind the lack of supports provided (Gregertsen et al., 2017).

In sum, all seven of the adolescents (100%) interviewed at the end of the study intended to transition to future ED or mental health care. Intent to transition is a metric that has not been captured in the related literature and, thus, cannot be compared to this result. In terms of actual transition, one in five adolescents for whom transition status is known (20%) was successfully transitioned by the end of the study, while three in five adolescents (60%) were at least receiving some form of medical or mental health care at post-transition prior to reaching their desired destination program. Rates of healthcare transfer or transition have been reported for adolescent

samples with psychiatric illnesses; in the TRACK study, 58% of youth continued to adult services (Singh et al., 2010) and 44% of youth from a retrospective observational study made the transition to adult mental health services (Reneses et al., 2022). Notably, these rates vary greatly study to study and depend largely upon methodology (de Haan et al., 2013; Reneses et al., 2022). When compared to the rate of transition for anyone receiving mental health care at one month post-transition (60%), the estimates reported by other studies is similar. However, these estimates are at least two times greater than the proportion of adolescents who reached their destination mental health program at this timepoint (20%). With only five adolescents, these rates of transition may have resulted from characteristics unique to individuals in the sample rather than being indicative of preliminary intervention effectiveness. For increased confidence in this outcome, a larger sample is needed to explore and report on rates of successful transition future studies of this intervention. It is also recommended that researchers studying healthcare transition should reach a consensus on methods of studying and reporting rates of intended and actual transition from pediatric to adult care to allow for easier and more accurate comparison between studies.

*Participant Perspectives and Experience of the Intervention.* Overall, the intervention was reported to be helpful by providing participants with information, resources, and the advance notice about the upcoming discharge from pediatric care to prepare for transition to adult mental health care. Each component was appreciated for different reasons: adolescents and parents enjoyed hearing the perspective and story of someone with lived transition experience in the Youth-to-Youth and Parent-to-Parent sessions; the Transition Meeting allowed adolescents to ask questions and consider treatment options with someone who knew them and they felt comfortable with; the Family Doctor Contact prepared those who intended to engage their doctor

in next steps to set this up; and, the Navigation Guide offered useful information which participants could revisit at any time. The consensus among the group was to start the intervention using the Navigation Guide to first gather a solid understanding of transition, followed by the other components in whatever order. Each component was identified as being the most helpful by at least one participant, with the Youth-to-Youth Session and Family Doctor Contact receiving the most credit; in future renditions of this intervention, the scope of these more highly preferred components should be expanded and their acceptability should be studied in more detail.

Through this intervention, participants learned of available care options outside of the natural next step of tertiary adult ED care (including anxiety treatment, support from family doctor, and private care), what to expect from transition and adult care, as well as a growing awareness of the changing role for both the adolescent (i.e., increased responsibility and autonomy) and the parent (i.e., decreased parental involvement and trusting the adolescent to make their own healthcare decisions). Learnings gleaned from different intervention components directly influenced the transition plan for adolescents in the study by putting their name on waitlists for private or public mental health care, requesting support from their family doctor, or looking into available supports at their post-secondary school. This was important considering that the waitlist at the local adult ED program was estimated to be a two to three year wait (Laliberte, 2021). Although some adolescents felt uncertain about what their future may bring when learning about these long waitlists, parents felt particularly more anxious and stressed that their child would be left with no support. This pattern is reflected in other literature reporting upon higher level of distress experienced by caregivers of individuals with EDs, compared with the individual with the ED themselves (Matthews et al., 2018). However, exposure to the stories

of others who have transitioned, an opportunity to learn more and discuss care options with their pediatric therapist or family doctor, and access to a written informational guide also led participants to feel positive emotions throughout the study and afterwards—including feelings of reassurance, hopefulness, and calm.

Participants offered suggestions to improve some of the less helpful aspects of the intervention components, such as by incorporating methods of facilitating interactions during the session (e.g., turning videos on, prompting participants to share their story, more time for discussion) and reformatting or shortening the Transition Video and the Navigation Guide. When asked what would improve their experience of the intervention, adolescents and parents made number of recommendations that have also been recorded in existing transition research: earlier transition planning (Gray et al., 2018; Nadarajah et al., 2021; Reiss et al., 2005; Singh et al., 2010; van Staa et al., 2011), a period of parallel care in the pediatric and adult settings (Nadarajah et al., 2021), active and clear guidance from the pediatric therapist (Lockertsen et al., 2020a), and meeting with the future adult provider (Dimitropoulos et al., 2015; Nadarajah et al., 2021; van Staa et al., 2011). With regards to this last recommendation, the original plan for the present study was to involve therapists from the local adult ED program to take part in the Transition Meeting. With the growing waitlist times and the administrative stress on this program due to the pandemic, their involvement was cancelled and the focus of the Transition Meeting pivoted to aiding adolescents and parents transition out of pediatric care to some other form of care, whether that is family doctor monitoring, general mental health adult services, private practice, virtual group treatment, or more. In the end, the absence of the adult care providers in this meeting may not have affected participants' experience too strongly, given that a large portion of adolescents decided to pursue treatment unrelated to their ED. Either way, this

feedback suggests that the reception of the Transition Meeting in particular may have been affected, given that adolescents' future adult provider was not involved.

Other ideas and suggestions from the literature, stakeholder meeting, or clinical expertise of JC for an ED transition intervention also could not be implemented for a variety of reasons. Although peer support for adolescents and parents undergoing this transition are well-supported in the literature (Beveridge et al., 2019; Cleverley et al., 2020; Couturier et al., 2020; Franklin et al., 2019)., members from the stakeholder meeting did not reckon it was safe the Youth-to-Youth and Parent-to-Parent Session presenters to be referred to as “peer supporters” or to lead the sessions alone. In Canada, the peer supporter title is associated with a standardized certification offered by Peer Support Canada that involves a written exam, a practicum that can last for up to 20 weeks, and significant cost per person (\$1,280 CAD) (Peer Support Canada, 2022); it was not possible with the time and funds of the project to set up the session presenters to do this. To accommodate for this, MN moderated the session with direct access to JC (a mental health professional) in case a mental health crisis took place during the session. Including MN in the meeting compromised of the true essence of “peer support” and may have dissuaded participants from sharing or asking questions they would have had it only been the session presenter.

It was also not possible to implement the recommendation to initiate transition planning earlier (e.g., a year prior to turning 18) (Gray et al., 2018; Nadarajah et al., 2021; Reiss et al., 2005; Singh et al., 2010; van Staa et al., 2011) given the short timeline to also study other outcomes of the project (e.g., whether the adolescent had transitioned or not). Currently, there are no policies in place in the MCH PED Program to systematically outside of the initiation of the transition conversation by the pediatric therapist, adolescent, or parent during a session. Qualitative support by participants in this study and in other transition literature should be used

to propose the possibility of integrating an automated reminder in each patient's profile in the MCH PED Program's medical electronic system that a transition conversation should be initiated, with resources or guides for the pediatric therapist to use.

Lastly, parental or family involvement in their child's adult ED treatment is supported in the literature (Boland et al., 2022; Colver et al., 2020; Lockertsen et al., 2020a). Unlike pediatric care however, many adult tertiary care programs do not allow parents to be directly involved in the adolescent's care to protect the confidentiality and decisions made by the adolescent—now, an adult (Baldock, 2009; Dimitropoulos et al., 2013); this can be troubling when the adolescent and parent are both accustomed to having access to the treatment plan or health information. In the present study, members of the stakeholder group recommended that parents require an invitation from the adolescent to attend the Transition Meeting and Family Doctor Contact, as these are meetings that concern the adolescent's future adult care. Notably, it is possible that components or recommendations for an ED transition intervention may have been implemented without any obstacles by another program, in a different setting, or at another time (e.g., pre-pandemic). If the intervention was designed in closer alignment to what as recommended by stakeholders, the feasibility and acceptability of each intervention components, the number of adolescents who transitioned and where they planned to transition to, and the change in adolescent and parent outcomes may have been different or, specifically, more exaggerated.

Unique to this study, participants also requested a list of disorder- and region-specific mental health providers or specialists and highlighted the importance of incorporating content into existing intervention supports or additional components that may be more relevant for youth considering treatment for other psychiatric symptoms (e.g., anxiety) in their adult care. Although some participants were on board with the idea of having a transition coordinator present in the

pediatric program to help with transition planning, some felt that what the coordination they experienced in the study was sufficient without this additional person. It is important to note, however, that participants would not have received tailored coordination or provision of transition supports had they not been part of this study, with MN essentially serving the role of a transition coordinator. This speaks to the importance of having a dedicated individual that identifies, supports, and follows up with adolescents leaving pediatric ED care, as has been identified by other stakeholders (Dimitropoulos et al., 2019; Dimitropoulos et al., 2013; Gray et al., 2018; Nadarajah et al., 2021; Singh et al., 2010). The incorporation of these suggestions into the existing intervention can potentially make it more helpful and ensure that more informational, support, and preparation needs are met for adolescents and parents facing a transition in ED care.

*Change in Adolescent Outcomes.* According to the EDE-Q, adolescents experienced an insignificant increase in self-reported ED symptomology over the course of the study. One potential reason for this trend is the tendency for youth with EDs to lean back into their ED behaviours in order to regain or establish a sense of control during periods of uncertainty (Lockertsen et al., 2020a), which is reflected in our data via comments from participants about their lack of surety about what to expect during the transition period. In fact, the mean TRAQ and SMSAG-Y total scores at both timepoints were nearly identical and both were over the half-way mark at baseline and post-intervention, which may indicate that their self-reported transition readiness or level of self-management skills were above average. This lack of significant change can be contextualized by some of the qualitative findings; some participants shared that they learned nothing new from some intervention components or already had a preliminary transition plan in place. Thus, it is possible that participants did not learn enough from the intervention for



there to be an appreciable increase in transition readiness or self-management skills. Finally, adolescents may not be experiencing a change in transition readiness or self-management skills because they are experiencing greater ED symptomology. Previous research has reported that the value that individuals with AN place on their disorder may hinder their motivation for recovery and engagement with treatment (Gregertsen et al., 2017). Thus, this re-emergence of ED symptoms may lead participants to be less motivated to prepare for continued treatment as an adult.

In addition to a slight and insignificant decrease in readiness to change (as measured by the Readiness to Change subscale of the ED-RR), participants' motivation to change their ED behaviours for themselves slightly decreased and increased for others—neither to a significant degree—as captured by changes in the Controlled and Autonomous Motivation subscales of the ED-RR. Given that the intervention is designed to place increased responsibility on the adolescent in their adult care, an anticipated direction for this measure was for participants to report wanting to change for themselves more over others by the end of intervention—the opposite of what was found. It is possible that this result occurred because participants completed this study to appease their parents, thus participating in the study for others and not themselves.

*Change in Parent Outcomes.* The only significant difference in an intervention-related outcome from baseline to post-intervention for the parent sample was a decrease in self-reported guilt as captured by the change in score of the respective EDSIS subscale. This may have been influenced by parents' participation in the Parent-to-Parent Session; one parent (P8) expressed that this session taught them “it is okay to move away from always being in red-alert mode and that it is important that we do”. Although no other aspects of caregiver burden decreased, the

insignificant increase in social isolation-related burden could also be related to the Parent-to-Parent Session, given parent reports of enjoying hearing other parents' perspectives and stories with some never having been exposed to other parents of children with EDs before.

With regards to parental needs for information and support, there was a significant increase for the needs regarding support for self. It is possible that partaking in the intervention components—especially the Parent-to-Parent Session—provided parents with an opportunity to care for themselves. In their qualitative interview, one parent (P5) reflected on their opportunity to release some harboured emotion with the group. According to the change in total CaNAM scores over time, parents experienced a significant increase in met informational and support needs by post-intervention compared to baseline; however, a large enough difference was not found for their needs specific to information about EDs or support from others or organizations, based on the responses to those CaNAM subscale. Given that many parents reported receiving more resources and getting more ideas (e.g., names of private therapists), it is possible that they received information that required further action rather than solutions to the problem at hand. This explanation is supported by the fact that some parents requested a list of more of providers and resources in their qualitative interviews and reflections.

Finally, parents did not report feeling significantly more confident in their ability to manage their child's ED, in their adolescent's awareness of their health condition, or their child's ability to make decisions related to their healthcare—according to the PACCS-C and SMSAG-P. Parents may not have experienced an increase in confidence because they described learning more about the enduring and long course of EDs and that their parental involvement will decrease from different components of the study, such as the Parent-to-Parent Session.

Overall, the lack of significant changes in all adolescent and most parent outcomes related to transition could be due to the small sample captured or the use of transition measures that were not standardized for a mental health or ED population. Adjusting existing intervention components based on participant feedback (e.g., making more videos for the Transition Meeting relevant for different diagnostic psychiatric illnesses, Navigation Guide with more visuals) as well as the inclusion of additional supports (e.g., reminders to healthcare providers to prompt earlier transition planning, a list of accessible, region-specific, and relevant mental healthcare providers outside of tertiary specialist programs) may also lead to a change in intervention-important outcomes among adolescents and parents in the future evaluations of this intervention. Lastly, it is possible that in a study with a larger sample and possibly a control group, there would be sufficient power to state hypotheses could be posed. In this scenario, one-sided tests would be used, which allow for a higher likelihood of significance if the direction of the difference aligns with the hypothesis.

#### **4.2 Study Limitations**

In addition to some limitations outlined for each outcome above, other potential caveats should be noted. Although the desired sample size of 10 adolescent-parent pairs was met, it is important to recognize the limitations of using a small sample. Small sample sizes have been known to threaten the generalizability and validity of the results—especially in quantitative research (Vasileiou et al., 2018). No hypotheses or claims about this small sample were made about the target population for this reason. Even considering these limitations, this sample size was justified for this project due to context- and project-specific factors. For instance, given the limited amount of time and funds offered by this Master’s project, a choice was made by MN

and her committee to prioritize the gathering of rich, complex data to answer multiple research questions rather than to expand the sample size past 20 participants. The use of maximum variation in the sampling approach was used to address or capture as many experiences as possible in this reduced sample size. Additionally, only a small group of patients were expected to graduate from the pediatric site during the proposed study timeline; at the time of project development in Spring of 2021, a clinician from the study site estimated this number to be around 27 patients. This number, combined with the requirement of adolescents and parents to be actively planning for a transition out of pediatric care contributed to the decision to recruit 10 adolescent-parent pairs for the study. Ultimately, the acceptability and feasibility of this intervention established by this thesis supports further research of this intervention using a greater sample with individuals from different contexts to increase the readers' confidence in the generalizability of the study findings.

Similarly, the homogenous demographic make-up of this sample—of Caucasian families with greater-than-average socioeconomic status and adolescents with AN from a singular pediatric program—means that the results of this study may not be easily generalizable or transferable to individuals with different EDs or life experiences. By focusing on including diverse samples with respect to type of ED, other comorbidities, gender, sexual orientation, race, and socioeconomic status, it is more likely that the outcomes of this intervention will be translated to all members of the target population. To better understand this issue, it may be worthwhile to compare the proportion of youth from marginalized or racialized communities who access the MCH PED Program with the proportion of these individuals who live with EDs in the larger population. This exploration may provide insight into whether the homogenous

sample in the present study (and other ED research) was indicative of the target population or if it highlighted systemic barriers that leave marginalized youth vulnerable to inadequate ED care.

Self-selection (or volunteer) bias may have played a role in this study. This form of bias occurs when the recruited sample is different from the target population in a way that systematically influences the studied outcome (Nunan et al., 2017; Nuzzo, 2021). Adolescents and parents who were already interested to find support for transition to adult care may have been more interested to participate in the present study, meaning the perspectives of individuals who may be more resistant to transition were not captured. This could have overemphasized the positive perceptions of the intervention experience or overestimated the number of participants with transition plans that would be representative of the true target population. Additionally, participants with increased ED severity—and thus, egosyntonicity—may also be less represented in the sample, meaning that the results may not represent all members of the target population along the ED severity spectrum. The elevated household income of the study sample may also mean that parents could financially support private interim therapy for adolescents while waiting for entry into publicly funded adult program in a way that families with lower socioeconomic status may not be able to offer. Overall, it is possible there is an overrepresentation of individuals who differ markedly from all transition-age youth with EDs who are considering adult care.

As mentioned above, it is possible that the measures used to gauge differences in transition readiness and self-management skills from before and after intervention did not lead to significant changes because they were not tailored for the completion of psychiatric or ED youth. The measures of concern are the TRAQ and SMSAG-Y, given that these were validated for youth with physical conditions or special needs (Williams et al., 2011; Wood et al., 2014). A mental health or ED healthcare transition may require adolescents to make different preparations

or develop other skills than these youth with chronic physical illnesses—by virtue of the differences in etiology, symptom presentation, and other factors related to their disorders. In future evaluations of this intervention, transition measures developed in the local context, such as the TRANSITION-Q (Klassen et al., 2015) which was created by a research group from McMaster University, or the TRAM and TROM—currently being validated for transition-age youth with mental health concerns by researchers of the MILESTONE study (Santosh, Adams, et al., 2020).

A methodological limitation of the present study was the lack of an additional coder when coding and analyzing the qualitative reflection and interview data. A second opinion while coding the open-ended and semi-structured nature of the interview—in contrast to the more structured written reflection—would have made the resultant analysis and interpretation less susceptible to inherent bias introduced by a single coder (Jonsen & Jehn, 2009). The opportunity for resolving conflicts made possible by having multiple people code the qualitative data would reduce the chance for bias to obscure participants' true experiences and perspectives of the intervention, thus enhancing the rigour of the study.

Even though this study did not intend to determine the effectiveness of the intervention, there were some aspects of the research design that would need to be strengthened in order to confidently pursue that or similar research aims in the future. For instance, determining transition status at one-month post-transition may not be enough time to gauge the success of these supports. Unfortunately, this was the latest follow-up timepoint that could be collected due to the short timeframe to complete this Master's thesis. In the future, the use of a quasi-experimental or RCT design with an embedded qualitative aspect and a bigger sample may be more appropriate when conducting additional research on this intervention.

Finally, the entirely virtual nature of the study may have indirectly affected recruitment and retention success and the quality of the data collected. Although there are benefits to virtually-led research—such as a lack of geographical constraints and increased convenience for all parties involved—meeting adolescents and parents in person for this study could have offered a chance to build increased rapport, buy-in, and connection that is not possible when communicating virtually (Lenoir, 2021). More patients or parents may have been interested if they were introduced by the graduate student in person, as they would be able to answer any questions or address concerns, in addition to the other benefits of being face-to-face. It is also possible that the rapport built through in-person interaction could have minimized the number of participants who were lost-to-follow-up or encouraged participants to share more or be more vulnerable, given the sensitivity of the phenomena being explored.

### **4.3 Strengths**

A notable strength of the following study is the use of a mixed methods design. When used alone, qualitative research often portrays the experiences of a small group of individuals and cannot be generalized (Creswell & Plano Clark, 2018). Similarly, a purely quantitative exploration of an outcome often erases the potential for understanding one's lived experience. The combination and integration of data from both of these approaches in mixed methods research allows for a more comprehensive understanding of the research question than either quantitative or qualitative methodology can provide on its own (Creswell & Plano Clark, 2018; Doyle et al., 2009). In the present study, the data regarding intervention and research process feasibility gathered using quantitative and qualitative approaches corroborated one another. This level of triangulation contributes to the accuracy and applicability of what was found.

The use of several strategies to ensure the qualitative rigour of the qualitative data contributed to the trustworthiness of this data. For this, future research that builds off the results from this study can be trusted to reflect participant experiences during transition.

The in-depth exploration of this transition intervention of this study was carried out using small sample from the same context—adolescents leaving MCH PED program in Hamilton, Ontario. Given the tailored nature of this study, researchers and clinicians from this setting can trust these results when informing transition-related change in their practice.



## **CHAPTER 5: CONCLUSION**

With a need for continuous and sustained care, adolescents with EDs face an increased risk of relapse and disengagement from services after being discharged from specialized pediatric ED treatment. To our knowledge, no research efforts have been made to assess any of the recommended ideas for supporting youth with EDs and their families as they prepare for this healthcare transition. In response to this gap in the literature, this thesis assessed the feasibility of the (1) intervention and (2) research methods and process, (3) adolescents' transition plans and outcomes, (4) intervention experience, and (5-6) changes in adolescent and parent outcomes of a literature- and stakeholder-informed intervention when implemented in a sample of 10 adolescents and their parents as they left pediatric ED care.

The integration of quantitative and qualitative data of the primary mixed methods study outcome indicate that this transition intervention is feasible, due to high completion rates of intervention components and the participants' reports of the intervention being easy, convenient, and helpful to complete. In addition, the communication and measures used to collect the data for this study were reportedly relevant, easy to complete, enjoyable, and convenient; thus, the research processes and measures employed in this study were feasible. Most participating adolescents have planned to transition from pediatric ED care to receive support their family doctor or a private therapist, while awaiting entry into specialized ED or anxiety treatment from a publicly funded outpatient adult program. At one month after transition, no adolescents had heard back from their specialized program, and were required to rely on pre-established interim supports after being discharged from their pediatric program. Participants found the intervention and its individual components to be instrumental and useful in helping them think about and plan for transition, while also offering recommendations for improvement. Many of the outcomes

intended to measure the preliminary effectiveness of the intervention were not significant, aside from alleviating feelings of guilt among parents in the sample. In its interpretation of these study findings, the discussion of this thesis offered various explanations when interpreting the results of this study, including the potential for logistical problems to influence the recruitment or retention success of the data as well as the role that egosyntonicity present in EDs may have played in the lack of motivation to pursue continued care among adolescents.

The purpose of this study was to ascertain the factors that influence the feasible implementation of this intervention in the context of Hamilton, Ontario; however, these promising preliminary results, and the recommendations made in the discussion above, support continued evaluation with a larger sample and across other pediatric and adult ED programs in Ontario or Canada. To expand on the findings of this thesis, it is recommended that future research explores the perceptions and experiences of this intervention among tertiary, specialized pediatric and adult care program clinicians and administrators as well as family doctors. Collectively, input from these various ED-treatment stakeholders have relevance for better understanding of transition service delivery. Future research exploring this intervention should also focus on gathering a more diverse sample with representation from men, sexual and gender minorities, and ethnic minorities. Even though EDs affect people from all backgrounds (Roane; Schaumberg et al., 2017), men and ethnic minorities are less likely to seek help for their ED overall (Bhattacharya et al., 2020; Coffino et al., 2019)—not only in relation to seeking further care as an adult while transitioning out of pediatric care. The use of appropriate sampling approaches, such as probabilistic or maximum variation sampling (Palinkas et al., 2015), and study designs, such as a participatory-social justice mixed methods design (Creswell & Plano Clark, 2018), will be instrumental to equitably involve members from these groups. By involving

these groups, an exploration of how one’s identity influences the likelihood of successful transition can be made—which is a future research recommendation made in existing transition literature (Burke et al., 2020). Finally, adolescent- and parent-provided recommendations—such as earlier transition planning, a meeting with the pediatric and adult care provider, and a list of disorder- and region-specific mental health providers—should be integrated into the existing intervention in an effort to increase the likelihood that it would be effective, if studied on a larger scale in the future.

If it is found to be effective in preparing youth and families for transition or increasing rates of transition in future trials, this intervention has the potential to decrease the amount of time adolescents with EDs spend without tailored mental health support, to reduce risk of relapse, and to improve the transition experience for youth, parents, and healthcare providers affected by EDs. Furthermore, this initiative may inspire researchers, policymakers, and clinicians specialized in other psychiatric fields to study interventions that can support the transition from pediatric to adult services among adolescents with other psychiatric disorders.

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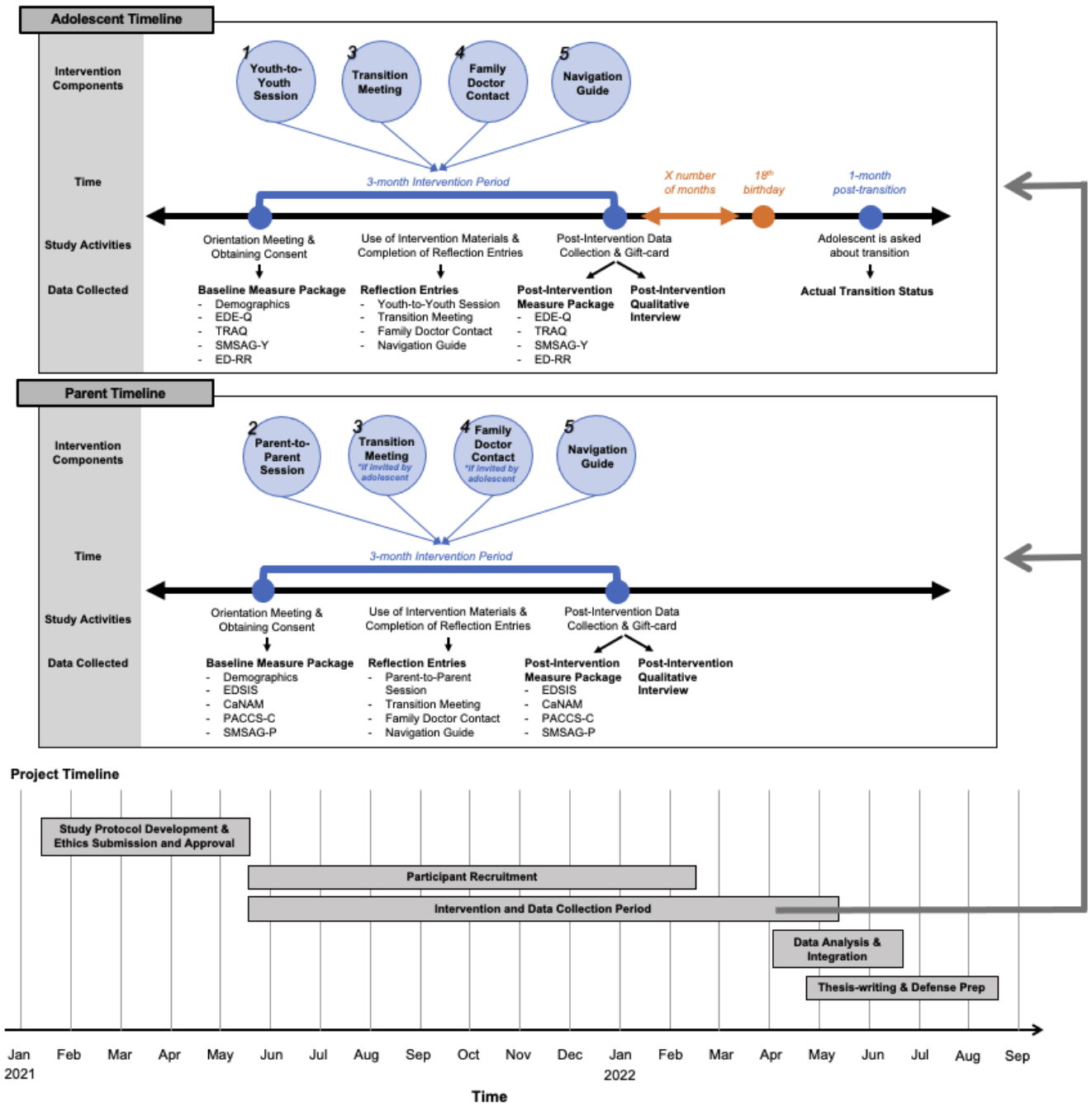
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APPENDICES

Appendix A. Project Timeline & Participant Intervention and Data Collection Timeline



**Appendix B. Data and Methodology Chart**

STUDY OUTCOME	QUANTITATIVE			QUALITATIVE		
	Data	Measures	Analysis	Data	Measures	Analysis
Intervention Feasibility ( <i>primary, mixed methods</i> )	Quantitative indicators for intervention feasibility (e.g., Completion rate of each intervention component, average time to complete each intervention component)	Participant Tracking Sheet and Qualtrics	Descriptive Summary	Perceptions of the feasibility of the intervention components and overall intervention	Reflections, Adolescent Interview, Parent Interview	Conventional and Summative Content Analysis
Feasibility of Research Processes and Measures	Quantitative indicators for feasibility of research processes and measures (e.g., recruitment and retention rate, missing data at the item and scale level, average time to complete each measure)	Participant Tracking Sheet and Qualtrics	Descriptive Summary	Perceptions of the study communication, intervention roll-out, and data collection measures	Adolescent Interview, Parent Interview	
Nature of Intended and Actual Transition				Transition Plans and Status	Adolescent Interview or Post-Study E-mail Check	
Participant Perspectives and Experience of Intervention				Self-reported experience, preferences, and suggested feedback	Reflections, Adolescent Interview, Parent Interview	
Change in Adolescent Outcomes	Presence, frequency, and severity of ED symptoms	EDE-Q 6.0 subscale and global scores	Repeated Measures (Paired <i>t</i> -test or Wilcoxon Signed-Rank test)			
	Level of readiness for transition to adult care	TRAQ subscale and total scores				
	Awareness of their condition and ability to make decisions relevant to healthcare needs	SMSAG-Y total scores				
	Readiness and motivation to change various ED symptoms and behaviours	ED-RR subscale scores				

Change in Parent Outcomes	Carer burden and impact of eating disorder symptoms on parents' lives	EDSIS subscale and total scores		
	Needs of carers of individuals with an eating disorder	CaNAM subscale and total scores		
	Carer parent self-efficacy and collaboration among carers of patients with an eating disorder	PACCS-C total scores		
	Perception of child's awareness of health condition and ability to make healthcare decisions	SMSAG-P total scores		

### Appendix C. Reflections

After the orientation meeting, each parent and adolescent will receive an e-mail with the four Qualtrics links that correspond to the components that they are expected to participate in or complete over the span of their 3-month intervention period. They have been instructed to complete the corresponding entry as soon as they participate in or complete each component of the intervention.

	Adolescent	Parent
A. Youth-to-Youth Session	X	
B. Parent-to-Parent Session		X
C. Transition Meeting	X	X
D. Family Doctor Contact	X	X
E. Navigation Guide	X	X

At the start of every entry for both the adolescent and parent, the following text will be present at the top.

“Please answer the following questions regarding this component of the intervention. Elaboration and detail are encouraged.”

At the end of every reflection entry for the adolescent, the following text will be present at the bottom.

“If you and your parent have completed all intervention components and their corresponding reflection entries, please e-mail [Name of Graduate Student] at [E-mail Address of Graduate Student] to tell her that you are done!”

#### *A & B. Youth-to-Youth (for Adolescent) or Parent-to-Parent Session (for Parent) Session Reflection*

- What is your Study Identification Number (e.g., A087)? *This number should be in your post-orientation e-mail. If you cannot locate this number, contact [Name of Graduate Student].*
- When did the youth/parent session take place? *Please provide the date and time. (e.g., March 1, 2021 from 4:00 – 5:00 PM)*
- What were your overall thoughts about the session?
- What was discussed in the session?
- Did you learn anything in this session that you did not know before? Please elaborate.
- How do you feel after this session?
- What did you enjoy about the session, if anything?
- What did you not enjoy about the session, if anything?
- How convenient or easy was it for you to participate in this session? What were the things that made it more or less convenient or easy for you to participate?
- Do you have any suggestions for how this component of the intervention could be improved?

- If there is anything else you would like to share about your experience in this session, please do so below:

*C. Transition Meeting Reflection*

- What is your Study Identification Number (e.g., A087)? *This number should be in your post-orientation e-mail. If you cannot locate this number, contact [Name of Graduate Student].*
- When did the transition meeting take place? *Please provide the date and time. (e.g., March 1, 2021 from 4:00 – 5:00 PM)*
- Who was present at this meeting?
- What were your overall thoughts about the transition meeting?
- What was discussed in the meeting?
- Did you learn anything in this meeting that you did not know before? Please elaborate.
- Was anything achieved or planned as a result of meeting with this group? If so, what?
- How do you feel after this meeting?
- What did you enjoy about the meeting, if anything?
- What did you not enjoy about the meeting, if anything?
- How convenient or easy was it for you to participate in this meeting? What were the things that made it more or less convenient or easy for you to participate?
- Do you have any suggestions for how this component of the intervention could be improved?
- If there is anything else you would like to share about your experience in this meeting, please do so below:

*D. Family Doctor Contact Reflection*

- What is your Study Identification Number (e.g., A087)? *This number should be in your post-orientation e-mail. If you cannot locate this number, contact [Name of Graduate Student].*
- When did the contact with the family doctor take place? *Please provide the date and time. (e.g., March 1, 2021 from 4:00 – 5:00 PM)*
- On what platform or where did this conversation take place? (i.e., in person, eHealth appointment, telephone call)
- Who was present at this call/meeting?
- What were your overall thoughts about the call/meeting with your family doctor?
- What was discussed in this call/meeting?
- Did you learn anything in this call/meeting that you did not know before? Please elaborate.
- How do you feel after this call/meeting?
- What did you enjoy about the call/meeting, if anything?
- What did you not enjoy about the call/meeting, if anything?
- Was the family doctor meeting guide helpful? Why or why not?
- How convenient or easy was it for you to participate in this call/meeting? What were the things that made it more or less convenient or easy for you to participate?
- Do you have any suggestions for how this component of the intervention could be improved?

- If there is anything else you would like to share about your experience in this call/meeting, please do so below:

*E. Navigation Guide Reflection*

- What is your Study Identification Number (e.g., A087)? *This number should be in your post-orientation e-mail. If you cannot locate this number, contact [Name of Graduate Student].*
- Please provide your best estimate regarding when you read the Navigation Guide below. *(e.g., I read all of it on March 1, 2021 or mostly read it on May 2, 2021, but revisited it on May 18, 2021.)*
- Did you read it alone or with someone?
- What were your overall thoughts about the Navigation Guide?
- Did you learn anything from this guide that you did not know before? Please elaborate.
- How do you feel after reading this guide?
- Did you refer back to the guide at times? If so, when?
- What parts of the guide did you enjoy?
- What parts of the guide did you not enjoy?
- How convenient or easy was it for you to access/read/understand this Navigation Guide? What were the things that made it more or less convenient or easy for you to access/read/understand it?
- Do you have any suggestions for how this component of the intervention could be improved?
- If there is anything else you would like to share about your experience with this guide, please do so below:

## **Appendix D.** Post-Intervention Interview Guide Scripts

### Adolescent Post-Intervention Interview Guide – Transition Study

Purpose: to qualitatively capture the adolescents' perceptions of the intervention, the research processes and methods, as well as their overall experience of the group.

*Thank you for participating in this study and in this interview, which is estimated to last around 30 minutes. I hope to gather your perspective on how practical this intervention and the various data measures you completed were and capture your experience completing the intervention. Please know that you are not required to answer any questions that you would like not to answer.*

#### *Setting the Stage*

1. To start, would you be able to share your experience with your eating disorder until now?
  - a. *Prompts:* from the time you started to show signs to where you are today
2. How did transition or this study fit into this experience?

#### *Feasibility of the Intervention*

- From what I recorded on my end, I see that you have completed [name components of the intervention completed].
- 3. How convenient or easy was it for you to participate in this intervention, on the whole?
  - a. What would have made it more or less convenient or easy for you to participate?
- 4. *If they did not complete an intervention component:* You did not complete a reflection for [component name(s)]. To understand a bit more about your experience, why did you not complete that/those component(s)?
  - a. *Potential responses:* didn't want to, forgot to complete it, not interested in doing it, didn't think it was relevant

#### *Feasibility of Study Communication and Access to Materials*

5. The way we interacted or spoke about the parts of the study was mainly via e-mail. This included me sending you links to the measures or sending you that original e-mail with all of the reflection links.
  - a. How did you like our communication throughout the study or me providing you with the documents/links you needed?
  - b. Do you have any suggestions on how to improve study communication or providing you with the materials?
  - c. Would it have been helpful if there was some sort of online portal where see a checklist of the intervention components and/or receive reminders through?

#### *Experience*

6. How would you describe your overall experience of the intervention?
7. What were the most helpful aspects or components of the intervention for you as you planned for your transition?
  - a. *Prompts:* Why or how come?
8. How about less helpful aspects of the intervention while you were planning for transition?
  - a. *Prompts:* Why or how come?

9. Do you have any suggestions for us on how to improve upon or change how we led this intervention for adolescents in your position?
  - a. What was the order you completed the components in? Would you have preferred a particular order to the intervention components?
  - b. How did you feel about the three months I provided you and your parent to finish the intervention in?
  - c. How did you feel about the timing of the intervention with respect to your 18<sup>th</sup> birthday?
  - d. Are there any other components you would have wanted to see be included?

*Transition*

10. After this intervention, are you planning to transition to adult care?
  - a. Where to?
  - b. Where you are in your transition to adult care now?
  - c. Are you still in communication with the pediatric program?
  - d. Do you consider yourself fully transitioned/not yet transitioned?

*Feasibility of Measures*

11. These last few questions regard the measures you completed throughout the study, so that includes the set of measures you did at the beginning of the study and just recently, the reflections you completed after each component, and this interview. If you do not remember something about any of these measures, let me know and I can jog your memory.
  - A) Starting with the baseline and post-intervention measures:
    - a. Overall, how did you feel about this measure?
    - b. Did you feel that the questions in this measure was relevant to the study? Why?
    - c. How did you feel about the length of this measure and/or the time it took?
    - d. Was it easy to understand?
  - B) Next, the reflections:
    - a. Overall, how did you feel about this measure?
    - b. Did you feel that the questions in this measure was relevant to the study? Why?
    - c. How did you feel about the length of this measure and/or the time it took?
    - d. Was it easy to understand?
  - C) Lastly, this interview:
    - a. Overall, how did you feel about this measure?
    - b. Did you feel that the questions in this measure was relevant to the study? Why?
    - c. How did you feel about the length of this measure and/or the time it took?
    - d. Was it easy to understand?

*Final Thoughts*

12. Any final thoughts about transition, this intervention, or this study before we close off?

*Thank you so much for participating in our study and for completing this interview.*



## **Parent Post-Intervention Interview Guide – Transition Study**

Purpose: to qualitatively capture the parents' perceptions of the intervention, the research processes and methods, as well as their overall experience of the group.

*Thank you for participating in this study and in this interview, which is estimated to last around 30 minutes. I hope to gather your perspective on how practical this intervention and the various data measures you completed were and capture your experience completing the intervention. Please know that you are not required to answer any questions that you would like not to answer.*

### *Setting the Stage*

13. To start, would you be able to share about your family's experience with [Name of Adolescent]'s eating disorder until now?
  - a. *Prompts:* from the time they started to show signs to where they are today
14. How did transition or this study fit into this experience?

### *Feasibility of the Intervention*

- From what I recorded on my end, I see that you have completed [name components of the intervention completed].
- 15. How convenient or easy was it for you to participate in this intervention, on the whole?
  - a. What would have made it more or less convenient or easy for you to participate?
- 16. *If they did not complete an intervention component:* You did not complete a reflection for [component name(s)]. To understand a bit more about your experience, why did you not complete that/those component(s)?
  - a. *Potential responses:* didn't want to, forgot to complete it, not interested in doing it, didn't think it was relevant

### *Feasibility of Study Communication and Access to Materials*

17. The way we interacted or spoke about the parts of the study was mainly via e-mail. This included me sending you links to the measures or sending you that original e-mail with all of the reflection links.
  - a. How did you like our communication throughout the study or me providing you with the documents/links you needed?
  - b. Do you have any suggestions on how to improve study communication or providing you with the materials?
  - c. Would it have been helpful if there was some sort of online portal where see a checklist of the intervention components and/or receive reminders through?

### *Experience*

18. How would you describe your overall experience of the intervention?
19. What were the most helpful aspects or components of the intervention for you as you planned for your transition?
  - a. *Prompts:* Why or how come?
20. How about less helpful aspects of the intervention while you were planning for transition?
  - a. *Prompts:* Why or how come?

21. Do you have any suggestions for us on how to improve upon or change how we led this intervention for adolescents in your position?
  - a. What was the order you completed the components in? Would you have preferred a particular order to the intervention components?
  - b. How did you feel about the three months I provided you and your child to finish the intervention in?
  - c. How did you feel about the timing of the intervention with respect to their 18<sup>th</sup> birthday?
  - d. Are there any other components you would have wanted to see be included?

*Transition*

22. Are they planning to transition to adult care, and where to?

*Feasibility of Measures*

23. These last few questions regard the measures you completed throughout the study, so that includes the set of measures you did at the beginning of the study and just recently, the reflections you completed after each component, and this interview. If you do not remember something about any of these measures, let me know and I can jog your memory.
  - A) Starting with the baseline and post-intervention measures:
    - a. Overall, how did you feel about this measure?
    - b. Did you feel that the questions in this measure was relevant to the study? Why?
    - c. How did you feel about the length of this measure and/or the time it took?
    - d. Was it easy to understand?
24. Next, the reflections:
  - a. Overall, how did you feel about this measure?
  - b. Did you feel that the questions in this measure was relevant to the study? Why?
  - c. How did you feel about the length of this measure and/or the time it took?
  - d. Was it easy to understand?
25. Lastly, this interview:
  - a. Overall, how did you feel about this measure?
  - b. Did you feel that the questions in this measure was relevant to the study? Why?
  - c. How did you feel about the length of this measure and/or the time it took?
  - d. Was it easy to understand?

*Final Thoughts*

26. Any final thoughts about transition, this intervention, or this study before we close off?

*Thank you so much for participating in our study and for completing this interview.*

**Appendix E.** Qualitative Content Analysis pertaining to Participants’ Perspectives of Intervention Feasibility

	<b>Number of adolescents</b> [interview (Int) and reflection (R) mentions]	<b>Supporting Quotes</b>	<b>Number of parents</b> [interview (Int) and reflection (R) mentions]	<b>Supporting Quotes</b>
<b><i>Convenience of Entire Intervention</i></b>				
Convenient	6 (10 Int)	<p>“...resources were right there for me...” (A7)</p> <p>“...everything was there, and everything made sense” (A10)</p> <p>“...good number of components...” (A4)</p> <p><i>Regarding the virtual nature:</i> “...if I had some downtime or something, I’m like “okay, I can complete this part of the study”...” (A9)</p>	3 (4 Int)	<p>“...easy to access...” (P9)</p> <p>“...pretty easy, because it was online” (P1)</p>
Timing of Intervention (3 months)	6 (6 Int)	<p>“Yeah, I think, that was plenty of time to get everything done without being rushed. And then it wasn’t like too much time.” (A10)</p>	4 (4 Int)	<p>“Oh yeah. Yeah.” (P9)</p>
Not Convenient	1 (2 Int)	<p>“...so, it was more personal problems that got in the way.” (A8)</p>		
<b><i>Convenience of Youth-to-Youth Session</i></b>				
Convenient	6 (1 Int, 6R)	<p>“Being on Zoom made it very easy to participate in this session.” (A1)</p> <p>“...it was easy because the content [Name of Youth-to-Youth Session Presenter] was talking about was near to my heart and I could understand where [they were] coming from because I experienced it myself...” (A7)</p>		

		<p>“...convenient because it was a small group.” (A9)</p> <p>“...allowed my voice to be heard.” (A9)</p>	
Not Convenient	2 (2R)	<p>“...nervous about seeing people I didn’t know though...” (A2)</p> <p>“...hard time finding a good time for it.” (A8)</p>	
<b><i>Convenience of Parent-to-Parent Session</i></b>			
Convenient			<p>“online saves having to commute” (P8)</p> <p>“very easy for me to participate in” (P5)</p> <p><i>Regarding format of parent-to-parent session:</i> “I think, like how we did the Zoom was good. Yeah, because that’s, I mean, if I got a question, there’s a person there.” (A2)</p>
Not Convenient			<p>“not so easy cause I’m not really open to discussion” (A4)</p> <p>“wasn’t easy to participate, hearing other stories made it easier” (A4)</p>
<b><i>Convenience of Transition Meeting</i></b>			
Convenient	4 (1 Int, 3R)	<p>“I already had an appointment had an appointment with her, so it wasn’t too bad” (A1)</p> <p>“safe space to discuss my worries and concerns” (A1)</p> <p>“easy to talk to my therapist and the video was easy to watch” (A7)</p> <p>“everything I wanted to say was heard” (A9)</p>	<p>3 (1 Int, 2R)</p> <p>“it was very easy” (P10)</p> <p>“video could do at own time” (P9)</p>
Both	1 (1R)	<p>“stressful at the start because I am nervous to get closer to leaving [MCH</p>	

		PED Program]. But after hearing all the information I was feeling a lot better, and I am very glad I participated in it.” (A10)		
<b><i>Convenience of Family Doctor Contact</i></b>				
Convenient	3 (1 Int, 3R)	“we had to go in anyways” (A1) “it was just one-on-one so I could talk freely” (A9)	1 (1R)	“it was easy” (P10)
Not Convenient	2 (2 Int, 2R)	“had to drive to doctor’s office” (A1) “a bit hard, but I ended up getting an appointment” (A7) “anxiety making appointments” (A7)		
<b><i>Convenience of Navigation Guide</i></b>				
Convenient	6 (6R)	“...clear heading above each section made the guide easy to navigate and gave clear indication of what each section was about.” (A1) “the information provided was straightforward” (A4) “I feel like the guide hit all the important points and facts.” (A4) “It was well organized in all the topic covered and I know it will be relevant for the many times I access it.” (A10)	5 (5R)	“convenient to get on iPad” (P9) “headings and links are helpful” (P1) “easy to read with appropriate groupings” (P9)
Not Convenient	1 (1R)	“It was a bit lengthy in my opinion” (A7)		
<b><i>Reasons Why Participants Did Not Complete the Youth-to-Youth Session</i></b>				
Stress and hesitancy to share	1 (1 Int)	“... there’s just a lot going on and I was stressed with balancing everything with school and appointments. On top of that, I was stressing about having to sit down and really think about everything that is going on with me, and then,		

		maybe having to share, so that was just like pretty stressful.” (A9)	
Virtual Nature			1 (1 Int) <i>on behalf of adolescent</i> “Like even, like the youth session, I don’t know. Like just being online too I think is, it’s gotten hard for [them].” (P10)
<b>Reasons Why Participants Did Not Complete the Family Doctor Contact</b>			
Anxiety making the initial call	1 (2 Int)	“I get too anxious doing it” (A4)	
Do not want them to be part of their adult care	1 (1 Int)	“I was never really in contact with [them] about it when I was going through [MCH PED Program] too much? Like, I kinda just went to [them] for just like regular family doctor things.” (A4)	
Finding Parking at Doctor’s Office	1 (1 Int)	“...[their] office is on [Street Name] so it’s not as convenient for me to get there...” (A4)	
<b>Reasons Why Participants Did Not Complete the Navigation Guide</b>			
Forgot to do it	1 (1 Int)	“Honestly, it was literally just because I forgot about it.” (A5)	
Missed it in the e-mail	1 (1 Int)		1 (1 Int)
Didn’t think it would be useful			1 (1 Int)
<b>Reasons Why Parents Did Not Complete the Transition Meeting and Family Doctor Contact</b>			
Presumed adolescent would complete on their own			1 (1 Int) “I presumed those two things I wasn’t to attend. [They were] to do those two things on [their] own. Because, to be honest, now [they’re] 18. [They] should be handling [their] doctor on [their] own, seeing a doctor on [their] own, you know, taking ownership for that sort of thing.” (P1)

Parent was not invited			1 (1 Int)	
<b><i>Suggestions for Increased Feasibility of the Intervention</i></b>				
Shorten Transition Meeting Video	1 (1 Int)	“... it could have been easier if the video with the therapist was a bit shorter?” (A7)		
More Flexible Timing for Parent-to-Parent Session			1 (1R)	“I would like to be able to go to a meeting sometime in the future. However with being a single mom working full time, it would be preferable to be in the evening.” (P4)
Make Youth-to-Youth Session or Parent-to-Parent session one-on-one	1 (1 Int)	“I think one-on-one just because I know it’ll just be me” (A10)	1 (1 Int)	

**Appendix F.** Qualitative Content Analysis pertaining to Participants’ Perspectives of the Feasibility of the Research Processes and Methods

	<b>Number of adolescents</b> [interview (Int) and reflection (R) mentions]	<b>Supporting Quotes</b>	<b>Number of parents</b> [interview (Int) and reflection (R) mentions]	<b>Supporting Quotes</b>
<b><i>Thoughts about Study Communication and Access to Materials</i></b>				
Convenient	6 (6 Int)	<p>“They were pretty convenient just because, you know, you e-mailed me directly, the links were there. I didn’t have to look anything up.” (A4)</p> <p>“I think your communication was really good and clear and the way you laid out your e-mails to everything was very helpful.” (A10)</p>	1 (1 Int)	<p><i>Regarding parent-to-parent session:</i> “You had a lot of different times, so you know people working through the day, there was options... there was nothing that was not convenient.” (P10)</p>
Satisfaction with E-mail Reminders	1 (1 Int)	<p>“I actually didn’t mind getting e-mails...” (A7)</p>	3 (3 Int)	<p>“... I’m always missing stuff... so, the reminders were great.” (P8)</p> <p>“... when you were re-sending “this is what you’ve done, this is what you still need to do”. Probably a lot of extra work on your part, but it was, I found that really helpful and made it easier.” (P10)</p>
<b><i>Thoughts about Baseline and Post-Intervention Measures</i></b>				
Overall Satisfaction with Measures	2 (2 Int)	<p>“I thought they were pretty good.” (A1)</p> <p>“I thought it was pretty good.” (A7)</p>		
Relevancy				
Items were relevant	3 (3 Int)	<p>“It was probably good to like be aware of some of the questions that were asked, like about, like I guess, just, taking care of my</p>	3 (5 Int)	<p>“Yeah, no, I didn’t feel any of the questions were not relevant.” (P1)</p>



		own appointments and what-not, when I’m an adult.” (A10)		<i>Regarding the EDSIS:</i> “Definitely relevant. I liked, even questions about not having friends over as often... we don’t, and it has been on my mind. We used to be a social household and people don’t come over anymore.” (P8)
Some items were not relevant	5 (5 Int)	<i>Regarding the EDE-Q:</i> “I mean there was a few questions that didn’t pertain to me, the ones about exercising, cause I don’t do it. With my eating disorder, I never used laxatives or never forced myself to throw up, so some of those questions didn’t pertain to me, so yeah.” (A4)	1 (1 Int)	<i>Regarding the EDSIS:</i> “It was a bit hard to fill some of them now that [Name of Adolescent] is an adult, because, [they weren’t] at home. So, a lot of the questions, were like “In the past 2 months, having [them] at home, has this gone well?” ... so I struggled to answer some of the last ones.” (P1)
Although some items were irrelevant for them personally, they may relevant for others	1 (2 Int)	<i>Regarding the EDE-Q:</i> “I know you have to ask a question to make sure that you get all the eating disorders in there, so obviously, like yeah, it’s not going to apply to everyone.” (A5)	2 (2 Int)	“...some things didn’t exactly apply, but I answered to the best of my ability. Everybody’s story’s different, right? So, I think you’re just trying to cover all your bases to just make sure you get the most facts possible.” (P4) “... some people it’s going to be appropriate for, some not.” (P9)
Comprehensibility				
Easy to understand	4 (4 Int)	“I mean some questions I had to think, but they were all easy.” (A4)	4 (4 Int)	“Yeah, yeah, yeah, very easy to understand, yeah.” (P1)
Less easy to understand			2 (2 Int)	<i>Regarding the EDSIS:</i> “Yeah, there was one section of

				questions that I didn't know if it was for me or if it was in regards to [Name of Adolescent]." (P8)
Suitable length	4 (5 Int)	"The surveys, they weren't too long..." (A4) "It wasn't too lengthy, which was good." (A7)	4 (4 Int)	"... it didn't take very long at all, around 10 minutes, maybe 15 minutes to complete all the questions and that?" (P1) "I think it was sufficient enough." (P4) "It was long, but yeah, doable. Absolutely." (P8)
<b>Reflections</b>				
Overall Satisfaction with Reflections	1 (2 Int)	"They were pretty good." (A7)	1 (1 Int)	"Yeah, no, they were fine." (P1)
Relevant	1 (1 Int)	"I found it, yeah, like relevant to everything." (A10)	1 (1 Int)	
Helpful to reflect	2 (4 Int)	"... but I they probably were helpful, just like, thinking about what I've, like, learned and what I already knew, what I found surprising and stuff..." (A1) "I think it's helpful doing it right after cause it's fresh in your mind." (A1)	1 (1 Int)	"No, I think you need to do it after each stage..." (P9)
<b>Length</b>				
Suitable Length	3 (3 Int)	"Yeah, I thought they were very reasonable." (A1) "They were a good length." (A8) "I think it was a good length. It wasn't too long, but I was able to actually writing what I needed to in a good time frame." (A10)	2 (2 Int)	"I think it was sufficient enough." (P4) "They don't take long to take, so anybody could easily complete." (P9)
Slightly Long	2 (2 Int)	"Those were okay. Some of them were like 15 minutes, and others were a little shorter." (A4)		

		“... they were just a little long.” (A9)		
Repetitive	1 (1 Int)	“I felt were a bit repetitive questions, so it kind of just reinstated the same things just in different words, so I maybe would have made those a bit more condensed, or like, made less writing.” (A9)		
Easy to understand	2 (2 Int)	“They were very easy to answer...” (A10)	2 (2 Int)	“... the questions were clear...” (P9)
<b>Interview</b>				
Helpful to Wrap Up Study	3 (3 Int)	“I think this interview was helpful to wrap everything up.” (A1) “I think it’s a good summary of everything we’ve done and, um, it kind of jogs my memory of what I’ve done over the last few months with this study.” (A4) “It’s nice to kind of like touch base in kind of the way we started and stuff, yeah.” (A8)		
Easy to Understand	2 (2 Int)	“It was really easy to understand.” (A7)	1 (1 Int)	
Enjoyed Interview	1 (1 Int)	“I actually enjoyed it.” (A7)		
Relevant	1 (1 Int)		1 (1 Int)	
<b>Suggestions for Research Methods (Prompted by Researcher)</b>				
More reminders	1 (1 Int)	“... if you send more e-mails to like remind me, if you had sent one earlier, I would have done it, I’m just really... I’m a procrastinator.” (A5)	1 (1 Int)	“Even if it’s, you say “Friendly Reminder”, “Task Due”, like, just, you know?” (P8)
Interview format over questionnaire format			1 (1 Int)	<i>Regarding preferring a talking format over a questionnaire format: “I find that is more transformative.” (P2)</i>
Reflections in Multiple Choice Format	2 (2 Int)	“I like ones that are more... almost like multiple choice over actually writing out		

		the answer. I enjoy the multiple-choice ones more.” (A4)	
<b>Suggestions for Research Methods (Prompted by Researcher)</b>			
Portal			
Fine as it was	2 (2Int)	<p>“...you basically have that portal in the sense of like you [e-mail] the chart saying what I’ve completed and what I haven’t... it kinda already seemed like what you kinda described the portal as.” (A4)</p> <p>“Yeah, I think that would make it more convenient, but it’s pretty good the way it, like it was.” (A8)</p>	
Neutral	A5 (1 Int)	<p>“Maybe, yeah, maybe a portal wouldn’t be bad.” (A5)</p>	
Would have liked one	3 (3 Int)	<p>“Yeah, definitely... I think that would actually help a lot.” (A7)</p> <p>“... yeah, that would have found more better, because then I didn’t, I have to go through e-mails to find what I had to do, and my ID, cause some of them had ID, some of them didn’t, so then I have to go through them, so yeah, like I would have found that... I think it would have just been easier on our part to get stuff done.” (A9)</p> <p>“... it would be helpful because I do like visually seeing where I’m at or the progress or like what I have to get done, so, I think that would be a good way to organize everything that needs to be done and what I have had to do.” (A10)</p>	<p>3 (3Int)</p> <p>“Yeah” (P4)</p> <p>“...that could work, absolutely...” (P8)</p> <p>“Yeah, yeah.” (P10)</p>

**Appendix G. Qualitative Content Analysis pertaining to Participants’ Perspectives of the Entire Intervention**

	<b>Number of adolescents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes	<b>Number of parents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes
<b><i>Helpfulness and Helpful Aspects</i></b>				
Generally Helpful or Enjoyed It	7 (12 Int)	<p>“... it was definitely helpful, I am a person who has a lot of questions and throughout all the different studies, those were answered.” (A4)</p> <p>“...it was pretty good and I think my parents appreciated it too.’ (A8)</p> <p>“... it was good, like I’m glad I did it.” (A10)</p>	2 (3 Int)	<p>“... it’s been very helpful.” (P4)</p> <p>“I thought it was great.” (P10)</p>
Informative	3 (5 Int)	<p>“I think it was pretty informative and I learned a lot.” (A1)</p> <p>“I have a lot more knowledge of the adult program now.” (A7)</p> <p>“I’m glad I had that, all that information available to me.” (A10)</p>		
<b><i>Learnings</i></b>				
Care Options Are Available	2 (2 Int)	<p>“I know there’s more options even if I don’t get in right away.” (A7)</p>		
<b><i>Influence on Transition Plan</i></b>				
Validated or Solidified Decision	1 (2 Int)	<p>“...this study actually kinda like allowed me to go a bit deeper, to like know, like it made, it helped clarify that, for me, eating disorder treatment isn’t something I specifically need going forward.” (A9)</p>		
<b><i>Feelings</i></b>				

Less Anxious	3 (3 Int)	<p>“...it’s a bit less nerve-wracking.” (A7)</p> <p>“So being able to have all that there, and easily get to it, was really helpful and took a lot of anxiety off.” (A10)</p>	
Uncertain	1 (1 Int)	<p><i>When asked about overall experience of intervention:</i> “... although I don’t know, like... cause I know there’s really long waitlists, so it’s kinda just like I did them but like where do I go now?” (A1)</p>	
<b><i>Not Helpful or Less Helpful Aspects</i></b>			
Already Had a Plan	1 (1 Int)	<p>“The only thing was, I don’t know if it exactly was the greatest thing for me, because I kind of already knew what I was doing...” ... “I kind of already knew what was happening before all of this.” (A5)</p>	
<b><i>Suggested Order of Intervention Components</i></b>			
Navigation Guide First	4 (4 Int)	<p>“I would probably say, well the navigation guide I found, I read that third, but that was kinda would have been a good starter kinda thing to do, so I probably would have done that first if I did it again.” (A9)</p> <p>“I think maybe reading the navigation guide probably the best to start with...” (A10)</p>	<p>1 (1 Int)</p> <p>“I think they should maybe read the navigation guide first before they get the parent to parent so they kind of have an idea of what they’re going to be talking about and help prepare them for what they’re saying.” (P9)</p>
The Youth-to-Youth or Parent-to-Parent Session Not Being First	1 (1 Int)	<p><i>Regarding the Youth-to-Youth Session:</i> “I think it definitely would have been helpful if I weren’t on that one first.” (A1)</p>	<p>1 (1 Int)</p> <p>“The parent-to-parent first I think might be too overwhelming for some people without having some idea of what a transition is.” (P9)</p>
Preferences	7 (9 Int)	<p>“I think getting the brochure first was helpful. Um, I probably would prefer to</p>	<p>4 (6 Int)</p> <p>“... you could do the doctor after the parent-to-parent, that could be a</p>

	<p>do the transition meeting before the youth session, but honestly, it didn't really make that big of a difference. And, like, the family doctor, I guess after getting that brochure is fine." (A1)          "I would probably do the navigation guide, and then, the therapist session, and then the family doctor and then the meeting with [Name of Youth-to-Youth Session Presenter] or, actually, the meeting with [Name of Youth-to-Youth Session Presenter] and then the family doctor." (A7)</p>	<p>floating one. But, with the parent to parent, then maybe, if you hear what their experiences are, then you know what to talk to the family doctor about. And say, "this is what we need, this is what we need, this is what other parents have done" and you can tell them kind of what you're looking for." (P9)</p>
<p><b>Suggestions</b> (Prompted by Researcher)</p>		
<p>Earlier Transition Planning</p>	<p>4 (6 Int)</p> <p>"... it might be helpful to do it, like, earlier. Around when they turn 17, so then they know what it is and they can put their name on the waitlist." (A1)  <i>Regarding earlier transition planning:</i>          "... it also gives you mental time to prepare. Like, there's a physical, which is like you gotta switch and stuff, ... I feel like talking about it in advance and setting a plan so you're not scared of when it comes up and you're like "I'm lost, I don't know what to expect or what to do"." (A9)          "I feel like it would have been a little bit better if I did do it while I was still with [MCH PED Program], but then at the same time, I like that I'm not doing it with them because it's giving me</p>	<p>4 (5 Int)</p> <p>"... had I known they had such a long waitlist, when [Name of Adolescent] turned 17, I would be saying to [MCH PED Program]: "get [them] on the waitlist now", but I didn't know, I presumed that [they] would transition straight from [MCH PED Program]." (P1)          "... the earlier, the better, because as long as they know that you're coming, hopefully they'll have the spot there for you when it is time." (P9)          "I personally would have felt it would have been nice to do it before [they] turned 18, before this all started happening, I just thought that day would never come, but unfortunately it has. But I think, with [them], [they] felt it was good because it was, [they]</p>

		something to do while I’m waiting to hear back...” (A4)		left [MCH PED Program], there’s this study, and now [they’re] onto [their] new program.” (P4)
Period of Parallel Care	4 (4 Int)	<p>“That seems like something that would be good and probably comforting for a lot of people, especially if they’ve gotten used to [MCH PED Program] and stuff.” (A8)</p> <p>“Yeah, cause then it’s not like trying cold turkey and then jump into somebody else, cause you have to tell your story all... they don’t really know you, so if you have to tell your story all again and like you’re basically starting from square one, if your therapist can talk and fill them in a bit, it’s not less, it won’t be as like rigid as they already know stuff about you?” (A9)</p>	2 (2 Int, 1R)	<p>“I thought that was meant to happen anyway.” ... “Because reading all the literature, that was the goal, wasn’t it? That [Name of Adolescent] would have a session with [their] old therapist and [their] new therapist together.” ... “So that they could thrash everything out so it was a smooth transition. So yeah, that definitely, definitely should happen.” (A1)</p>
Receiving Updates from Adult Program Waitlist			1 (2 Int)	<p>“They should be able to say “you are 10th on the waitlist, you know most people are staying for 8 months, so it’s going to be like 2 years” or whatever. They should be able to tell you something...” (P1)</p>
Transition Coordinator				
In agreement with	2 (2 Int)	“Definitely.” (A7)	1 (1 Int)	<p>“Yeah, I think it would be good to have a point of contact, so if things weren’t going quite right, you could contact them and say “look, the guide says this, but that hasn’t happened, can you sort this out for us?” or “who do we speak to, to sort it out?” ... “Yeah, I think it would be good to have a</p>



				head-hunter person that's looking over it all.” (P1)
Neutral	2 (2 Int)	<p>“I think that would be, because that kind of takes away that whole, my anxiety around making appointments. So, as someone like a coordinator doing that for me in that sense? Like I find that could have been a little bit helpful, but for the most part, I think... what you’ve done has already been pretty good.” (A4)</p> <p>“I did find everything helpful the way it was, but I guess adding something like that would only make things even more helpful.” (A10)</p>		
<b>Suggestions</b> (Prompted by Participant)				
List of Providers	2 (3 Int)	<p>“... a list of therapists in the Hamilton area, just in case they didn’t get their name on the waitlist in time.” (A1)</p>	2 (3 Int)	<p><b>Private Care:</b> “I know you sent a list of what’s available, like, in terms of private care, but I don’t know, that’s probably something I... I wouldn’t mind knowing more about.” (P10)</p> <p><b>Region-specific:</b> “... lists of people, I said, for social workers or whoever you can contact more applicable for the region that you’re living in? Because who knows if they’ll all do virtual, and if they don’t, you need something where you can get there.” (P9)</p>
Earlier Transition Planning			2 (3 Int, 2R)	“I think maybe that should have been six months from before [they] turned 18?” (P2)

			“Patients should be signed up for the [Local Adult ED Program] on their 17th Birthday so they get into [Local Adult ED Program] once they turn 18.” (P1)
Making Parents Aware of Long Waitlists		1 (1R)	“Parent should be advised of the long waitlist so they can put in place help whilst they wait to get into the program.” (P1)
Clearer Direction from the Pediatric Therapist		1 (1 Int)	“The only thing is maybe more clear with the program of what the transition period looks like.” ... “say “okay, here’s what we suggest you do over the next four or five months” type of thing.” (A9)
Meeting with Future Therapist		1 (2R)	“It would be good to have a session prior to leaving [MCH PED Program] with [their] therapist at [Local Adult ED Program] just so [Name of Adolescent] feels confidence.” (P1)
Components to Guide Transition for Other Mental Illnesses	1 (1 Int)		“... ‘cause I wasn’t as eating disorder focused, but maybe add, like I know this is supposed to be for eating disorders specifically, but usually other mental--like anxiety, depression-- always usually gets linked in somehow, it’s usually corresponding, so maybe add a bit more, cause I know it’s eating disorder focused, but maybe add more of those components in, because that probably affects people too?” (A9)

**Appendix H.** Qualitative Content Analysis pertaining to Adolescent Participants’ Perspectives of the Youth-to-Youth Session

	<b>Number of adolescents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes
<b><i>Helpfulness or Helpful Aspects</i></b>		
Generally Helpful or Enjoyed It	6 (6 Int)	“I liked everything.” (A7) “... it was very helpful.” (A9)
Considered it the Most Helpful Component	5 (7 Int)	“Definitely the youth-to-youth session.” (A5)
Hearing the Perspective of a Person with Lived Experience	7 (7 Int, 6 R)	“It was nice to hear some things that [they] thought of, like, before getting into the program for, like, some similar problems I’ve had. Like just questions and the uncertainty and not knowing? And it’s nice to hear someone else’s perspective on it who’s actually been through it?” (A4) “It’s nice to hear somebody else’s perspective, even though our stories aren’t exactly the same, I can kind of sympathize with them, I knew what [they were] going through and things like that, like the struggles. And I really think... yeah, it was helpful to be able to hear somebody else share their story.” (A5) “Because you actually saw someone that’s experienced it, like it’s different than seeing a therapist, like it’s someone that actually went through it yourself [sic].” (A7)
Informative/Resourceful	4 (1 Int, 4R)	“It provided me with good information and helped me to start thinking more about transitioning when I’m 18.” (A7)
Group Discussion	2 (3R)	“I enjoyed the conversations we all shared and how even though none of us know one another, we were all able to come together for a session to speak on our feelings.” (A4)
Message of Session	1 (1R)	“I enjoyed how [Name of Youth-to-Youth Session Presenter] did not sugar coat anything and was vulnerable and told us the truth about the future and that it will be tough but it will be okay in the end.” (A7)
<b><i>Learnings</i></b>		
Other Care Options	2 (2R)	“I learned a bit more about Body Brave. I’d heard about it before but wasn’t sure what kind of services they offered and what it was like there.” (A2)
That Adolescent can Advocate for Their Care	2 (2R)	“I learned that I can speak up about if treatment is not working for me and that the program will be understanding of my feelings.” (A4)

Existence of Adult Care Programs	2 (2R)	“I did not know there were any type of outpatient programs for adults.” (A8)
Information About Local Adult ED Program	1 (2R)	“I also did not know about group sessions there which would help me a lot.” (A7)
What Transition Would Look Like	1 (1R)	“I just learned a little bit more on what the transition will look like.” (A1)
<b><i>Influence on Transition Plan</i></b>		
Validated Existing Plan	1 (1 Int)	“... even hearing the, in the youth-to-youth session, the other persons’ story, like going through it, I was like “that doesn’t really, like I’m past that point, like I’m not in the same mindset or anything”. So, it kind of helped me figure out what I needed to transition in.” (A9)
Motivated to Think about their ED	1 (1 Int)	“... when [they] talked about it, I started to think about my eating disorder more, because most of the time when I think about it, I kind of just focus on my anxiety because my eating disorder is tied to my anxiety. Like, if I didn’t have anxiety, then I wouldn’t have this eating disorder, you know? So, it’s kinda like, that’s why I’ve been focusing on the anxiety, but it also, but it helped me to think about my eating disorder more.” (A5)
<b><i>Feelings</i></b>		
Comforting	2 (2 Int)	“... it was kind of almost comforting to know that there is still treatment out there and that it’s worked for someone.” (A8)
More Prepared	1 (1R)	“I felt more prepared after the session.” (A1)
More Confident	1 (1R)	“It made me feel more confident that I will be able to successfully transition my care and know other people went through the exact same thing as me and got the care they needed.” (A9)
Less Nervous	3 (3R)	“I feel less nervous knowing that I spoke to someone who had transitioned into the adult program with similar worries as I have. It is nice to know that I am aloud to feel this way.” (A4) “I feel a lot more comfortable and I am not as anxious about the future couple of months.” (A7) “More relaxed about my future.” (A8)
Less Alone	2 (3 Int)	“... it kinda helps me to see that there’s someone else who has to deal with the same things I do, it’s not just me, I’m not alone in this, you know?” (A5)
More Nervous	1 (1R)	“...a bit nervous about the wait time in between care. I now know of some other supports, like Body Brave, but am still worried about being more vulnerable during that transition and relapsing.” (A2)
<b><i>Non-Helpful or Less Helpful Aspects</i></b>		
Not Memorable	1 (2 Int)	“... the meetings, I like them, but I don’t necessarily remember them.” (A4)

Wanted to share more, but did not want to trigger others	1 (1R)	“I wanted to share about my experience a little, but I am afraid of triggering somebody else.” (A7)
Long and Repetitive	1 (1R)	“It was a bit long and repetitive.” (A1)
<b><i>Suggestions</i></b>		
Facilitate or Improve Interaction	3 (3R)	<p>“I think maybe having check points during the presentation where we could ask questions and interact rather than waiting until the very end for the interactive piece.” (A9)</p> <p>“Maybe having more people in a meeting at once with cameras and [microphones] on or in person so it may cause more conversation.” (A8)</p> <p>“Ask more questions to the participants to make it more interactive.” (A1)</p>
Discuss Programs for Other Mental Illnesses	2 (2R)	<p>“I wished it was more than just eating disorder based because my bigger focus was on anxiety. Although it was helpful, some of the information was not applicable for me as I am not going forward with eating disorder treatment once I turn 18. I would have added more information about transitioning from youth to adult services with other mental illnesses.” (A9)</p> <p>“We could possibly touch more on other programs besides the ed program because the person with me wanted the anxiety program.” (A7)</p>

**Appendix I.** Qualitative Content Analysis pertaining to Parent Participants’ Perspectives of the Parent-to-Parent Session

	<b>Number of parents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes
<b><i>Helpfulness and Helpful Aspects</i></b>		
Generally Helpful or Enjoyed It	3 (1 Int, 3R)	“I thought the session was helpful.” (P6)
Helpful to Hear From Parents Who Have Lived Experience	8 (3 Int, 11R)	“...it was helpful to learn how others [sic] families have coped with their children's situations and supported them as they move on to university and living more independently.” (P6) “They've already been through it, so you know, it's good because they know and they can inform other parents, ""this is what we've noticed, this is how we dealt with it.""” (P2)
Informative	4 (4 Int, 5R)	“All the information that was available. I found that very helpful.” (P2)
Resources	2 (2R)	“Getting some helpful information from the parents re good counsellors” (P1)
Discussion	2 (1 Int, 1R)	“... the openness of the parents overall to share...” (P5)
Prepares Parent	1 (2 Int)	“So, yeah, having all the information means just being prepared. Whether it’s difficult to hear or not.” (P10)
Appreciation that this session took place well in advance of transition	1 (1R)	“I like that the idea of transitioning has been introduced early, in my case, 6 to 7 months before my [child’s] 18th birthday.” (P6)
<b><i>Learnings</i></b>		
Resources	4 (4R)	“I did learn about some of the various supports.” (P6) “That there are more resources and stories of hope than I realized.” (P8)
Potential for EDs to Endure	3 (2 Int, 3R)	“... it was scary to know that there’s setbacks that I need to keep watching for. I’m hoping that doesn’t happen, but you kind of forget that’s the reality of this.” (P10) “There will be relapses.” (P5)
Consent to Be Involved in Care	2 (1 Int, 2R)	“I think the thing I found the most interesting form the session was the fact that, I have to ask [Name of Adolescent] if [they’re] happy for me to know information and stuff like that. I’m so used to, like, being told information and then all of a sudden [they’re] the adult now and it’s down to [them] whether [they give] us the sign off.” (P1)

Child Will Need to Take Responsibility	1 (1R)	“It was an eye-opener to the fact that our child will be 18 and need to take more responsibility for [their] health, treatment, and care.” (P8)
Length of waitlist	1 (1R)	“... how long the actual waitlist is to get into [Local Adult ED Program].” (P1)
It's okay to calm down	1 (1R)	“The idea that it is [okay] to move away from always being in red-alert mode and that it is important that we do.” (P8)
<b><i>Influence on Transition Plan</i></b>		
Facilitated Thoughts Among Parents Regarding Treatment Options or how to adapt to changing role	4 (3 Int, 6R)	“it got me thinking and then saying “okay, I need to do this” and gave me some tips” (P9) “Thinking about also how to support my child now that they are an adult.” (P5)
<b><i>Feelings</i></b>		
Less alone	6 (6 Int, 3R)	“... it’s nice to know you’re not alone.” (P4) “...it provided some solace in a time that we needed some solace and realizing that we’re not alone.” (P8)
Hopeful	2 (1 Int, 1R)	“... you know, it gave me hope.” (P9) “Hopeful. I can see that I can, and should, stop living in “red-alert” mode.” (P8)
Good	1 (1R)	“Good. I felt good. I think [Name of Adolescent] felt more confident after I went to the session.” (P2)
Confident	1 (1R)	“It made me feel like it is possible to continue navigating through my [child’s] illness and to be aware of the potential pitfalls in the future.” (P6)
Emotional Outlet	1 (1R)	“I felt the session was very good [and] informative, also felt very emotional. Up to this point, I have not felt able to let my stress and emotion to show as I have been supporting my [child]. This gave me an outlet to feel ok sharing the stress and pressure I have been feeling.” (P5)
Concerned and reassured	3 (3R)	“I felt both concerned and reassured. It is clear that we are not necessarily out of the woods; however, I was pleased to know that there is a parent support system.” (P6) “Some hopefulness was diminished but it is good to know what we may be in for.” (P10)
Concerned regarding Long Wait Times	1 (2R)	“Concerned re waitlist time. I was under the impression the time we had to wait would not be long.” (P1)
Overwhelmed	1 (1R)	“A little overwhelmed.” (P4)
<b><i>Less Helpful Parts</i></b>		

Difficult to open up to others	1 (1 Int, 1R)	“there’s a lot of people watching and talking. I mean it’s just I’m not used to that.” (P4)
Not knowing what to share	1 (1R)	“Not knowing what to share, or not share about our story - historically I have shocked people with our story and put them in a position they do not know how to act or communicate with us... .” (P8)
Too short of a discussion time	1 (1R)	“That the open discussion time wasn’t very long, felt a bit rushed when sharing.” (P3)
Having to notify adolescent of waitlist	1 (1R)	“The fact I have to burst [Name of Adolescent]’s bubble and advise [them] there is a year waitlist and on [their] session, [they] will not meet a future therapist, as it may not happen for a year.” (P1)
<b><i>Suggestions</i></b>		
Hearing from Adolescents	2 (2R)	“I would even like to hear from the children who have gone through this experience and what their personal challenges have been, particularly with becoming independent and living in a new environment in a new city. They are a similar age to my [child] and I would like to hear it from their perspective. I recognize the importance for the parents and teens meeting separately; however, I wonder if there could be an opportunity for them to meet together.” (P6) “...it would be really helpful to connect and hear from and speak with survivors of such things.” (P8)
In-person	1 (1 Int, 1R)	“...it would have been nice to, honestly, to be in person, I think. Cause I don’t find it as, not cold, that’s not the word I mean, it’s just, it’s not as personable as if you were there, sharing stories, in person, I think that would have been more helpful, rather than doing it online.” (P4)
More time for discussion	1 (2R)	“The discussion between parents, wish there had been more time for that.” (P3)
List of private care providers	1 (1R)	“Have a list of private therapists who specialize in eating disorders already ready for parents” (P6)



**Appendix J.** Qualitative Content Analysis pertaining to Participants’ Perspectives of the Transition Meeting

	<b>Number of adolescents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes	<b>Number of parents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes
<b><i>Helpfulness or Helpful Aspects</i></b>				
Generally Helpful or Enjoyed It	2 (1 Int, 2R)	“I think the transition session was like helpful.” (A1)	1 (1 Int)	“I found that pretty helpful.” (P10)
Considered it the Most Helpful Component			1 (1 Int)	
Informative	3 (8R)	“Yes it was helpful because it provided me with more information that will help me better navigate the adult system.” (A1)	2 (2R)	“Getting information so I can help [child] make a decision/form a plan on where to continue care....” (P9)
Ability to Ask Questions or Speak to Therapist	2 (1 Int, 1R)	“I enjoyed being able to talk with [Name of Pediatric Therapist] about transitioning because we haven’t really had the chance to yet....” (A10)		
Answered Participants’ Questions	1 (1 Int, 1R)	“...it answered a lot of questions I had that I don’t really know where I would’ve gotten in depth answers like that. And, it just being able to talk about that was good.” (A10)		
Comfortable talking to therapist	1 (1 Int)	“... it was comfortable to talk to [them] about, just cause, you know, I’ve known [them] a while and I felt comfortable speaking about those things with [them].” (A4)		
Video				
Generally Helpful or Enjoyed It	1 (2R)	“I liked the video.” (A1)	1 (1 Int)	“That video during the transition meeting was really good.” (P10)

Informative	1 (1R)	“I thought the transition video was very interesting and informative.” (A9)	2 (1 Int, 3R)	“The video really described well the program at [Local Adult ED Program].” (P10)
Thorough			1 (2R)	“... it was very thorough in the explanation about what happens when you go.” (P10)
<b><i>Influence on Transition Plan</i></b>				
Offered ideas	1 (1R)	“We have not decided exactly on what will happen in the future but it will be planned soon after we can sit and give everything more thought. But having this meeting will help the planning.” (A10)	2 (2R)	“No, more things to think of. After the meeting, [Name of Adolescent] and I discussed further whether [they] felt [they] would want the referral.” (P10)
Influenced plan	2 (2R)	“With my meeting with my therapist about my transition, I think we both made a game plan until and after I turn 18. We talked about what skills I am going to try and work on before our time is up, and other therapy options after I turn 18 so there is no gap in my care.” (A9)		
Did not influence care plan	1 (1R)	“No.” (A1)		
<b><i>Learnings</i></b>				
Nothing new	3 (3R)	“I already had an idea of what it was so I didn’t learn anything new in the meeting.” (A4)		
Information about local adult ED program	4 (8R)	“I did not know there were different stages of treatment in the adult program, such as the symptom portion and then the group therapy portion.” (A7)	1 (1R)	“What the [Local Adult ED program] program offers and what it entails for adults.” (P9)
Variety of Treatment Options Available	1 (2R)	“Good to know there’s more resources out there.” (A8)	1 (1R)	“Helped in getting knowledge about the various programs in Ontario.” (P9)

Consent			1 (1R)	“Reinforced that [Name of Adolescent] will have to give permission for [their parents] to speak to health care provider.” (P9)
What to expect from adult care			1 (1R)	“We learned more about what treatment and therapy would look like in the adult program.” (P10)
<b><i>Feelings</i></b>				
Calm, Comforted, Relieved, or Reassured	4 (7R)	“I felt more calm about this transition as a result of the meeting with this group.” (A4) “... comfort that I will be ok and well no matter what happens.” (A9) “... like a weight was lifted off my shoulders [because] I knew what I needed to do moving forward.” (A7)		
Less Stressed	1 (1R)	“I was stressed going into it but after the meeting I was better.” (A10)	1 (1R)	“A bit less stressed on what to do when [they turn] 18 this summer.” (P9)
More Prepared	2 (2R)	“I felt comfortable knowing everything was planned out before and after I turn 18 so there won’t be any panic and confusion when the time comes.” (A9)		
Supported	1 (1R)	“... knowing that both my parents and therapist are on my team and will do everything they can to make this transition as easy as possible.” (A9)		
Less Alone	1 (1R)	“I am not alone in this and so many others go through something similar in their teenage years.” (A4)		
More Nervous	1 (1R)	“I felt a little bit nervous.” (A1)	1 (2R)	“I’m feeling very anxious and nervous about this transition.” (P10)

More Alone	1 (1R)	“Like it’s up to me and I’m more alone.” (A8)	
Uncertain	1 (1R)	“I didn’t like the uncertainty of everything.” (A1)	
Not wanting to leave pediatric care	1 (1R)	“... realizing I’m going to be 18 soon and will have to lose the wonderful team I have now.” (A9)	
<b><i>Non-Helpful or Less Helpful Aspects</i></b>			
Did not enjoy Transition Meeting with therapist they had	1 (3R)	“Just how my therapist presented it.” (A8)	
Not memorable	1 (2 Int)	“...whereas the meetings are kind of like, they’ve almost completely left my mind, you know?” (A4)	
Video			
Not relevant because participant is not pursuing ED treatment	2 (4 Int)	“...that wasn’t really as applicable to me...” (A9)	1 (1R) “Other part of the video had good information but some of it was not pertinent as [Name of Adolescent] will not be going to [Local Adult ED Program].” (P9)
Long and Hard to Pay Attention to	2 (3R)	“It was a bit lengthy, I found it hard to pay attention at times.” (A7)	
Information Overload	1 (1 Int)	“It’s just a lot of information at once.” (A7)	
Repetitive	1 (1 Int)	“The video felt kind of repetitive after, cause I’d already been on like the youth session. So, it just felt like they were repeating some of the same stuff.” (A1)	
Not easy to refer back to	1 (1 Int)	“... if you need to go back, like trying to figure out what point it is...” (A9)	
<b><i>Suggestions</i></b>			
Content about Other Mental Health Services	2 (1 Int, 1R)	“I wished there was more about other mental health services not just eating	

		disorders because although my eating disorder is a part of the transition, it is not the only component.” (A9)
Different Therapist	1 (2 Int, 1R)	“... it would have been better had I had a different therapist...” (A8)
Video		
Shorter and More Concise	1 (1 Int)	“Making videos shorter and more straight to the point” (A7)
More Visuals	1 (1 Int)	“I mean, more visuals will probably be better than them just talking the whole time.” (A7)

**Appendix K.** Qualitative Content Analysis pertaining to Participants’ Perspectives of the Family Doctor Contact

	<b>Number of adolescents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes	<b>Number of parents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes
<b><i>Helpfulness or Helpful Aspects</i></b>				
Generally Helpful or Enjoyed It	2 (2R)	“There was nothing I didn’t enjoy about this meeting because it was a good discussion and didn’t leave me feeling bad or worse about the transition process.” (A9)		
Considered it the Most Helpful Component	2 (5 Int)	“I have to say, the most impactful which was kind of surprising for me, part of the study, was with my family doctor? Like the talk we had?” (A9)		
Helpful in Contributing to the Transition Plan	4 (2 Int, 9R)	“Yes it was very helpful. It was an opportunity to talk about the future for my treatments and how she can be involved going forward.” (A10) “...now I have at least some sort of medical care after I’m 18, even if I don’t get into [Local Adult ED Program] right away.” (A7)		
<b><i>Influence on Transition Plan</i></b>				
Did influence involvement of family doctor	4 (2 Int, 3 R)	“We discussed how [they] will monitor me and the medication I’m on and [they are] there to refer me to any adult programs if I feel that is necessary.” (A10) “...now, I’ll start doing monthly check-ups with them.” (A5)	1 (2R)	“Our doctor will continue to follow [Name of Adolescent]’s progress after we are finished at [MCH PED Program]. [They] will continue to monitor [Name of Adolescent] on [their] meds as well as schedule regular “check in” appointments with [Name of Adolescent].” (P10)

Did not change involvement of family doctor	3 (3 Int, 2R)	“I think we just decided that they wouldn’t really be involved because there was one point in my treatment where I had to... stop in with her and she doesn’t really specialize with eating disorders and stuff? So, if need be I could, but otherwise, if there’s another program that’s more specialized with it, it’d be a better choice.” (A8)		
<b><i>Feelings</i></b>				
Reassured or Comforted	3 (7R)	“I felt really good knowing I will have the support system I need when I turn 18.” (A9) “I’m glad I was able to go and have this discussion because it did relieve a lot of anxiety about the unknown.” (A10)	1 (2R)	“Knowing [Name of Adolescent] will be in good hands with [them].” (P10)
Neutral	1 (1R)	“I felt fine.” (A1)		
Supported	1 (1 Int)	“... [they were] very supportive and saying, “whatever you need, we’ll, I’ll help you with” and stuff.” (A9)		
Valued	1 (1R)	“While on the phone, I felt valued as a patient and person.” (A9)		
<b><i>Less Helpful Aspects</i></b>				
Family doctor won’t be part of care, so wasn’t very helpful	2 (2 Int)	“I guess, I, like I know, like I don’t ... know how involved [they]’ll be. I just liked knowing that [they] was there and liked knowing some of the role [they] could have going forward. I just, I guess it was comforting to talk to [them], but I guess just not maybe as much as the other two things that I did, if that makes sense.” (A10)		
<b><i>Suggestions</i></b>				

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Talking to family doctor closer to the transition date	1 (1 Int)	“I’d be even more prepared to transition and I really have to get everything sorted out, so, I think talking to [them] closer would be a good idea as well.” (A10)
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**Appendix L.** Qualitative Content Analysis pertaining to Participants’ Perspectives of the Navigation Guide

	<b>Number of adolescents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes	<b>Number of parents</b> [interview (Int) and reflection (R) mentions]	Supporting Quotes
<i>Helpfulness or Helpful Aspects</i>				
Generally Helpful or Enjoyed It	4 (3 Int, 2R)	“I found the navigation guide very helpful.” (A9)	3 (2 Int, 4R)	“I thought the guide was really good, like it held your hand step by step as to what happens when you transition out and when you transition in, and stuff like that.” (P1)
Considered it the Most Helpful Component	2 (2 Int)	“I would probably say that like 8-page word document.” (A1)		
Informative	6 (2 Int, 12R)	“... it contained a lot of important information about adult care and what additional resources are available if needed.” (A1) “I enjoyed reading the points about what transitioning means, why it’s important and how to plan for it.” (A4)	3 (4 Int)	“I like the way this navigation guide laid out in quite some depth what the transition from [MCH PED Program] to [Local Adult ED Program] would look like ....” (P1) “I found that it thoroughly explained all the information we need to guide us through the transition to adult care.” (P10)
Resources Provided	3 (3R)	“It’s helpful to have links to different programs towards the bottom of the page because all the information is easy to read and is provided for me.” (A4)	2 (2R)	“What I found most helpful was the list of therapists and outreach programs.” (P6)
Helpful to Revisit Guide	3 (6 Int)	“But I like with the navigation guide, I can go back and forth to it. Like, if I have a question that comes, like out of nowhere, I can refer back to that. Um, so, I really liked that just because I have a physical copy that I can go back to,	1 (1 Int)	“it’s a resource guide, so, I hope that when I go to reach out for it, I can find it easily and I can find what it is that I need....” (P8)

		and, many questions I do have were pretty much answered there, so...” (A4) “I found the navigation guide very helpful which actually I’ve saved in case I need it, so yeah.” (A9)		
Organized	2 (1 Int, 1R)	“I liked how it had different sections so if I ever need to go back and look at it, I can find what I need.” (A9)		
Straightforward	1 (1R)	“I enjoyed the bullet points because they were straight to the point and told you straight up what was going to happen.” (A7)		
<b><i>Repeated Reference to Navigation Guide</i></b>				
No & They Plan To	3 (1 Int, 3R)	“I just read it but I will refer back to it closer to my 18th birthday ....” (A7) “I have not referred back to it at this time, but I may in the future.” (A9)	3 (3R)	“I will yes. Absolutely.” (P8) “No I did not. ... however, I am sure this will be helpful to look back on.” (P5)
No & They Do Not Plan To	3 (3R)	“No as I mostly knew all of the information that was covered in this guide already.” (A1)		
Yes			2 (2R)	“I did read the guide over a couple of times, just to check sure I was clear on how the handover works.” (P1)
<b><i>Learnings</i></b>				
Nothing New	2 (2R)	“I knew the basis of everything in this guide.” (A9)	1 (1R)	“This information had already been provided by [Name of Pediatric Therapist].” (P6)
Programs or Resources Available	1 (1R)	“...various programs for different regions...” (A4)	3 (4R)	“Where there are adult treatment programs are available in Ontario.” (P9)
Parental Involvement Post-Transition	2 (2R)	“I thought parents just weren't involved anymore after 18.” (A7)	1 (2R)	“Parent limitations without child’s permission and give them more

		“...it went more in detail about different parts like how parents can still get involved in treatment...” (A9)		control over medication renewal and appointments.” (P9)
Healthcare Platform used at Local Adult ED Program	2 (2 R)	“I did not know about [Name of Healthcare Platform]. This resource will be helpful in planning my medical appointments while away at university.”		
Existence of Adult Programs	1 (1R)	“Yes, I didn’t know that there [were] really any treatment places for adults and I didn’t know there [were] so many.” (A8)		
Differences between Pediatric and Adult Care			1 (1 Int)	“how different adult care is from, you know, [pediatric] care...”
How Transition Works			1 (1 Int)	“... how the transition worked...” (P1)
Tips for Successful Transition			1 (1R)	“... what needs to be done for a successful transition.” (P9)
Responsibilities as an Adult	1 (1R)	“I was reminded of what I’ll need to do as an adult involving eating disorder treatments such as arranging my own appointments and ‘speaking up’ for myself.” (A10)		
<b>Feelings</b>				
Less Anxious	2 (5R)	“I feel less anxious and more calm reading the guide so I get an idea of what my care will look like.” (A4)	1 (1R)	“... fills me with relief as [they] will have a similar team to what [they have] at [MCH PED Program] supporting [them].” (P1)
Less Alone	2 (2R)	“I don’t feel alone going through this journey because there are services and professionals to help me.” (A9)		
Ready for Transition	2 (2R)	“I feel ready to transition to adult care because I will have the support I need to get me through it.” (A9)		

More Confident		1 (1R)	“More confident that when [Name of Adolescent] leaves [MCH PED Program], [they] will get the care [they need] at [Local Adult ED Program].” (P1)	
Nervous, but informed		3 (3R)	“Still nervous about transition but glad to see what support is available.” (P9)	
<b><i>Non-Helpful or Less Helpful Aspects</i></b>				
Did Not Like Content, but Understood its Purpose	1 (1R)	“I didn’t enjoy reading about my responsibilities as an adult seeking eating disorder treatment because that is something I have a lot of anxiety around. However, although I didn’t enjoy reading this because it is intimidating, it was helpful.” (A10)	1 (1R)	“I suppose I don't enjoy being told that I will be losing control over my [child's] healthcare and treatment; however, I appreciate the necessity of making this age group more independent and responsible for their future health needs.” (P6)
Too Long	1 (1R)	“...it felt like a lot of reading and my attention span is short.” (A7)		
Too Much Text	1 (1R)	“...there was a lot of text.” (A1)		
<b><i>Suggestions</i></b>				
Add More Visuals	1 (2R)	“...the addition of more visuals would help make the guide more engaging.” (A1)		
Present Information Verbally rather than a Written Text		“... it would be better if it was read out loud.” (A7)	1 (2R)	“I prefer to hear the information from an individual.” (P6) “...a pamphlet comes across as impersonal. It is much more reassuring to discuss this information with members of the [MCH PED Program] team, rather than just reading it.” (P6)
Shorten It	1 (1R)	“You should make the brochure smaller because it felt quite lengthy but informational.” (A7)		

More Bullet Points	1 (1R)	“...there should be more bullet points because it is a lot of reading and confusing at times...” (A7)
Include Content Regarding Other Mental Health Concerns	1 (1R)	“I wished there were more parts about mental health services beside at the bottom because I feel many people have other mental health issues besides an eating disorder that have to be acknowledged.” (A9)
Provide Names of Therapists		1 (1R) “I would prefer to have specific names for potential therapists.” (P6)