

Transitioning from Child/Adolescent to Adult Mental Health Services

Meagen McNeill

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School Of Nursing
Faculty of Health Sciences
University of Ottawa

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Co-Authorship

1. Amanda Vandyk RN, PhD

Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa

As my thesis supervisor, Dr. Amanda Vandyk co-authored this thesis and provided exceptional support throughout the writing process. Amanda was influential in all aspects of this thesis including the design of this thesis and data analysis.

2. Krystina Lewis RN, PhD

Professor, School of Nursing, Faculty of Health Science, University of Ottawa

As a member of my thesis committee, Dr. Krystina Lewis co-authored this thesis and was very supportive every step of the way. Krystina gave valuable insight into all aspects of my thesis but more specifically the findings and discussion section. I am very grateful to have had the opportunity to learn from her and for her support throughout the writing process.

3. Julie Chartrand RN, PhD

Professor, School of Nursing, Faculty of Health Science, University of Ottawa

As a member of my thesis committee, Dr. Julie Chartrand co-authored this thesis and provided support and encouragement throughout the writing process. While Julie provided influential insight into all aspects of my thesis, she particularly contributed to the findings and discussion sections.

Abstract

The purpose of this qualitative study was to explore the experiences of young adults transitioning from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) from the perspectives of patients. Using convenience sampling, six participants were recruited for individual semi-structured interviews. Using conventional content analysis, I identified five categories reflective of the participants' experiences: 1. 'Expectations', 2. 'Transition is a Gradual Process and not an Abrupt Change', 3. 'Factors Influencing Transition', 4. 'Living the Transition' and 5. 'Improving the Transition'. These categories included subcategories, when appropriate, to highlight variation within the main experiences. The findings provide insight into the experiences of young adults who are - or have lived - the transition from CAMHS to AMHS from their perspectives. The participants' stories are useful to understand the physical and emotional challenges associated with shifting to adult care, and their recommendations can help to inform healthy transitions in this context.

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Glossary

Adolescent: As per the World Health Organization [WHO] (2022), “Adolescence is the phase of life between childhood and adulthood” (Para. 1), and ranges from 10 to 19 years of age.

However, as adolescents’ age out of CAMHS at 18 years in Ontario, Canada, the age limit will be between 10 and under 18 years of age.

AMHS: Adult Mental Health Services. Services that provide mental health support to individuals over the age of 18.

CAMHS: Child and Adolescent Mental Health Services. Services that support mental health to individuals under the age of 18.

Inhibitor: In the interest of transparency, I have specifically chosen to use the term inhibitor rather than barrier because a barrier suggests that something is immovable, whereas an inhibitor infers that something is moving albeit slowly. This is further supported by Meleis (2010) who uses the term inhibitor when referring to the transition process.

Mental Illness: As per the Government of Canada (2019), mental illness is “characterized by alterations in thinking, mood or behavior associated with significant distress and impaired functioning” (Para. 1).

Transition: “The purposeful, planned movement of adolescents with chronic physical and mental conditions from child-centered to adult-oriented health care systems” that is designed “to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive” (Schraeder & Reid, 2017, p. 317).

Transition ‘Healthy’: Previous research has suggested four criteria for an ‘optimal’ transition which are: “*Continuity of care* -either engages with AMHS three months post-transition or

appropriately discharged; and the following three further variables; *Period of parallel care (relational continuity)*, i.e., a period of joint working where the service user is involved with both CAMHS and AMHS; *Transition planning meetings (cross-boundary and team continuity)*, i.e., at least one meeting discussing the transition from CAMHS to AMHS, involving the service user and/or carer and key professionals, prior to the handover of care from CAMHS to AMHS; *Optimal information transfer (information continuity)*, i.e., any or all of the following transferred from CAMHS to AMHS: referral letter, summary of CAMHS contact, and any notes and a contemporary risk assessment” (Singh et al., 2010, p. 44). However, Schumacher and colleagues (1999) used the word *healthy* instead, which encompasses more than just success when looking at the transition process. Thus, the term *healthy* will be used when referring to transitions in this thesis.

Young adult: is used to refer to any person aged 18 to 25 years, a categorization that is supported by over 40 publications, and as per the position statement by The Society for Adolescent Health and Medicine (2017). The lower limit is 18 years because in Ontario, Canada, this is the age when people transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) (Dimitropoulos et al., 2015; Loos et al., 2018). The upper limit of 25 years will be used to ensure that participants have recent memories of the transition process. To note, there is inconsistency in the literature, with some authors using the terms children, adolescents, youth, and young adults interchangeably.

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Chapter One: Introduction

Transitioning from Child/Adolescent to Adult Mental Health Services

Awareness of mental health issues in the pediatric population is increasing exponentially. According to the Mental Health Commission of Canada [MHCC] (2020), there are approximately 1.2 million children and/or youth affected by some form of mental illness. In Canada, at least 70% of mental health issues initially present in childhood, adolescence, or young adulthood (Cappelli et al., 2014), yet less than 20% of youth receive the mental health treatment they need (Cappelli et al., 2014; Jabbour et al., 2016; MHCC, 2020; Schraeder & Reid, 2017). Similar rates are found worldwide, with one recent European study reporting that 50% of mental health problems develop by the age of 16, and 75% emerge by the age of 24 (Tuomainen et al., 2018). Child and Adolescent Mental Health Services (CAMHS) are an essential support for the 20% of Canadians who will develop a mental illness by the age of 25 (MHCC, 2020).

Each year, approximately 750,000 children in the United States with long-term mental healthcare needs transition from CAMHS to Adult Mental Health Services (AMHS) (Inman et al., 2017). Researchers interested in this topic conclude that a systematic, organized, and coordinated transition approach is crucial to enhance health and encourage the highest level of functioning during this time (Eke et al., 2019; Inman et al., 2017; Leavey et al., 2019). This type of planned and purposeful approach to transition is well-supported by researchers who share a common vision of what constitutes a transition: it is a process, not a change (Dimitropoulos et al., 2015; Inman et al., 2017; Loos et al., 2018; McLaren et al., 2018; Schraeder & Reid, 2017).

Adolescence is a high-risk time for psychological morbidity, and youth with severe mental illnesses are at an increased risk of self-harm and suicide (Dimitropoulos et al., 2015; Schraeder & Reid, 2017; Swift et al., 2013). As transitions in care are challenging and, at times, complicated processes, they can prevent adolescents' timely treatment and exacerbate their

symptoms (Eke et al., 2019; Leavey et al., 2019; Schraeder et al., 2020). Importantly, there is evidence that having a poor transition can further increase morbidity and mortality in young adults with mental illnesses (Hergenroeder et al., 2015). If maintaining contact with healthcare professionals during this time is unsuccessful, the health and overall well-being of these adolescents is at risk (McLaren et al., 2013; Perera et al., 2016).

In Canada, the transition from child and adolescent (i.e., pediatric) to adult mental healthcare services generally occurs once a person reaches the age of 18 years (Schraeder et al., 2020). However, in a study by Weissberg-Benchell and colleagues (2007), participants aged 18 to 30 years with mental illnesses reported not yet meeting the typical milestones of adulthood, particularly being responsible for one's own care. This study highlights how individuals reach stages of development at different times, and that maturity can be affected by mental or physical health disparities (Weissberg-Benchell et al., 2007). Likewise, Swift and colleagues (2013) asked 10 transition-aged youth (17 to 19 years) about how they felt regarding the pre-determined 'age of transition'. The participants reported not understanding why they must transition based on age and wanting consistent support for their mental health needs over their lifespan, rather than fragmented services (Swift et al., 2013). In a study by Broad and colleagues (2017), there were two reasons reported by participants for wanting mental healthcare across the lifespan which were: the difficulty of having to leave a trusting relationship with their former CAMHS worker and having to tell their story all over again to someone they do not yet trust (Broad et al., 2017). Although routinely relied upon, it is evident that using the age of 18 years as a rigid threshold for transition from CAMHS to AMHS is problematic for some (or many) patients (Weissberg-Benchell et al., 2007).

While there is no consensus on an optimal age for transition, ensuring a steady

preparation that is individualized and started early, is shown to improve health outcomes (Canadian Association of Pediatric Health Centres [CAPHC], 2016). Unfortunately, lack of communication between services (CAMHS and AMHS) and infrequent care planning is common, and young adults and their families report having little to no impact on transition planning (Leavey et al., 2019). Allowing young adults and their families to provide input into decisions about their transitions facilitates continuity and ongoing care during and after transition (Leavey et al., 2019).

Given that health outcomes for patients are related to their transition (Dimitropoulos et al., 2015), it is important to understand how to best support people through this process. Within the current healthcare context, unless an adolescent has a severe and persistent mental illness like schizophrenia, or they meet the strict eligibility criteria set by AMHS, they are not well-supported during their transition (Appleton et al., 2019; Cappelli et al., 2014; Leavey et al., 2019; MHCC, 2020; Swift et al., 2013; Tuomainen et al., 2018). More work is needed to ensure smooth and supportive service transitions for all persons requiring mental healthcare.

Caregivers of persons with mental illnesses are also affected by poor transitions from child to adult mental health services. A qualitative study by Brown and colleagues (2019) outlined various challenges during the transition process from the perspective of caregivers (i.e., parents). These challenges were categorized as ‘a deep sense of loss’, ‘an overwhelming process’, ‘parents making transition happen’, ‘a shock to the adult healthcare system’, and ‘the unbearable pressure’. According to the caregiver participants, the loss they felt was related to no longer having access to vital services, as well as losing the trusting relationship they had with their CAMHS providers. They found establishing a new healthcare team to be overwhelming, confusing, and complex, with uncertainty caused by lack of coordination, and they described

having to fight for services and spearheading the transition due to the poor coordination and management by the adult team. Ultimately, the caregivers believed that the adult healthcare system was unprepared for their child's complex mental healthcare needs, and dismissive of their parental concerns. They felt obligated to take on more responsibility for their young adult's complex conditions, as well as their general health (Brown et al., 2019).

Not only are young adults required to change mental health services and providers, but they also experience several other transitions simultaneously. These include major emotional, physiological, and social changes that can impact all facets of their lives, such as forming new relationships (or losing existing ones), preparing for college or university, moving out on their own, and being responsible for their health (CAPHC, 2016; Cappelli et al., 2014; Inman et al., 2017; Perera et al., 2016; Swift et al., 2013; Weissberg-Benchell et al., 2007). Swift and colleagues (2013) linked these additional life changes to the transition to AMHS. They found that challenges during the transition from CAMHS to AMHS were exacerbated when young adults were going through other developmental and situational changes at the same time. Due to co-occurring transitions, a period of heightened uncertainty occurs, which often perpetuates a decline in mental health (Swift et al., 2013).

While the previously mentioned study by Brown and colleagues (2019) sheds light on important aspects of the transition process, it does so from the perspectives of caregivers. Young adults who have lived this transition may express their experiences differently (Swift et al., 2013). While there is minimal evidence about the needs of transition-aged youth with chronic mental health conditions (Eke et al., 2019), studies that exist found that young adults have a lack of trust and lack of stability during their transition out of CAMHS and into AMHS (Loos et al., 2018); experience a lack of communication between service interfaces and themselves (McLaren

et al., 2013); encounter poor transition planning (Dimitropoulos et al., 2015; Leavey et al., 2019; Swift et al., 2013); and have unclear expectations regarding the transition process and AMHS services (Loos et al., 2018; Swift et al., 2013). To face these challenges, participants made several recommendations for improvement, such as a more collaborative approach including young adult and their family (Dimitropoulos et al., 2015); a supportive and understanding communication style (Swift et al., 2013); providing individualized transition planning early (Loos et al., 2018); and ensuring shared responsibility between CAMHS and AMHS during transition (McLaren et al., 2013). When the transition from CAMHS to AMHS is poorly managed, young adults may disengage from mental healthcare services despite the need for ongoing care (Appleton et al., 2019; Leavey et al., 2019; Schraeder & Reid, 2017). To assure the well-being, safety, and positive outcomes of young adults with mental illness(s), investing in a seamless transition between CAMHS and AMHS should be a priority (Appleton et al., 2019; Schraeder & Reid, 2017). Young adults themselves have firsthand knowledge of what it is like during the transition process and can articulate what made their experiences positive or negative. More research from the patient perspective is needed to create a robust evidence base, compare findings across studies, and draw conclusions to inform practice and policy.

Personal Impetus

During my time as a nursing student, I had several placements in varying areas within my rural community, as well as urban city centers. During my placement at the Royal Ottawa Mental Health Centre located in Ottawa, Ontario, I had the opportunity to work with individuals who were diagnosed with schizophrenia. I initially thought that the mental health nursing setting was not for me, but I quickly found that I really enjoyed working with the nursing team and the patients we treated. Since that time, my passion for mental health has grown stronger, as has my

passion for working with youth. After my placement in mental health, I had the opportunity to practice in a pediatric centre. As I developed my skills as a nurse at the Children's Hospital of Eastern Ontario, I found there were many youths who were admitted for mental health issues, which is what prompted me to decide that I wanted to start my career as a nurse in this milieu.

After graduating, I worked part-time on medical surgical inpatient units, while working elsewhere full-time. I was offered a position in the Emergency Department (ED), where I fell in love and have worked for the past eight years. During this time, I have seen a lot of youth with mental health issues come through the ED in acute mental health crises. Over the years, the number of young people seen in the ED for mental health issues has been increasing and now, we are routinely over capacity. I often work in triage and speak with youth who come in for mental health concerns. Many of them are 16 or 17 years old, and I often get asked "where do I go when I can't come here anymore?". Other than offering resources, there is not much I can do for these young people or their families once they reach the age of 18 – I find this quite unsettling.

I often wonder about the youth I have provided care for and how they are doing once they 'age out' of pediatric healthcare. I will sometimes see parents of these patients who have younger children and come to CHEO for them. Some remember me caring for their child and offer me an update about them. Unfortunately, many parents have told me that the adult mental healthcare system is nothing like they or their child expected, and that they are not receiving the care they need. The increase in mental healthcare needs and the heartbreaking stories from families were the reasons for this study; I wanted to make a difference in the lives of youth with mental health issues and their families, as well as provide them with a safe space to share their stories. During my initial research into the topic, I was surprised to find limited evidence about

the transition process from CAMHS to AMHS. This is when I decided to change my master's program from the clinical project stream to the thesis stream, so I could add to the knowledge base on transitioning from CAMHS to AMHS.

Purpose and Objectives

Due to the rise of mental illnesses in the pediatric population and the increasing awareness of the problems young adults face when transitioning to adult services, it is important to explore how to best support them during this vulnerable time. When I first started my Masters, I found minimal research on youth transitioning from pediatric to adult mental health services. Recently, some work has been published about this population, however, the evidence primarily includes literature reviews and surveys, with very few studies qualitatively exploring the phenomenon from the perspectives of young adults. Therefore, the purpose of this study was to explore young adults' transitions from CAMHS to AMHS. The specific objectives were:

1. To describe the transition from Child and Adolescent Mental Health services to Adult Mental Health Services from the perspective of patients.
2. To identify facilitators, inhibitors, and gaps in care that affect transition from Child and Adolescent Mental Health Services to Adult Mental Health Services from the perspective of patients.

Organization of the Thesis

This thesis is organized into several chapters. In this first chapter, I introduced the topic of study and provided my purpose. Chapter two is an overview of the current evidence on this topic, including a review of the literature – focusing on common ideas and a discussion of key concepts. In Chapter three, the theoretical underpinnings used for the study are described, and

the methodology and procedures explained. Chapter four presents the findings, with embedded participant quotes. Chapter five is a discussion of the findings within the context of the extant literature, including implications for practice, policy, research, and education, followed by, strengths, limitations, and conclusions.

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Chapter Two: Literature Review

Literature Review

This chapter provides an overview of the literature relevant to my topic. First, mental illness is discussed, such as what defines mental illness and its cost on society. Second, depression and anxiety are defined because they are the diagnoses most relevant to the participants. Next, I describe the differences between CAMHS and AMHS, followed by a review of transitions and what transition means for both physical and mental illnesses. The effects transition has on the mental health of young adults is also explained. Lastly, I provide a summary of the extant literature on the topic.

Conduct of the Literature Review

Four databases were searched for literature on the topic of young adults transitioning from CAMHS to AMHS: CINAHL, MEDLINE (OVID), PSYCARTICLES, and NURSING AND ALLIED HEALTH. The nine concepts used in the search included: transition, child to adult, mental health services, mental health, emergency department, inhibitors/barriers and facilitators, pediatric to adult mental healthcare, pediatric health care, and adult health care. To narrow the search, I added limitations, which were full text, peer reviewed, and English. From these databases and the limitations added, 28 articles were identified and used for this literature review.

Mental Illness

To build on the definition of mental illness given in the glossary of terms ([Page 4 and 5](#)) a person's behavior, feelings, perceptions, and thoughts can be affected by mental illness (Canadian Mental Health Association [CMHA], 2020). Mental illness usually presents in childhood or adolescence, but can affect persons of all ages, cultures, education, and income levels (CMHA, 2020; Government of Canada, 2019). Individuals may also develop a mental

illness (or psychiatric symptoms) when an event or situation occurs causes them distress, such as a job loss or death of a loved one (Government of Canada, 2019). It is estimated that the global prevalence of mental illness in children and adolescents is 10-20%, with one third of these children and youth being affected for life (Mulvale et al., 2015). In Canada, 15-21% of children and youth have at least one diagnosable mental illness, with multiple diagnoses being more common among older youth (Manteuffel et al., 2008; Mulvale et al., 2015). It is imperative to identify and manage mental illness in childhood early and effectively, given the lasting effects in adulthood if left untreated. Some of these negative effects include substance use, criminal activity, and increased risk of suicide (Mulvale et al., 2015). When these disorders present in childhood and/or early adolescence, the person is up to three times more likely to also experience these disorders in adulthood. For example, depression often continues into adulthood and anxiety disorders usually predict other adult mental illnesses (Manteuffel et al., 2008).

The continuation of mental illness from childhood to adulthood also leads to ten times higher healthcare costs, which impact the sustainability of the healthcare system (Singh et al., 2017). As per the Centre for Addiction and Mental Health [CAMH] (2022), it is estimated that, in Canada, the annual economic cost of mental illness is 50 billion dollars. These costs include lost productivity, reduction in health-related quality of life, and healthcare expenses. Furthermore, unemployment rates for people with mental illnesses are as high as 90%, with the cost of workplace disability leave, related to mental illness, being double the cost of leave related to physical illness (CAMH, 2022). Mental illnesses that affect youth are ranked the second highest hospital care cost in Canada, and yet, only one in five receive the mental health services they need (MHCC, 2013). Programs, such as early interventions aimed at children and families, mental health programs in the workplace, and improved treatment for depression and anxiety

disorders, have demonstrated positive outcomes (CAMH, 2022). Providing proper support over the course of one's illness trajectory will not only improve health outcomes for patients, but also reduce healthcare costs related to emergency visits and admission to psychiatric units (Jabour et al., 2016).

Depression and Anxiety

The Diagnostic and Statistical Manual of Mental Disorders, (American Psychiatric Association [APA], 2013) defines the common features of a “Depressive Disorder” as “the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function” (APA, 2013, p. 155). This differs from persistent depressive disorder, which is characterized as “a more chronic form of depression, persistent depressive disorder (dysthymia), can be diagnosed when the mood disturbance continues for at least two years in adults or one year in children” (APA, 2013, p. 168).

Anxiety disorders are defined as “disorders that share features of excessive fear and anxiety and related behavioral disturbances. *Fear* is the emotional response to real or perceived imminent threat, whereas *anxiety* is anticipation of future threat” (APA, 2013, p. 189). Within the spectrum of anxiety, it is important to note that “anxiety disorders differ from developmentally normative fear or anxiety by being excessive or persisting beyond developmentally appropriate periods. They differ from transient fear or anxiety, often stress-induced by being persistent (i.e. typically lasting 6 months or more)” (APA, 2013, p. 189).

Mood and anxiety disorders are the most prevalent diagnoses in community-based studies, with depression and anxiety being the most common mental illnesses among young adults (Schraeder & Reid, 2017). While some young adults can have chronic or persistent depression (10 to 18%), most have periods of exacerbation and remission. The unpredictable and

sometimes sporadic nature of depression can make it difficult to ensure consistent access to care, especially when transitions between services occur during times of remission. Although experts in this area state that young adults with ongoing mental health issues should be considered for transition planning, regardless of whether their illness is persistent or episodic, this does not routinely happen in practice. With the trajectory of depression and anxiety typically consisting of periods of wellness and illness, youth with these disorders are more likely to disengage from mental health services than people with severe and persistent mental illness (e.g. Schizophrenia or bipolar disorder) (Schraeder and Reid, 2017).

According to Statistics Canada, persons aged 15 to 24 years have the highest rates of anxiety and mood disorders compared to other age groups (Statistics Canada, 2017). A survey conducted by the Public Health Agency of Canada (PHAC, 2015) revealed that an estimated three million Canadians aged 18 years or older have a mood and/or anxiety disorder. Of these persons, 27% indicate that their life is affected ‘quite a bit’ or ‘extremely’ by their illness (PHAC, 2015). According to the Mental Health Commission of Canada (MHCC, 2013), 3.2 million Canadian youth aged 12 to 19 years are at risk for developing depression. Within this same group, 5% of youth who identify as boys and men and 12% of youth who identify as girls and women have experienced a major depressive episode. Furthermore, the rates of suicide in Canada are the third highest in the developed world, with approximately 4000 deaths per year in youth aged 15 to 24 years being the result of suicide, making it the second leading cause of death in this age group (MHCC, 2013).

A survey completed in 2020 during the COVID-19 pandemic found that the prevalence of positive screens for generalized anxiety disorder and major depressive disorder were over three times higher among young adults aged 18 to 24 years, than among older adults (Statistics

Canada, 2021). Overall, this same study found that Canadians who experienced feelings of isolation or loneliness, due to the COVID-19 pandemic, had an increased prevalence of major depressive disorders (6% to 29%) and anxiety disorders (6% to 25%) (Statistics Canada, 2021).

Depression and anxiety are both common mental illnesses, which sometimes occur together and can have negative effects on an individual's quality of life (CMHA, 2020). Receiving professional care for these illnesses is essential to support the everyday health and functioning of affected persons (PHAC, 2015). Accessing mental healthcare services early is important because it can lead to better health outcomes and improve achievements in many aspects of life, such as school or work (CMHA, 2020). Unfortunately, mental health services are designated as pediatric and adult, meaning that at some point, patients must transition from one system to the other. This results in changes in providers, location of services, philosophies of care, among others.

CAMHS and AMHS

CAMHS is the acronym for Child and Adolescent Mental Health Services, which are provided to children and youth under the age of 18 years in Ontario, Canada (Young Minds, 2021). AMHS stands for Adult Mental Health Services, which are offered to individuals over the age of 18 years (Young Minds, 2021). However, the eligibility criteria for acceptance differs significantly between the two services, making it difficult for some individuals to simply transfer services once they reach transition age (Appleton et al., 2019; Butterworth et al., 2017; Mulvale et al., 2015; Vyas & Singh, 2014). For instance, CAMHS are inclusive and offer various complementary services to persons with a wide range of mental illnesses that may not meet specific diagnostic criteria, as per the DSM-V (Butterworth et al., 2017; Mulvale et al., 2015; Vyas & Singh, 2014). This differs from AMHS who have rigid eligibility criteria where persons

often need to have a severe or persistent diagnosable mental illness, as outlined in the DSM-V, to qualify for care (Butterworth et al., 2017; Mulvale et al., 2015; Vyas & Singh, 2014).

While age boundaries exist, they are debated because they often do not meet the needs of young adults, nor are they well-received by patients and their families who would prefer a later shift to adult care (Signorini et al., 2018; Vyas & Singh, 2014). Experts in this area appear to have varying views regarding the optimal age for transition from CAMHS to AMHS, with some making generalized statements that current age-specific criteria are rigid and counterproductive (Leavey et al., 2019), and others advocating for an increase in the base age (Butterworth et al., 2017).

Differences in healthcare philosophies also exist between services, with CAMHS using a child-centered approach, compared to AMHS that uses an adult-oriented approach (Appleton et al., 2019; Mulvale et al., 2015). In CAMHS, a multidisciplinary team embraces a style that is protective of the children and youth they serve, while providing age-appropriate mental healthcare, such as using toys or play material during assessments and treatment (Appleton et al., 2019; Canadian Association of Pediatric Health Centres [CAPHC], 2016; Mulvale et al., 2015). The terminology used in CAMHS is also age appropriate, simple, and easy to understand (Mulvale et al., 2015). Providers aim to consider the young person's situation at the psychosocial level, including the family and/or schools, in the decision-making process (CAPHC, 2016; Mulvale et al., 2015).

In contrast, AMHS takes a diagnostic approach, mainly focusing on symptom management in a context geared towards adults (Appleton et al., 2019; Mulvale et al., 2015). Instead of a nurturing environment like CAMHS, adult mental health services have clinical atmospheres that may not allow for specific needs of young adults to be met, such as including

family or other social structures (Mulvale et al., 2015). They have expectations that young adults will be responsible for their own care, self-motivated, and able to make independent treatment decisions (CAPHC, 2016; Mulvale et al., 2015). The care approach is individualized, which does not consider social structures when decisions about care need to be made (Mulvale et al., 2015).

Young adults who are not prepared for such an autonomous approach upon service transition often find it challenging to adapt (CAPHC, 2016). The terminology used in AMHS can be confusing for young adults who are used to straightforward direction, instead of having to interpret more complex statements (Mulvale et al., 2015). While these differing philosophical approaches are expected, CAMHS users may lack self-management skills and personal responsibility they need in adult services. One pertinent example of difference is pertaining to parental involvement. Parents are expected to be highly involved in all aspects of their child's care while in CAMHS, which may undermine their child's independent involvement in decision-making (CAPHC, 2016). Once in AMHS, these same patients are expected to independently navigate the system, despite not being prepared to do so (CAPHC, 2016). Some researchers suggest that it might be advantageous for both services to share responsibility for young adults over a period of three months to facilitate transition, such as the CAMHS worker attending the first meeting between the young adult and their new AMHS worker and ensuring the young adult feels comfortable navigating the adult healthcare system (CAPHC, 2016; Dimitropoulos et al., 2015; McLaren et al., 2013; Swift et al., 2013).

Transition

Healthcare transition between services is defined as “the purposeful, planned movement of adolescents with chronic physical and mental conditions from child-centered to adult-oriented health care systems” that is designed “to provide healthcare that is uninterrupted, coordinated,

developmentally appropriate, psychosocially sound, and comprehensive” (Schraeder & Reid, 2017, p. 317). Although there are several variations of what defines transition, common to all is the notion that transition is a *process*. Given this lens, it is important to ensure collaboration and coordination between health professionals and the patient to optimize a healthy transition (Registered Nurses Association of Ontario [RNAO], 2014; Schraeder & Reid, 2017). To coordinate care, interprofessional healthcare teams need to work directly with patients during and after their transition, which includes embedding structures into organizational processes to support care transitions (RNAO, 2014). Specific suggestions, found within the literature, include: 1. identifying elements that support an effective transition, 2. examining transition practices and modifying them to accommodate the needs of young people, and 3. identifying all transition points so that care can be appropriately included into care pathways, as well as service delivery models (Munoz-Solomando et al., 2010; RNAO, 2014). These suggestions further support the need for a systematic, organized, and coordinated transition approach.

The Process of Transitioning in Healthcare

A healthcare transition is a process that is planned and purposeful (Appleton et al., 2019; Butterworth et al., 2017; Eke et al., 2019; Leavey et al., 2019; Manteuffel et al., 2008; Mulvale et al., 2015; Price et al., 2019; Signorini et al., 2018; Singh et al., 2017). Appleton and colleagues (2019) went one step further calling it a “therapeutic process” (p.1431). While this is acknowledged, the planning, implementation, and evaluation of the transition from CAMHS to AMHS is often poor (Appleton et al., 2019; Butterworth et al., 2017; Mulvale et al., 2015; Singh et al., 2017). When transition is treated as a process (rather than as an abrupt change), mental health can be optimized, adverse events minimized, and continuity of care can be ensured (Singh et al., 2017). Some authors report that a flexible, informal, and individualized strategy, allowing

the adolescent to steadily transition, is an effective approach (Manteuffel et al., 2008; Mulvale et al., 2015). Using a process approach that is coordinated across systems is needed for provision of care that is psychologically sound and developmentally appropriate (Mulvale et al., 2015).

When we think of transition as a process, one key point to consider is ‘at what age does the transition planning phase of the process start?’. While there is no definitive answer, most authors suggest the best time is when the young adult is ready ‘developmentally’ (Appleton et al., 2019; Butterworth et al., 2017; Manteuffel et al., 2008, Mulvale et al., 2015). Butterworth and colleagues (2017) provided more concrete direction, stating that 16 years is an appropriate age to start transition planning, though they also acknowledged that moving towards a more flexible transition age of 25 years would allow a more gradual approach, rather than an abrupt change in services (Butterworth et al., 2017).

Since most individuals transition out of CAMHS at age 18, starting transition planning early is crucial. Poorly planned transitions increase the likelihood of young adults discontinuing care due to lack of follow-up, which can cause non-adherence to recommended treatments and poor outcomes for their mental health (Butterworth et al., 2017; Leavey et al., 2019; Mulvale et al., 2015). For example, in a study of youth and young adults in foster care, a population likely to experience multiple transitions, researchers found that when their transition to AMHS was poorly planned and implemented, they reported a lack of stability and trust (Butterworth et al., 2017). Although some young adults do transition from child-centered to adult-oriented mental health services without proper planning, the transition is often turbulent (Leavey et al., 2019). Having appropriate transition planning at an early age will likely help to facilitate a positive transition experience (Manteuffel et al., 2008).

Part of transition planning and a core component of an *optimal* transition is to have a discussion between the primary CAMHS healthcare professional and the patient about the transition process (Leavey et al., 2019). In a study by Leavey and colleagues (2019), only 38% of CAMHS users had a transition-planning meeting documented in their chart, and only 16% of clinicians documented that they informed their patients that they would be transferred to AMHS. In another study, the timing of the discussion about transition also varied from person to person (Dimitropoulos et al., 2015). Some individuals had weeks or months to process the upcoming transition, while others found out at their last visit with CAMHS (Dimitropoulos et al., 2015). Young adults value shared decision-making, clear communication, autonomy, and self-advocacy during their transition process (McLaren et al., 2013; Swift et al., 2013). To facilitate a healthy transition, service planning that is individualized and patient-centered and inclusive of the young adult and their family is essential (CAPHC, 2016; Manteuffel et al., 2008).

While preparing young adults for their transition is important, preparing their families for the change in roles and expectations is equally so (Mulvale et al., 2015). Family members, as well as young adults, need to have an opportunity to provide their thoughts and ideas about transitioning and be involved in decisions regarding their care (Mulvale et al., 2015). However, lack of shared transition planning is common between CAMHS and young adults, as well as between services (Price et al., 2019). When patients and families are included, their input does not appear to influence the final transition experience (Signorini et al., 2018).

Transition Guidelines

The National Institute for Health and Care Excellence (NICE) conducted a review in 2016 on the transition from child-centered to adult-oriented care and discovered that there was no rigorous evidence supporting models on transitional care. Notably, CAPHC (2016) outlined

recommendations and a framework to support patients who are transitioning to adult health services in their navigation of the system and ability to manage their health. There were 19 recommendations in total, organized into three groups: “Centered”, including two recommendations emphasizing the need for youth and family involvement, “Clinical” consisting of 11 recommendations highlighting the healthcare professional's role in provider-to-patient support, education, and planning, and “System-level” comprised of six recommendations focusing on the need for transitional policies in all settings, ongoing commitment to education, and expanding the evidence base on the topic (CAPHC, 2016, p. 12. Para. 1).

Subsequent to the NICE (2016) report, other researchers published on this topic. Singh and colleagues (2008), for example, published their ‘Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services: TRACK’ study designed to identify specific criteria that would lead to optimal transitions. Thereafter, Singh and colleagues (2017) conducted a 5-year study called MILESTONE (Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare), aimed at improving the transition from CAMHS to AMHS. Although work in this area is increasing, and some recommendations and guidelines exist, they are not equivalent to the rigorous guidelines established for physical health conditions (like service transitions for people with diabetes), and their use in clinical practice is limited (Schraeder & Reid, 2017).

An ‘Optimal’ Transition

The word *optimal* is currently used to describe the success of a transition in literature (Appleton et al., 2019; Leavey et al., 2019; Singh et al., 2010; Singh et al., 2017; Swift et al., 2013). An optimal transition is defined as “having a number of important stages, such as good information transfer across services, joint working, and continuity of care following transition”

(Swift et al., 2013, p.2). As per Singh and colleagues (2010) the following elements constitute an optimal transition from CAMHS to AMHS:

- “*Continuity of care* -either engages with AMHS three months post-transition or appropriately discharged; and the following three further variables.
- *Period of parallel care (relational continuity)*, i.e., a period of joint working where the service user is involved with both CAMHS and AMHS.
- *Transition planning meetings (cross-boundary and team continuity)*, i.e., at least one meeting discussing the transition from CAMHS to AMHS, involving the service user and/or carer and key professionals, prior to the handover of care from CAMHS to AMHS.
- *Optimal information transfer (information continuity)*, i.e., any or all of the following transferred from CAMHS to AMHS: referral letter, summary of CAMHS contact, and any notes and a contemporary risk assessment” (Singh et al., 2010, p. 44).

It appears as though an optimal transition is an elusive notion, with Singh and colleagues (2010) finding that less than 5% of people who transitioned from CAMHS to AMHS experienced the traits of an optimal transition, and Swift and colleagues (2013) reporting that only 5% of CAMHS cases experienced an *optimal* transition. In a more recent study by Appleton and colleagues (2019), results were similar with only 4% of individuals experiencing an ‘optimal transition’. Lastly, Leavey and colleagues (2019) used the elements mentioned above when they reviewed 252 transition cases across five Health and Social Care NHS Trusts in Northern Ireland. They found that for young adults aged 18 years who transitioned, 73% received some level of continuity of care, 18% had a period of parallel care, 38% had a transition planning meeting, 3% had optimal information transfer, and 0%

met all four criteria (Leavey et al., 2019).

While the term optimal is used in contemporary literature when describing a transition that is successful, earlier work by Schumacher and colleagues (1999) used the word *healthy* instead. These authors identified seven transition process indices that portray a healthy transition which were: “1. Redefining meaning/awareness, 2. modifying expectations, 3. restructuring life routines, 4. developing knowledge and skills, 5. maintaining continuity, 6. creating new choices, and 7. finding opportunities for growth” (Schumacher et al., 1999, pp.2). Knowing what an optimal or healthy transition looks like is important to be able to appropriately assess how a transition is progressing. To illustrate these indices in relation to the transition of young adults from CAMHS to AMHS, some examples are described below:

1. REDEFINING MEANING/AWARENESS: Finding a new meaning in AMHS. Finding what it means to be an adult and not dwelling on services offered in CAMHS and exploring the services that are now offered in AMHS.
2. MODIFYING EXPECTATIONS: Modifying expectations according to new services (AMHS). For example, expecting to take control of their health.
3. RESTRUCTURING LIFE ROUTINES: Adapting and restructuring their routines so that they correspond with their new situations.
4. DEVELOPING KNOWLEDGE AND SKILLS: Learning how AMHS functions and what they can offer them. Developing new skills such as seeking and attaining employment, continuing education opportunities, and housing.

5. MAINTAINING CONTINUITY: Maintaining continuity in relationships with loved ones and friends enables young adults to cope with changes caused by the transition which can often be complex and challenging.

6. CREATING NEW CHOICES: Making new decisions about themselves and not limiting the choices that are available.

7. FINDING OPPORTUNITIES FOR GROWTH: Allowing the opportunity for personal growth such as forming new relationships, a new identity and being self-aware. For young adults transitioning, taking control of their own health, and forming new and trusting relationships with workers at AMHS are big steps towards self-development.

Although these indices are listed, they may not occur in a linear fashion and young adults may backtrack several times during their process of transition.

Healthcare Transitions for People with Physical Illnesses

Literature exists on the topic of transition for young adults with medical illnesses to adult healthcare services. For example, Iversen and colleagues (2019) explored the experiences of 11 young adults aged 19 to 23 years with type 1 diabetes transitioning from pediatric to adult services in Norway. Higginson and colleagues (2019) also explored this for persons with chronic pain and interviewed nine young adults ages 18 to 23 years in Canada. Both in the United States, Sobota and colleagues (2016) explored young adult perspectives on a successful transition with 15 participants aged 18 to 28 years with sickle cell anemia and Bashore and Bender (2016) evaluated the utilization of a workbook to facilitate a successful transition to adult services for 30 young adult cancer survivors between the ages of 16 to 21 years. There is also a systematic review available on the topic, for which Gray and colleagues (2017) included 57 articles. Their

main findings were that young adults with physical illnesses who transition from child to adult care describe: ‘lack of knowledge about the transition process’; ‘follow-up that was infrequent post transition’; ‘a need to be seen as a whole person’; and ‘limited expectations of how the healthcare services were organized’ (Gray et al., 2017).

Emerging quantitative data indicates poor clinical outcomes after transitioning from child centered to adult oriented services (CAPHC, 2016). For example, in a study done in Manitoba, Canada, 40% of young adults with Type 1 Diabetes discontinued adult care before a transition program was initiated (Van Wallenghen et al., 2018). Furthermore, in another study in British Columbia, Canada researchers investigated young adults with kidney transplants and, within two years of transition, 24% had incidence of graft loss and/or death prior to transition program initiation (Prestidge et al., 2010). Despite literature describing transitions between pediatric and adult health services for persons with physical illness, clearly gaps in care and negative outcomes persist post-transition.

Healthcare Transitions for People with Mental Illnesses

Although literature on the topic of transition for patients with mental illness is scant, study findings identify common pitfalls in this process affecting the overall well-being of young adults: a lack of effective communication, poor transfer, and the absence of monitoring post transition (Dimitropoulos et al., 2015; Jabbour et al., 2016; Loos et al., 2018; McLaren et al., 2013; Schraeder & Reid, 2017; Swift et al., 2013; Thomas et al., 2018). Of note, qualitative evidence reflects different settings and populations with different mental illnesses, challenging transferability of these ideas. Below I summarize the most pertinent articles that I found on the topic, which include qualitative and quantitative methodologies.

- *Dimitropoulos and colleagues (2015)* explored the experiences of young adults aged 17 to 21 years with eating disorders transitioning into adult services in Ontario, Canada. They found that increased communication, coordination, and collaboration between CAMHS and AMHS improved the transition to adult services.
- *Swift and colleagues (2013)* explored the phenomenon with young adults aged 17 years or older with ADHD in Nottinghamshire. Their study concluded that joint working, parental support, timely preparation, and good clinician relationships help facilitate the process of transitioning from child to adult services.
- *Loos and colleagues (2018)* used group discussion and interviews with 29 youth aged 16 to 25 years with mental illness in Germany to explore their perceptions and evaluations of healthcare. They found that there is a need for more support and autonomy in practice, as well as needs-based care during the transition period.
- *Butterworth and Colleagues (2017)* looked at the experiences of 12 ‘care-leavers’ aged 18 to 22 years in the United Kingdom with mental illnesses transitioning into adult mental health services. They found that the differences between approaches (CAMHS and AMHS) need to be discussed prior to transition to clarify expectations. For their participants, transition was a stressful time, and not knowing what to expect exacerbated their mental illness symptoms.
- *Price and Colleagues (2019)* conducted a systematic review of qualitative data with the aim to better understand the experiences of healthcare transitions for ‘young people’ aged 14 to 25 years with ADHD. They learned that these young people believed they were let down during their transition from CAMHS to AMHS. One of the reasons for these feelings was due to the abrupt loss of services - and even medication - that had a

traumatic effect, resulting in a negative view of AMHS. One of the major changes was the absence of parental involvement when leaving CAMHS and entering AMHS.

- *Mulvale and colleagues (2015)* also completed a systematic review with the intent to describe the influences of CAMHS and AMHS care philosophies on transition for patients aged 12 to 25 years, including all mental illnesses. They found that without parental involvement, youth were more likely to drop out of mental health services, even when a formal transfer of care occurred.
- *Signorini and colleagues (2018)* conducted a survey involving individuals with expertise on child and adult mental health services about transitional policies in 28 European countries. The findings identified that parental involvement is controversial for young adults in AMHS, with some patients wanting their parents involved and others not.

Overall, research findings indicate that the mental health of young adults declines during the transition process from CAMHS to AMHS (Butterworth et al., 2017; Eke et al., 2019; Manteuffel et al., 2008; Price et al., 2019; Singh et al., 2017). For example, young adults are often navigating multiple situational and developmental transitions simultaneously causing emotions to be heightened, possibly exacerbating their symptoms (Appleton et al., 2019; Price et al., 2019; Singh et al., 2017). Feeling unprepared is another reason that mental health declines during transition, as well as uncertainty regarding services provided by AMHS (Butterworth et al., 2017; Price et al., 2019). Issues at the interface between CAMHS and AMHS also contribute to a decline in mental health during this period, such as having no designated healthcare professional or team to spearhead the transition process or provide interim care (Singh et al., 2017). The way the transition process itself is carried out can have negative effects on the mental health of young adults by contributing to negative psychological outcomes (Butterworth et al.,

2017). Several studies, guidelines, and government documents emphasize the challenges that young adults face when transitioning from CAMHS to AMHS, including the risk of deterioration in health (Eke et al., 2019; Manteuffel et al., 2008).

When the needs of transition age patients with mental illnesses are not met, research findings show an increase in unemployment, school dropout, homelessness, unplanned pregnancy, and issues with the criminal justice system (Manteuffel et al., 2008; Price et al., 2019). In a systematic review, Price and colleagues (2019) found that negative impacts on mental health occurred when there is a lack of access to support or treatment, which leads to youth feeling distressed, helpless, and disempowered, affecting their physical and mental functioning. These feelings are intensified when there are negative attitudes from clinician towards the young adult during transition, causing further emotional distress and impaired functioning.

Dimitropoulos and colleagues (2015) reported that none of the young people who participated in their study were accepted into AMHS immediately following discharge from CAMHS because they were not 'sick enough'. All young adults, except for one, experienced relapse, with 40% relapsing immediately and 46% relapsing within two years, after which only half resumed treatment (Dimitropoulos et al., 2015). What happens to young adults who disengage from care during their transition to AMHS is unknown, and no studies that I could find have explored this phenomenon (Appleton et al., 2019). This issue is a "serious cause for concern" (Appleton et al., 2019, p. 1432), and represents a significant knowledge gap (Appleton et al., 2019; Healthcare Safety Investigation Branch, 2018; NICE, 2016). As a safeguard, it is important that when a young adult is not accepted into AMHS or is on a wait list, they are informed about available resources and services they can access prior to discharge from CAMHS (Price et al., 2019).

Challenges to Continuing Mental Healthcare

There are many obstacles to continuous care for young adults with mental illnesses, and approximately a third are lost from care while transitioning to AMHS and a third experience disruption in their care (Appleton et al., 2019; Leavey et al., 2019). Issues at the interface between the two services and between services and patients are known. For example, there is a lack of collaboration (Signorini et al., 2018) and communication (Singh et al., 2017) between services due to differences in the organization and delivery of care (Vyas & Singh, 2014), as well as differing perspectives on diagnosis and treatment (Leavey et al., 2019). Ideally, the interface between CAMHS and AMHS would be cohesive, however, in reality, it is said to be the weakest link in the system (Signorini et al., 2018). Additional barriers include the following:

- Leaving trusted healthcare professionals and having to build new therapeutic relationships with unfamiliar people (Manteuffel et al., 2008).
- Lack of resources in AMHS, premature discharge, and referrals being rejected (Price et al., 2019).
- Lack of communication where some young adults know about their upcoming transition and others do not, as well as long wait times (Butterworth et al., 2017).
- Poor information transfer and sharing between services. Sometimes AMHS has very little or no information about the young adults coming into their care (Butterworth et al., 2017, Leavey et al., 2019).
- Clinicians or CAMHS workers who do not refer their patients to AMHS because they do not believe that they would not be accepted by AMHS (Appleton et al., 2019; Butterworth et al., 2017; Eke et al., 2019; Leavey et al., 2019; Mulvale et al., 2015; Paul et al., 2013; Price et al., 2019; Signorini et al., 2018; Vyas & Singh, 2014).

This final point about clinicians who do not refer their patients to AMHS is interesting. In studies exploring this phenomenon, Eke and colleagues (2019) found that of all eligible cases for transition over one year, 40% were not referred to any adult service. Mulvale and colleagues (2015) also found that, of their 154 eligible participants, 42% were either not referred to or not accepted into AMHS. Finally, Appleton and colleagues (2019) discovered that the percentage of rejected referrals to AMHS is as high as 73%. When young adults have high mental health needs and they leave CAMHS with feelings of isolation, distrust, abandonment, powerlessness, instability and alienation, the likelihood of them accessing AMHS is low and the likelihood of them using emergency services is high, which is not the ideal way to receive mental health care (Butterworth et al., 2017).

Summary

Young adults are staying at home longer and relying more heavily on their parents for support (CAPHC, 2016). There are specific attributes and developmental milestones that need to be attained prior to adulthood, such as being able to make autonomous decisions and accepting responsibility for one's own care. However, *when* these attributes are acquired differs from person to person, making it challenging for youth to transition out of CAMHS if they have not yet mastered these life skills. Based on the literature reviewed, it does not appear that providers working in AMHS verify the attainment of these skills nor check that the incoming patient has the emotional maturity to manage their care.

The transition process itself is problematic and there are inconsistencies in the management of it for young adults with mental illnesses. For example, patients routinely transition to AMHS without fulsome discharge planning or assistance with booking their first AMHS appointments (Dimitropoulos et al., 2015; Schraeder & Reid, 2017). Poor transition

results in decreased mental wellness and an increased reliance on emergency services (CAPHC, 2016; Jabbour et al., 2016). Strategies, such as collaboration and coordination through joint working and clear communication between all healthcare professionals and the patient, are found to be key factors to healthy/optimal transitions (Dimitropoulos et al., 2015; Loos et al., 2018; McLaren et al., 2013; RNAO, 2014; Schraeder & Reid, 2017; Swift et al., 2013; Thomas et al., 2018). Unfortunately, these strategies are rarely used in practice and there is a lack of literature supporting their implementation.

From the qualitative evidence, young adults who are transitioning from CAMHS to AMHS require proper transition planning and education, joint working between services, discussions about the expectations for adult care while in CAMHS, and policies that are routinely used and fully integrated into practice (Butterworth et al., 2016; Dimitropoulos et al., 2015; Swift et al., 2013; Loos et al., 2018; McLaren et al., 2013; Schraeder & Reid, 2017; Thomas et al., 2018). While these cited authors all conducted qualitative studies, there is limited current research on the transition process from CAMHS to AMHS from the perspective of young adults, and while existing quantitative methodologies, such as systematic reviews, case note reviews, surveys and retrospective chart reviews conducted from this perspective are useful, they do not fully capture the experiences of patients who are or have lived the phenomenon under study (Loos et al., 2018).

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Chapter 3: Methodology

Theoretical Underpinnings

My understanding of this topic is informed by the Bridges Transition Model (Bridges, 2002), as well as the Meleis transition theory (Meleis, 2010). These theoretical frameworks describe how *change* is an event, whereas *transition* is a psychological process that individuals go through as they internalize and start to realize that they are in a new situation that was caused by a change (Bridges, 2002; Meleis, 2010). Together, these frameworks can be used to explain how some transitions are layered and interwoven (Meleis, 2010), while others have distinct starts and finishes (Bridges, 2002).

Bridges Transition Model

The Bridges transition model provides a frame to help individuals and organizations effectively manage change (Bridges, 2002). This change initiates a transition, with successful transitions including all three phases: ‘Endings’, ‘Neutral Zone’, and ‘New Beginnings’, as described in the model. Although the first phase *Endings* seems paradoxical, a transition begins here so people have space to realize what they are losing and cope effectively. Once an individual let’s go of what they lost, the second phase *Neutral Zone* begins. This critical part of the transition process is when people start to create new attitudes and begin to learn their new roles. The final phase, *New Beginnings* involves finding a new direction and forming a new identity. It is a time for new understandings, attitudes, and values. When the transition is healthy, people accept their new roles and responsibilities (Bridges, 2002). Refer to [Appendix A](#) for the diagram of the Bridges Transition Model.

Meleis’ Transition Middle-Range Theory

Meleis’ transition middle range theory is used to explain the process for individuals who are going through a transition (Meleis, 2010). The theory articulates how people go through a

transition, focusing on the effect of the transition on their well-being. To achieve this, the Meleis theory identifies four main components related to a transition (Appendix B): ‘Nature of Transition’, ‘Transition Conditions: Facilitators & Inhibitors’, ‘Patterns of Response’, and ‘Nursing Therapeutics’ (Meleis, 2010). Each of these concepts is described below.

Nature of Transition. The ‘Nature of Transition’ component includes the ‘*Types*’, ‘*Patterns*’, and ‘*Properties*’ of a transition (Meleis, 2010). The *type* of transition can be ‘developmental’, ‘situational’, ‘health/illness’, or ‘organizational’ and the *patterns* of transition can be ‘single’, ‘multiple’, ‘sequential’, ‘simultaneous’, ‘related’, or ‘unrelated’. After the *type* and *pattern* of the transition are identified, the five *properties* essential to the transition are considered. These include ‘awareness’, ‘engagement’, ‘change and difference’, ‘time span’, and ‘critical points and events’. These properties are interconnected, resulting in a complex process (Meleis, 2010). Each property is described below.

Awareness relates to the individual being aware that changes are happening (Meleis, 2010). *Engagement* is about how engaged or involved the individual is in the transition process. *Change and Difference* connect closely with engagement because change and its resulting uncertainty is involved in all transitions. *Time span* describes how everyone goes through transition differently and within different time frames. *Critical points and events* suggest that an event or a critical moment in a person’s life is often the reason for transition (Meleis, 2010).

Transition Conditions: Facilitators & Inhibitors. The ‘Transition Conditions: Facilitators & Inhibitors’ is another component of this theory with ‘personal’, ‘community’ and ‘society’ as categories within it (Meleis, 2010). *Personal* conditions are ‘Meanings’, ‘Cultural Beliefs and Attitudes’, ‘Socioeconomic Status’, and ‘Preparation and Knowledge’. *Meanings* refers to a special meaning attributed to events leading up to the transition process that either facilitate or

inhibit optimal transitions. *Cultural beliefs and attitudes* focus on the attachment of stigma to a transitional experience, such as stigmatizing people who have a mental illness. *Socioeconomic status* is tied to transition and can influence psychological health. Finally, *Preparation and knowledge* impact transition, in that having time to properly prepare for a transition is a facilitator, and not having proper preparation is an inhibitor. Directly related to preparation is knowing what to expect throughout the duration of the transition and adopting strategies for proper management (Meleis, 2010). ‘*Community*’ and ‘*Societal*’ conditions are also part of transition conditions (Meleis, 2010). Meleis (2010) describes ‘community’ as groups of people in one geographical location who have aligning interests or living the same experiences. Having a community that is supportive and offers resources that are accessible can facilitate a positive transition. As per Meleis (2010) ‘society’ can either facilitate or inhibit transitions, with society acting as an inhibitor when, for example, a transition holds stigmatized and/or stereotyped connotations (Meleis, 2010). Positive societal conditions, such as social inclusion and access to resources (CMHA, 2023), facilitate the transition process (Meleis, 2010).

Patterns of Response. Patterns of Response have process and outcome indicators as the main components, each with characteristics (Meleis, 2010). Meleis (2010) contends that a transition is characterized by the *Process Indicators* and *Outcome Indicators* within the concept of Patterns of Response. Under process indicators, ‘feeling connected’ to healthcare professionals, ‘interacting’ with family members during the transition experience, ‘location and being situated’ and ‘developing confidence and coping’ are important patterns of response of the transition process. The outcome indicators include ‘Mastery’ and ‘Fluid Integrative Identities’. An example of the former is taking control of one’s own health, and the latter, forming a new identity following transition (Meleis, 2010).

Nursing Therapeutics. Meleis (2010) defines nursing as “facilitating transitions to enhance a sense of well-being” (p.68), which suggests that nurses have insight and influence over the transition of their patients. While disciplines other than nursing focus on transitions, nursing care facilitates transitions in the direction of health and strives for a sense of well-being (Meleis, 2010). When a patient has an encounter with a nurse, it is usually during a period of transition, thus, Meleis (2010) suggests that transition is a central tenant of the nursing discipline. The focus of nursing therapeutics is often on preventing transitions that are not ‘healthy’ and working with those who experience transitions. Examples of nursing therapeutics used during transitions include ‘assessment by the nurse’, ‘ensuring a healthy environment’, and ‘organizing resources.’ Meleis (2010) also addresses *caring* as a process within the transition framework that can facilitate a *healthy* transition; further, caring is not constrained by a beginning and end that is medically established, such as admission and discharge of patients. Nurses who view their patients’ needs as transitional process experiences – rather than fixed points in time – are more likely to support ongoing coping and continuity of care (Meleis, 2010).

Integrating the Frameworks

The main concept of interest for this study is the transition from child and adolescent to adult mental health services, thus the type of transition is ‘health-illness’ and ‘situational’ (Meleis, 2010). Depending on whether the individual undergoing transition is experiencing a single transition or multiple transitions determines their pattern, and all patterns of transition are relevant to this study. The factors that either inhibit or facilitate transition are a particular focus of this research, thus highlighting the relevance of Meleis’ transition theory (Meleis, 2010).

The Bridges transition model (2002) is used in conjunction with Meleis’ transition middle-range theory (2010) because it articulates a simple and systematic process with a

beginning, middle and end. The first phase (Ending) begins with letting go or ending something, which might lead to a sense of loss (Bridges, 2002). In preparing for this study, I learned through my literature review that young adults leaving CAMHS feel like they are losing something that can affect their emotional state. Once young adults decide to let go of their relationships with CAMHS, they start to prepare for something new, even though they do not know what to expect. This preparation is the second phase of Bridges' model (Neutral zone). Finally, evidence suggests that when young adults enter the third and final phase (New beginning), new relationships are formed, and the development of new skills are refined (Bridges, 2002). Of note, Bridges model portrays these stages as linear, despite study findings revealing their parallel, sequential, or overlapping natures. For this reason, I considered both Bridges' and Meleis' conceptualizations of transition in the planning and execution of this study. Specifically, these writings informed my thinking on the topic, the development of the interview guide (described later), and interpretation of the findings.

The Constructivist Paradigm

Paradigms are what lead researchers in epistemological and ontological ways (Guba & Lincoln, 1994). Appleton and King (1997) contend that paradigms are philosophical viewpoints that offer a frame of reference for how we see the world as either individuals or as a group. The purpose of the constructivist paradigm is to understand human experience, and the researcher does this by exploring the participants' views of, and experiences with, the phenomenon under investigation (Appleton & King, 1997). Moreover, the researcher working from the constructivist lens acknowledges that one must interpret meaning to understand it (Schwandt, 1998). As explained by Schwandt (1998) constructivism emphasizes an individual's experience as it is felt, undergone, and lived.

A relativist ontological position is assumed within the constructivist paradigm, which emphasizes the existence of multiple realities that are influenced by context, rather than a single objective and knowable reality (Mills et al., 2006). The transactional epistemology of the constructivist paradigm places importance on the relationship between the researcher and the participants in the creation of data. Due to the researcher being part of the research instead of an objective observer, their beliefs and values need to be taken into consideration by themselves and their readers (Mills et al., 2006). The researcher must acknowledge that their beliefs and values might differ from others', based on their past experiences, and work with these differing perspectives to create an understanding of the phenomenon under investigation (Appleton & King, 1997).

Constructivism aligned with my view of the world, as well as my (pre-study) understandings of the topic of interest. I was curious about my participants subjective realities and conscious that my clinical experience as a nurse working in a child and youth hospital emergency department likely affected my views. Finally, I conducted a qualitative study and constructivism often underpins this type of research.

Qualitative Research

Qualitative research is a methodology that aims to examine the perceptions, understandings, or experiences of people in relation to a specific phenomenon being examined (Pathak et al., 2013). Qualitative research is conducted to obtain an in-depth understanding of the 'how' and 'why' of phenomena - in simplest terms, it uses words and not numbers (Pathak et al., 2013). Qualitative research is often underpinned with the assumptions espoused by the constructivist paradigm because the goal is to understand lived experience from the perspective of the individual or group (Lee, 2012).

Design: Interpretive Description

Interpretive Description (ID) by Thorne (2016) was chosen for its qualitative approach, as well as being compatible with the constructivist paradigm. This design allowed for an in-depth investigation into the transition from CAMHS to AMHS for young adults. As nursing is an applied healthcare field, nurse researchers often focus on phenomena related to the experiences of human health and illness (Thorne, 2016). According to Thorne (2016), research questions posed by nurses are asked to enhance their knowledge and “set the stage for the work they will do” (p. 12). However, to advance nursing as a profession, complex, diverse, and multifaceted knowledge is required (Thorne, 2016). Attempting to follow the strict principles of methodologies such as phenomenology, grounded theory, and ethnography, for nursing research proves difficult because they are not designed for an applied health field (Thorne, 2016). ID is a qualitative research method that is defensible and credible, and well-suited to practice-driven nursing research (Thorne, 2016).

The goal of ID is to interpret a situation by finding meaning in an action, or understanding what that particular action means (Thorne, 2016). The analysis approach is inductive, meaning that findings are generated from the data collected and are not pre-defined (Thorne, 2016). When using this method, the researcher must recognize the role they play in establishing meaning within the data about the phenomenon under study. Exploring the patterns and variability within the experiences of patients transitioning from CAMHS to AMHS is well-suited to a qualitative, interpretive approach. (Thorne et al., 2004).

Sampling Methods

Convenience sampling was used for this study. This sampling approach uses the most conveniently available individuals as participants (Polit & Beck, 2017). According to Thorne

(2016), convenience sampling is “compatible with interpretive description studies” (p. 98), however, it is important to recognize the potential for a biased sample, given that people who volunteer for research most likely differ from those who do not (Polit & Beck, 2017). To offset this limitation, principles of maximum variation are often employed as this sampling technique prioritizes having participants from diverse backgrounds, which allows for varying perspectives, leading to richer data (Appleton & King, 1997; Polit & Beck, 2017). This type of sampling also permits the researcher to ensure, when appropriate, that participants reflect the population, which includes persons of different genders, socioeconomic statuses, etc., who might hold varying viewpoints on the phenomenon being studied (Polit & Beck, 2017). While I hoped to employ principles of maximum variation sampling with my convenience approach, this was not possible due to the limited number of persons who consented to participate. Sample size limitations are discussed in Chapter 5.

Inclusion and Exclusion Criteria

To be enrolled in the study, participants met the following eligibility criteria: 1. able to speak, read and understand English; 2. turning 18 years old or no more than 23 years old in the 2023 calendar year; 3. currently transitioning or have transitioned from CAMHS at CHEO to an AMHS facility within the last five years; 4. self-disclosed having a diagnosis that meets the DSM-V criteria for depression and/or anxiety disorder; and 5. able to provide informed consent. The exclusion criteria included: 1. less than 17 or greater than 23 years of age; 2. unable to recall their transition experience; 3. suffering from acute symptoms that could affect their participation in an interview; and 4. unable to provide informed consent.

Sample Size

In qualitative research there has been much debate about what is an appropriate sample

size (Polit & Beck, 2017). Thorne (2016) states that there is no set sample size for an ID study, but that it is up to the researcher to generate a proposed number of cases and defend their decision. She also indicates that time and resources are reasonable reasons for having a smaller sample size because most researchers do not have an unlimited supply of either. Finally, it is appropriate to select an anticipated range, with upper and lower limits (Thorne, 2016).

Some authors refer to data saturation as a common method of determining sample size (Hennink & Kaiser, 2022). However, as per Thorne (2016), while data saturation is often used to justify a sample size, it requires that all variation expressed by the participants be fully explored until no new information is identified. Given the subjective nature of qualitative research and the role of the investigator in the collection and analysis of data, Thorne (2016) describes data saturation as a “hollow statement” (p. 108), and not nearly as credible as an explanation of the process used by the researcher to reach confidence that their findings are developed enough to permit reporting. Instead, Thorne (2016) suggests that data saturation is better thought of as information redundancy, which occurs when something (an idea, for example) has been heard so frequently that it can be expected.

Guest and colleagues (2006), state that if the goal is to describe a phenomenon among a homogeneous group, then a sample of 12 is likely large enough for rich data collection. Therefore, I aimed for a range of 10 to 14 participants for my sample size. I also included a stopping principle, so that I could determine when, within this range, to stop data collection (Moser & Korstjens, 2017). While my initial sample size estimate was ‘at least ten’, after six interviews were completed, I noted instances of data redundancy, and thus strived to follow the guidance provided by Moser and Korstjens (2017), who suggested carrying out two or three more interviews to ensure that no new themes or ideas emerge. Unfortunately, no other potential

participants consented to be contacted and I was unable to recruit more participants due to the COVID-19 pandemic context. Refer to [Appendix C](#) to view the participant recruitment flow chart. My final sample size was six.

Setting

This study was conducted at the Children's Hospital of Eastern Ontario (CHEO). CHEO is located in Ottawa, Ontario and serves children and youth until they reach 18 years of age, unless followed by specialty services. CHEO is a tertiary centre and one of seven level 1 trauma centres in Canada for children. It serves children in Eastern Ontario, Northern Ontario, Nunavut, and the Outaouais region of Quebec (CHEO, 2021). While the recruitment was done onsite in collaboration with a gatekeeper at CHEO (described below), due to the COVID-19 pandemic the interviews were held virtually.

Transitional Age Youth Program

Within CHEO, I focused on the Transitional Age Youth Program. The focus and goal of this program is to help youth successfully transition from CAMHS to AMHS (CHEO, 2021). The program is intended to meet the needs of youth with complex mental illnesses that require a more intensive level of services to be successful in their transition out of pediatric care. The healthcare professionals working in this service recognize that navigating the transition process to adult care alone (i.e. without external support) is difficult, thus they offer preparation, planning, education, and tools to make it easier (CHEO, 2021).

In the last three years (2019-2021) approximately 340 individuals have transitioned from CAMHS at CHEO to AMHS with the support of this transitional program. Typically, 90 to 100 young adults are seen per year in this program, however during the most recent year, the program helped 140 people. A referral is needed from the young adult's clinician to be seen by this

service, and depending on when the clinician requests the referral, the individuals in the program can range from 16 to 24 years of age. The upper limit is 24 because some young adults may not have been referred by their clinician when they reached 18 years of age, were not accepted by AMHS initially (or continuously), or their wait time to get into AMHS was several years.

The program is run by a coordinator, who holds approximately three sessions with the patient. In the first session, a parent or guardian is sometimes present if consent is provided by the patient and the initial assessment is completed. At the second meeting, the session is solely between the coordinator and the patient. In this session the coordinator and the young adult discuss goals and how they will achieve them. Following this discussion, the coordinator provides the patient with a summary clinical document outlining what was said. This is a document that can be given to AMHS once they have been accepted. The coordinator will also explain some of the differences between CAMHS and AMHS that can be expected, barriers to accessing AMHS, and discuss the changes the patient is going through to learn if this is a single transition or multiple transitions. The coordinator normally helps the patient schedule their first appointment at an AMHS facility to ensure ongoing care. The third session is usually where the coordinator accompanies the young adult to their first AMHS appointment, however, due to COVID-19 and the increase in patient volume, this was not always feasible.

Key Informant and Recruitment

To gain access to the research site, I worked with a gatekeeper or, according to Thorne (2016), a “key informant” (p.99). A key informant is a member of the community who is well-suited to provide the researcher with access to the people and spaces needed to complete their study. Ultimately, Thorne (2016) suggests the use of experts who are experienced in the field of research you are working in.

The key informant for this study was the Coordinator for Transitional Mental Health Services for Youth and runs the Transitional Age Youth program that assists young adults with mental illnesses going through the transition process from CAMHS at CHEO to AMHS. He has been in the coordinator role at CHEO since 2019 and made the initial contact with the potential participants by providing them with information about the study, using an information sheet provided by me. If the young adult was interested, he requested permission to give their contact information to me for research study purposes, and I followed up with them accordingly.

Data Collection Tool

A topic guide, including probing questions, was created to (semi) structure the interviews. This was pilot tested with the transition coordinator to ensure relevance and appropriateness of the questions. The Bridges transition model (2002) in conjunction with Meleis' transition middle-range theory (2010) were used in the development of the topic guide. Specifically, drawing on the assumptions of the Bridges transition model (2002) that articulate all transitions as having a beginning, middle, and end, questions were asked in that order. Examples include: "describe your experience while in CAMHS" (beginning), "how did you feel during the transition process" (middle), and "what were your experiences with AMHS" (end).

Meleis' transition middle-range theory (2010) was also used in the development of the topic guide to ensure that I identified the type of transition experienced, as well as considered different transition patterns. For example, questions/probes pertained to the properties 'Awareness,' 'Change and Difference,' and 'Transition Time Span,' and included queries about when they found out about their transition, what changes or differences were noted between CAMHS and AMHS and whether they felt the time for transition was sufficient. Inhibitors and facilitators were asked directly, involving both 'Personal' and 'Community', such as whether

they felt prepared and ready to transition, and what support systems they had in place out in the community. The topic guide is in ([Appendix D](#)).

Data Collection

Data were collected using semi-structured interviews with open-ended questions following the topic guide described above. Semi-structured interviews were used to keep the participants and myself on track and to encourage participants to continue their train of thought, as well as for me to ask questions based on responses (Bolderston, 2012; Polit & Beck, 2017; Swift et al., 2013). The participants had the option of using the phone, Skype, Zoom or Teams which are all appropriate methods of data collection for qualitative studies (Nehls et al., 2015). Azad and colleagues (2021), for example, explored the use of phone interviews during the COVID-19 pandemic, which restricted the use of in-person interviews. They found that conducting interviews via phone call provided several advantages, including balanced power relations and anonymity, flexibility, and positive effects on emotional display and self-disclosure. For virtual interviews, Nehls and colleagues (2015), found that videoconferencing is a popular method used for interviews in qualitative research studies. Some of the benefits of videoconferencing include real time and face-to-face interviews, location of comfort in natural environment, increase in participation due to flexibility and the ability to work around multiple schedules, low or no cost to participants (no bus or parking fees) and researcher (no cost associated with cancellations), increased level of privacy for those who do not want to be seen with a researcher, developing a rapport, and ability to pick up on non-verbal cues such as voice changes, hand gestures, and eye movement (Nehls et al., 2015). Five participants chose Zoom with video and one chose a phone call.

Bolderston (2012), explains how interviews vary in length depending on the participant

and mode of interview, however, they tend to last between 60-90 minutes. The duration of my interviews ranged from 45 to 90 minutes; they were audio and video recorded using the Zoom recording device and voice recorder was used for the phone interview. Field notes were used to capture non-verbal cues when interviews were completed via video conference. Furthermore, each interview was transcribed verbatim by me. At the beginning of the interview, I explained my clinical background as a pediatric emergency nurse at CHEO for eight years and reiterated that I am a master's student conducting research and my role in the data collection process. I gave an overview of the research study and how the data were going to be used as part of the informed consent process. Once the interview was concluded each participant received a \$20 e-transfer as a thank you for participating in the study.

Distress Protocol

All participants were above the age of consent and if there was any concern regarding the ability to consent, I would have asked if they know the purpose of the study, potential risks, and benefits of choosing to participate (Mental Health Commission of Canada [MHCC], 2020). As this research involved participants with a mental illness, I ensured they felt comfortable with speaking to me prior to starting the interview. In case the participant did exhibit signs of mild to moderate distress, such as irritability or inability to concentrate, I planned to offer resources and a rescheduled interview. Resources included the Ottawa and Region Distress Centre or local emergency department. If distress was severe, such as talk of self-harm or suicidal thoughts, and I believe the participant was a risk to themselves or others, emergency services would have been called. In this event, I would have enacted the following protocol: (a) remain on the line with the participant until emergency services arrive; (b) engage in a conversation that is therapeutic and helping to facilitate any immediate needs; (c) contact an individual in their circle of care such as

a social worker to ensure next-day follow-up; (d) researcher to follow-up with a phone call the next day; and (e) contact my thesis advisor (Vandyk et al., 2018). This protocol was used effectively in a previous study by Vandyk and colleagues (2018) who also conducted interviews with individuals who had a mental health-related issue, and thus was used here. Thankfully, no participants required this.

Regardless of whether the participant became distressed or not, a 24–48-hour follow-up call was offered after the interview to answer any questions and allow for comments. Each participant agreed to receive a follow-up phone call, however, some were more than 48 hours due to the participants work/school schedule and instead were followed up in 72 hours. No concerns were brought forth by the participants during this follow-up, but some had questions which were answered by me.

Data Analysis

There are two distinct types of coding methods that can be used for qualitative research (Yi, 2018). Deductive coding involves starting the analysis with a framework (or set of codes) that is predefined, whereas, with inductive coding, one does not start with predefined ideas, but creates codes based on the raw qualitative data collected. For this study an inductive approach to data analysis was used (Yi, 2018). More specifically, conventional content analysis as described by Hsieh & Shannon (2005). As the aim of this study was to describe a phenomenon that has a dearth of research on the topic, this approach was appropriate to use (Hsieh & Shannon, 2005). This type of content analysis starts with data immersion, which is the process of listening to recordings and reading the transcripts repeatedly, which was completed. The data were then read word for word to find key ideas within the participants' stories. After transcribing the data, my thesis advisor and I made notes separately based on our first impressions of the data and began to

label ideas with preliminary codes. These codes were then sorted into categories or clusters based on how they related to each other (Hsieh & Shannon, 2005). As per Hsieh & Shannon (2005), it is ideal to have between 10 and 15 clusters to keep them broad enough for sorting through a larger number of codes. This was done by printing off the transcripts and cutting out quotes and arranging them on a table. They were then separated into 13 envelopes which were my clusters based on their commonalities. These clusters were then organized into a smaller number of overarching categories. Next, definitions were developed for the categories, subcategories, and codes (Hsieh & Shannon, 2005). To illustrate the findings, I embedded participant quotes within the descriptions of these categories. To visualize this process in a flow chart, see [Appendix E](#).

As one of my objectives for this study was to identify facilitators, inhibitors, and gaps in care, these were sought after during the analysis phase. They were classified as such because a facilitator is something that makes a process easier, and an inhibitor is something that slows down or prevents a process (Collins Dictionary, 2023). Further, these terms (facilitator and inhibitor) are in keeping with Meleis' middle range transition theory who uses these terms within *transition conditions* (2010).

Rigor

Five rigor criteria were used to enhance the trustworthiness of the study, which included 'credibility', 'dependability', 'confirmability', 'transferability' and 'authenticity' (Appleton & King, 1997; Polit & Beck, 2017). For *credibility*, I ensured adequate time to collect and analyze data, as well as engaged in rechecking data with participants if any misunderstanding by me occurred (Polit & Beck, 2017). This was done by clarifying statements and repeating information when answers were misheard. *Dependability* refers to the ability to repeat the study with

comparable results. This was enhanced by keeping an audit trail, which is a systematic collection of documents and materials, including an example of the coding process and the rationale for what codes were clustered together to create categories. *Confirmability* is a criterion that asserts that the information presented in the findings is from the participants and not from my biases. To enhance confirmability, I used a reflective journal to document my biases, thoughts, and assumptions after the interviews were completed and relayed this information to my thesis committee as the study progressed. This ensured that the data provided were the actual interpretation and not data created by me. *Transferability* is the fourth criterion and refers to the ability to use the data collected in various settings, which was done by using thick description (Polit & Beck, 2017). The fifth criterion is *authenticity* and characteristic of the constructivist paradigm (Appleton & King, 1997; Polit & Beck, 2017). Authenticity is reached when the reader has a rounded understanding of the senses portrayed by the participant such as feelings or mood, as well as the context of the participant's lives. To enhance authenticity, I aimed to portray my findings in a way that permitted my readers to understand the experiences of the participants by using direct quotes from the raw data. Using these quotes should also give the reader a sense of the participants mood and perspectives (Polit & Beck, 2017).

Ethics

For this research study, ethical approval was obtained from the Children's Hospital of Eastern Ontario Research Ethics Board and an Administrative review from the University of Ottawa Research Ethics Board. As per the guidelines set out by the CHEO Research Ethics Board (2016) and the University of Ottawa Office of Research Ethics and Integrity (2019) the following items were included in the recruitment documents: name of primary researcher, contact information including an email address of the institution, research project topic, and

synopsis of participation details. The inclusion criteria were discussed with each participant before obtaining informed consent ([Appendix F](#)). The consent form was created using the consent form template link on the Children's Hospital of Eastern Ontario Research Institute (2016) website and was adapted accordingly to fit my research needs ([Appendix G](#)).

Information Protection

The contact information sent to me by the transition coordinator was encrypted and password protected. Potential participants were contacted by me via email and/or text messaging for those who preferred this method. Once I received a response from the participants, a date and time for a phone call was confirmed to discuss the research activities and what is expected at the participation level which included but was not limited to the purpose and objectives of the study, anticipated duration, potential risks associated with participation and the choice to withdraw from the study at any time. If the participants agreed to the research study and met the eligibility criteria, I inquired about their communication method of choice (i.e., phone, videoconference preference) and identified a date and time that worked for them. Once a date and time had been set between myself and the participant, I ensured that I had a signed copy of the consent form before starting the interview which was sent in the initial email or text by me. One individual was unable to provide an electronic consent form due to technical issues but gave verbal consent before commencing the interview.

At the time of the interview, I ensured the participants wished to continue with participation and again stated that they could withdraw at any time. To ensure security and confidentiality only videoconferencing programs that offer Advanced Encryption Standard such as Zoom, Teams and Skype were used. The participants names were not used, instead a letter and number identification code were used to maintain anonymity. This coding process is a measure

for safeguarding information. I also used password protection for electronically recorded information and did not use any identifiers either direct or indirect after data collection (CHEO Research Ethics Board, 2016; Polit & Beck, 2017; University of Ottawa Office of Ethics and Integrity, 2019). As per the CHEO Research Ethics Board (2016) guidelines, all information will remain secure and held for a maximum of 10 years post completion of the research.

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Chapter 4: Findings

In this chapter, I present the findings of my study, which explored the participants' transitions from CAMHS to AMHS. First, I describe their characteristics including age, pronouns, ethnicity, level of education, employment, living arrangements, age of onset of mental illness, age of diagnosis by a healthcare professional, and self-reported diagnoses. Next, I explain the process of transition from CAMHS to AMHS as experienced by the participants, including the inhibitors and facilitators of their transition. Finally, recommendations to improve transition, as reported by the participants, are described.

Participant Characteristics

The ages of the six participants ranged from 17 to 19 years old. For gender, three participants identified as she/her and one each as he/him, they/them, and she/they. One participant self-identified as a man, with the remaining five self-identifying as women. All individuals described their race as 'white'. Two participants reported currently being in high school, two completed high school, one was in adult education, and one was in their first year of university. Employment status also varied, with two participants unemployed and four working part-time. In terms of living arrangements, four reported living with parents and/or other relatives, one was living with their best friend and with parents, and one resided with their boyfriend but was also with their parents at times. The age of onset of mental illnesses ranged from seven to 15 years old, with two participants stating that their symptoms began when they were seven to eight, and the rest beginning in their early to mid-teens. The age of diagnosis by a healthcare professional for three participants was between the ages of 13 to 14, one was 16, and two were 17 years old. There were 11 self-reported diagnoses, with two participants reporting two diagnoses, one having three, two having four, and one having five different psychiatric

diagnoses. The two most common mental illnesses reported by participants were depression and generalized anxiety, reported by 4 and 3 participants respectively ([Table 1](#)).

Participants' Experiences with Transition to AMHS

The experiences of the participants with their transitions from CAMHS to AMHS are portrayed using five categories: 1. 'Expectations', 2. 'Transition should be a Gradual process and not an Abrupt Change', 3. 'Factors Influencing Transition', 4. 'Living the Transition', and 5. 'Improving the Transition'. When appropriate, subcategories were also used, which include: 'Loss of Services', 'Cooccurring Transitions', 'Facilitators', 'Inhibitors', 'Differences in Care Philosophies', 'Transition is a Vulnerable Time', 'Support Systems', and 'Family Involvement' ([Figure 1](#)). Finally, each category and subcategory are explained, and participant quotes are embedded to substantiate the narrative results.

Expectations

The participants included in this study spoke about their expectations regarding both their transition to AMHS and the adult services themselves. Three participants reported feeling comfortable with their shift in care because they expected the services would be equivalent: "I felt I wasn't nervous about it [transitioning] because I felt it [AMHS] would be the same as child and adolescent services" (P02), or they would receive a lot of support: "It's not that scary, for me, because I know there's going to be a lot of support" (P05). One participant received formal transition planning once they reached 17 years of age and was made aware of what to expect: "So I feel okay with it. I think it's going to be okay" (P06).

Three participants felt nervous about their transition and uncertain about what to expect moving forward: "The fact that I didn't know what to expect, the fact that I didn't know that I'd have to transition at all I thought like you know, hey, I'll just be with the same people forever"

(P03). One participant reported feeling “misled” (P04) regarding what would be expected of them upon entering AMHS: “I wasn't expecting that much independence in the adult system like I wasn't, I guess I wasn't fully prepared for that responsibility to be independent in the adult mental health system” (P04). Another reported not knowing what to expect of the AMHS workers: “I found like, just people in the general world have a hard time understanding like my anxiety and stuff like that. So, I was worried that transitioning some of the professionals would have a hard time understanding as well” (P01). An overwhelming concern for most participants was that they did not know what to expect once they turned 18: “And it's not that like I didn't know I had to transition, it was more that I didn't know to what extent, I just kind of assumed that she [CAMHS worker] would be there all the time” (P06). Participants provided suggestions for how to manage these expectations prior to transitioning, which can be found at the end of this chapter.

Transition Should be a Gradual Process and not an abrupt Change.

Three participants described their transition as “very sudden” (P01), “abrupt” (P03), and “quick” (P04), which caused them to feel ill prepared. It appears some youth transitioning to AMHS received no advanced warning:

It was right as I was turning 18 in September... so it was very soon, sudden, and like quick (P04);

It was in September of last year, it was just before I turned 18 and it was my last appointment with [psychiatrist], and I told her that I didn't think I was ready and that I needed somebody there to support me and then she put a referral in to [transition coordinator] (P01);

It was during COVID. So, I want to say I was like, almost 18. I was like, a handful of months away from being 18 (P03).

As illustrated by the quotes above, instead of having time to process their shift in care, participants typically found out about their transition to adult services at their last CAMHS visit. When this occurred, it was described as traumatizing and ineffective:

I was seeing [psychiatrist] a lot and then just didn't really know what to do without [psychiatrist] at that point, because she was so helpful for me. So, I feel like it probably would have been beneficial for me to know come like May or June that year, that way I could have started to, you know, disconnect from her a little bit because I definitely had quite a connection to her and reliance on seeing her a lot (P01).

This last-minute notice of transitioning left participants feeling abandoned with no help from their trusted providers: “And then I figured out that I would have to transition. I wouldn't have any of the eating disorder team or anything like that to help me with medications” (P06). Upon leaving CAMHS, the loss of this trusting relationship had a notable impact on them.

To insulate patients from an abrupt loss of support, participants explained how the transition to AMHS should be gradual and smooth:

I feel like the transition should be gradual rather than just by the way we are going to refer you to adult mental health services, and you are no longer a youth anymore, so it's up to you. I feel like it would be much better if it's a very slow gradual transition (P03).

One participant specifically spoke to how their services and care ended abruptly once they reached 18 years of age: “--I was in the middle of a DBT [Dialectical Behavior Therapy] program. And it was like, just ended up stopping” (P04). And another participant felt that they had to be ready to transition even if they were not: “I feel like I kind of made myself feel ready

because all of a sudden, it happened really quick and I kind of had to be ready, but now thinking back I don't think I was ready" (P01).

Although not a common experience, one participant received transition planning prior to turning 18 years old, which permitted them time to accept and prepare for the upcoming changes: "I mean it was always there, because I was already 16 turning 17, so I was kind of glad that I had that extra time" (P06). While two others did not receive transition planning, they reported feeling ready to transition because they had someone available to help them through the transition: "I'm ready. Personally, I think I'm ready to change" (P05) and

I feel like it was an appropriate time because they weren't really sure how long it would take before I got an appointment with adult services. So, they didn't want me to be in the middle of my program and be telling me, oh, you've also got, you know, the adult program. So, I feel like it was good timing (P02).

For those who had appropriate preparation, their shift in care didn't feel abrupt, sudden, or quick, but rather they felt ready for a change in services. These participants who felt ready for their shift in care had support workers helping them during the transition process.

Co-occurring Transitions

Three participants spoke about how the transition to AMHS coincided with other life transitions. They described transitions related to adulthood, school, work, relationships, and living arrangements, among others:

So, like, trying to find a new doctor because pediatricians won't see you if you're an adult, then also transitioning from school, so having to find new supports at my school now,

and then also trying to find mental health supports from the adult systems. So that was like three separate transitions going on, literally at the exact same time (P03).

Participants described how these co-occurring transitions can be challenging for their mental health: “For my specific situation, I took an excessive amount of energy to do well for school, and that ended up affecting my mental health” (P05). They also spoke about how their mental health could affect their other life transitions:

That was a really rough year for me. That year I graduated from high school, which was stressful, my dog passed away, and I was seeing [psychiatrist] a lot and then just didn't really know what to do without her-- So it was a very, very stressful year for me (P01).

Participants reported that while these co-occurring transitions were anticipated as developmental stages in their life, they did not realize how many transitions would happen simultaneously, especially the change in support persons and services.

Loss of Support

Most participants (n=5) spoke to difficulties associated with transitioning, such as lost support from various services (community and school social workers, psychologist, pediatrician, and CAMHS):

Because I graduated half a year early so I didn't have access to my support, my social workers anymore. And then I didn't have a doctor anymore. And then I didn't have access to mental health services because I was on a waitlist. So, I was like, where am I supposed to get help now? (P03).

While two of these participants lost several support services simultaneously, the rest lost one or two at a time, such as community social workers and psychologists: “I think I've gone through at

least 10 different social workers, and then three, or two or three psychologists” (P02), or social workers from school and CAMHS help lines: “Social workers through school—And also like, the Kids Help Phone, most of those they really helped me a lot. And I no longer qualify for either” (P03). Most stories revealed that services ceased because of funding and age, however, participants sometimes lost services for other reasons:

And she set me up with a counselor through open doors that was coming to the school I actually really liked that counselor. And they were really, really great, talked me through a lot of stuff gave me a lot of really good coping mechanisms. And then they ended up moving to a different district (P01).

Two participants reported difficulties associated with losing all CAMHS services at once:

“You’re an adult, now you’re cut off from the Children’s Services, and you have to wait forever to get into the adult ones” (P03), and “I was upset because I didn’t have any support [CAMHS] going on anymore. It was kind of just I had to wait, but it didn’t sound promising either” (P04).

From the participants’ stories, co-occurring transitions and loss of one or multiple support services affected their mental wellness.

Factors Influencing Transition

There were several factors that influenced the process of transition from child/adolescent to adult services, which either facilitated or inhibited a healthy one.

Facilitators

Participants identified three main facilitators to transition including referrals by healthcare professionals, social workers, and support from transition coordinators, which are discussed below. Additional facilitators are listed in [Table 2](#).

Referrals by Healthcare Professionals. Participants found it helpful when their existing CAMHS referred them directly to AMHS: “I mean my pediatrician putting in the referral was helpful, because without that, I wouldn’t have any services. Like, without that I wouldn’t have even had the official assessment done” (P03). Referrals were also made to specific groups, when appropriate: “So, he’s made a referral for me to join [transition group], but apparently, wait times are like really long’ And so that would help just to have other kids I guess who are going through the same thing” (P06), and “I know that he did put a referral in for me to get into group sessions” (P01).

One participant, who was in a program in CAMHS, was referred to a comparable program in AMHS partway through their care, which helped maintain continuity:

Midway through one of my programs, because the program was mainly focused towards child and adolescent services. And I applied when I was 17. And then I got in when I was 18, because my birthday was just there. So, they accepted me. And then they didn’t want me to stop treatment afterwards. So, they referred me into adult services (P02).

Supportive People. While referrals were helpful, participants stressed the importance of being helped by a person, often their former and current social workers: “Personally, I’ve had a really good experience with school, specifically like talking about social workers. I really had good experiences; I always had the help I needed” (P05) and “I found that the majority of my support came from social workers through schools” (P03). Social workers were also from the community or other locations “The social worker that I had, that I was working with. I got really lucky. And she was like an amazing person. So that was good” (P04) and “Yeah. I feel supported. I feel like I still have someone I can talk to about the problems and or keep me on track until I get into adult services” (P02).

For participants who had access to a dedicated transition coordinator, they explained how this person helped not only with referrals, but also assisted with their mental health needs: “Definitely the support from [transition coordinator] because he was really great to talk to, he related to me really well” (P01), “But I mean, I was very, I’m still very grateful that [transition coordinator] was there to help with me, and like, you know, really, like, help me look through it” (P04), and “My mom had been asking questions like what happens when she’s turning 18? And then they’re like, Oh, well, this and then she [physician] referred me to [transition coordinator], which explained a little bit more” (P06).

One participant reported that while their experience with a transition coordinator was positive, the outcome was not as anticipated: “[Transition Coordinator] did do a good job. It’s just that unfortunately, the main service that I was supposed to receive to help the transition, I did not have the chance to” (P03). The facilitators above were common across the participants.

Inhibitors

Three main inhibitors to transition were reported most often by participants throughout the interviews, which included the COVID-19 pandemic, wait times, fragmented care, and therapeutic relationships. Additional inhibitors are listed in ([Table 3](#)).

COVID-19 pandemic. All participants were affected by restrictions related to the pandemic at some point in their transition, and most of the participants (n=4) felt this inhibited their experience. The specific challenges associated with the COVID-19 pandemic included:

- Difficulty navigating services: “I feel like it’s tough with COVID, too, because now there’s this extra layer, like you have to not only navigate services yourself, but try to navigate all of your own services yourself” (P03).

- Not being able to visit AMHS ahead of time: “No, I think they’re, they used to allow you to go look at some of the services. But I’m wondering, because of COVID, if they don’t allow that anymore” (P01), and “Maybe I would really like to have like, just to go to the place and just see where it would happen and maybe meet the people in person, we would probably do that without having COVID” (P05).
- Not having access to in-person meetings or groups: “I think I would have liked it [transition group] better in person. Just because I’m not as good of an online as I am like in person” (P04), “I think because we can’t meet in person, it’s a lot more difficult to understand. I’m still not entirely sure if he wrote me up or signed me up for that group” (P05).

Overall, participants felt that virtual options for support during their transition to AMHS were not ideal because of the complexities of mental health and the importance of body language when meeting with mental healthcare professionals, which may go unnoticed when meeting online:

It’s a bit more complicated than actually talking with somebody and you know, people get annoyed on the phone at you. But if you’re in person, and they can see through your physical body language that you’re getting really stressed out. They’re a bit easier to talk to because they’ll let you take your time. But on the phone, it’s like okay, hurry up. I have stuff to do (P03).

While transitioning to AMHS through a pandemic was not the focus of this study, it is important to recognize the role this played in their experiences. Besides the pandemic, two additional inhibitors, ‘Wait Times and ‘Fragmented Care,’ were mentioned by most participants.

Wait Times. Most participants (n=5) experienced long wait times between leaving CAMHS and initiation of AMHS. This delay in access prompted some of them to seek care elsewhere: “By that point I had already needed these services for such a long time that I was trying to find other services” (P03) or to enroll in programs that did not meet their needs: “The programs that we ended up looking at to transition, it was like I had to settle. It wasn’t like I could find one that really worked for me or that was really going to meet what I needed” (P04). While this was challenging for most participants, two were not surprised by it: “And I’m not surprised by the long wait that I have to get into adult services, because that’s just how it is, there is always a long wait with mental health services” (P02) and “I’d say probably about four months now [waiting period]. Which isn’t very long compared to other things that I’ve heard” (P01).

Of note, wait times occurred in several contexts, such as waiting for intake appointments: “He had talked to me a little bit about wait times—Because he said he knows that the transition can be a long haul, and it can be stressful for people” (P01), or subsequent consults: “It was difficult because I found, I felt like I was in the dark a lot of times, a lot more wait. I would go close to two months, waiting just for a callback after an assessment” (P04). While a waiting period was expected after being discharged from CAMHS, participants reported having limited options during this time.

Fragmented Care. Participants reported receiving fragmented care through AMHS and confusion about next steps:

Like I’m still not quite sure what’s going on. I’ve been in adult services for like a year and a half, almost two—it feels like a handoff you know, like you’re just given from one [service] to another—So there’s no continuity—It feels like you’re hitting a wall (P03).

Even after the initial consultation with AMHS, when selecting what programs would be of interest to them, it was unclear whether they were accepted or not:

I explained what was my situation and what I'm looking for in a role that could help me, and they [AMHS] just suggested this program and said, okay we're going to look into it or we're going to sign you up. And I think that's all I've been told. Yea, so I don't know when it's going to happen. I don't know when it starts or anything like that (P05).

Sometimes, participants had difficulty qualifying for services, despite being accepted into similar programs in the pediatric context: "So far it was constantly not being able to get into groups...So I currently don't qualify for any services because I wasn't able to do CAJAR [French transition planning group]" (P03). In the stories mentioned above, participants used terms such as groups, services, and programs interchangeably, but jointly referred to the programs offered to them during their transition to AMHS:

At first, I was like, okay, maybe this [transitioning] will be a bit smoother. But it ended up being really bad and really rough, because they set it up to make it look like there's a lot of support with the transition, but then after I had the four weeks or the four calls with [transition coordinator] it was nothing. And it didn't feel like a transition, it felt more like we're going to give you like a bit of hope. And then like, absolutely no resources. That was just how I felt like I felt very lost kind of very confused (P04).

Therapeutic relationships. Fragmented care compromised therapeutic relationships and, often, participants described feeling discouraged because of their experiences with AMHS:

The assessment that I had done where I got my diagnosis with a clinic. I was supposed to have a second appointment with them. They never reached back out to me. I reached

back out to them afterwards and nothing happened. They never called me again, they never followed up on my diagnosis, they never followed up on my medication they prescribed me. They never even took the time to tell me about the medication, they never asked if I felt like it would be the right medication (P04).

Ultimately, this participant felt abandoned by their healthcare professionals and spoke to the difficulties accessing AMHS programs due to substance use:

They [AMHS] said I was using too much substances [marijuana and cocaine] and that I was using to the point where I'd qualify for a substance use program and then the substance use program told me that I wasn't using enough to be in there (P04).

Not being able to form a therapeutic bond in response to fragmented care with healthcare professionals was problematic, and when a professional bond was previously formed, participants had a difficult time re-establishing this relationship with someone new:

I think I've gone through at least 10 different social workers and two or three psychologists... As soon as I would get to the point of a bond, you know, professional bond with the healthcare provider, I was basically turned over to someone different so I couldn't really get proper treatment because of that (P02).

And then after that [first counselor], I had a really hard time connecting with any counselor/therapist after that. I just found none of the rest of them really connected as well as the first one did (P01).

Living the Transition

Participants had various feelings about their transition experiences and used descriptive terms such as: "alone" and "lost" (P04), "anxious" and "nervous" (P01), "worried" (P06) "left

behind” and “terrified” (P03). For instance, one participant stated: “Terrified, because I didn’t think it was a big transition and so I was like, oh, you have to transition to adult services. So, I was like, oh, wait, what, and yea just terrifying” (P03). Another participant expressed feelings of confusion over what the transition meant for them: “I felt very lost and like I was waiting for somebody to tell me what to do” (P04). Ultimately, participants were concerned about losing access to services only offered by CAMHS: “I felt left behind and lost. I just felt like my support system had been completely taken away from me” (P03), and “I felt very, like absolutely stranded and didn’t know how to move forward” (P04). Below are four sub-categories that represent the different aspects of living the transition: ‘Differences in Care Philosophies’, ‘Transition is a Vulnerable Time’, ‘Support Systems’ and ‘Family Involvement’.

Differences in Care Philosophies

Most participants (n=4) spoke about the differences in care philosophies between the two services, with CAMHS described as child-centered and AMHS as adult-oriented:

The child and youth services were very warm and like friendly, and like colorful and just very open. Whereas the adult ones were very like, kind of like cold, you know, you’re on your own, you’re an adult, you can deal with this on your own (P03).

Some participants (n=3) viewed adult services as requiring more independence and self-management of their illness: “Best way to put it, is it’s a lot less coddly [than CAMHS], is the best way to put it is there—its more you are independent with it” (P02). Participants were divided about whether or not they preferred this focus on the patient (rather than the parent-child dyad): “I did find in child services, a lot of the time I felt like I wasn’t listened to, because I was seen as a child and not as an adult” (P01); “You’re an adult now, kind of feeling that I got from them [AMHS]” (P02); and

Yeah, I did find I did not feel involved [in the decision-making process] at all. In more so in the child services, definitely in the adult one too but I felt he [AMHS worker] was talking to me more than my mom (P04).

In contrast, two participants preferred the CAMHS approach: “Adult services. It was more like, cold cut—it felt almost robotic in a way” (P04) and “I prefer the child workers because they’re much more patient, understanding, and compassionate. Whereas my experience with her [AMHS worker] was more like, this is a business transaction” (P03). Some participants appreciated aspects of both CAMHS and AMHS, such as the friendly environment in CAMHS and the autonomy in AMHS. This was seen in the quote above by P04 who did not feel involved in the decision making while in CAMHS, despite feeling more comfortable in the CAMHS environment.

Transition is a Vulnerable Time

Most participants (n=4) spoke about the physical and mental symptoms they experienced after being discharged from CAMHS: “I was in a fairly decent spot mentally after I had left child services. But then, things fell out with [my job], and I ended up back in not so great spot again” (P01). They explained how they were stable in terms of their mental health upon leaving CAMHS, but because of long wait times for intake with AMHS, they experienced exacerbation of their illnesses: “I felt very, like absolutely stranded and didn’t know how to move forward and I had prolonged stress, I was self-medicating again, and having manic spurts” (P04). As articulated in the previous and next quotes, self-medication was common during this period of waiting:

I had tried a variety of different medications, none worked for me that well and the last one I was on, I was only receiving the side effects and not the actual intended effects. So, I stopped it and I was kind of out of options is the best way to put it (P02).

Unfortunately, during the delays in care, one participant experienced a mental health crisis, yet had no access to tailored mental healthcare:

I was struggling really bad with like suicidal ideation and thoughts. And I could not necessarily guarantee that I would or wouldn't do anything—And so I needed support like now, which sucks because I needed support at that moment. And I still had to wait eight months...(P03).

Support Systems

Half of the participants (n=3) expressed having support systems in place during their transition, such as programs embedded within their schools, dedicated youth mental health programs, or tailored care for specific diagnoses (e.g., eating disorder programs). Participants felt that the support offered through these networks was beneficial to them:

And if you want, we also have therapists that come once or twice a week, depending on what the person needs, like I have someone that comes (to school) once every week. But now I'm at the point where I see her once every two weeks (P05).

I chose once every second week, just to make sure I was on track until I get accepted into adult service and until the adult services starts (P02).

But I've had pretty good support in the outpatient. I have a social worker that I see every week. And that's helping a little bit and she's able to kind of like communicate for us to the team... it helps to have someone who's going to do that for us (P06).

The participants who had support systems in place stated that these supports helped them smoothly navigate the transition process and made them feel more prepared for their upcoming shifts in care. Unfortunately, participants also explained how these supports are limited in quantity and function; at times, they did not meet their mental health needs. For those who did not have support systems in place, their experiences of navigating the transition processes were vastly different:

I feel like if you're still in Child Services, but then 16, you meet with a worker [in AMHS], and you're like, okay, this is what I would expect and have that slow transition. By the time that you reach an adult, which is a big transition in itself. You have somebody who you already first of all know and what to expect, and you have somebody to help you navigate the system you're not at square one floundering about to try and find things again (P03).

A pointed example of this, was how there is only one adult helpline in a setting that offers multiple helplines for youth:

And also, there like no helpline for adults, other than the crisis centre. And if you're like me and you need somebody to talk to, but you're not in an ultimate crisis, you're not going to call your like, well I'm not about to commit suicide, so why would I waste their time (P03).

Similarly, restrictions on the number of visits permitted within publicly available mental health services was also problematic when care was needed prior to acceptance into AMHS: "But there was, I would say, lack of funding is best way to put it because I was bounced around a lot with healthcare providers, because they couldn't spend enough time with me"

(P02). This was difficult because “I can't create a connection with the person to actually tackle my harder issues”. (P02).

Family Involvement

Participants had varying perspectives on family involvement, with some stating that family support is needed during and after transitioning:

I feel like having family support, at least for the first little bit, and by a little bit, I don't mean like few weeks or months. I mean, like for the first few years, because it's a big transition. It would help make the navigating easier instead of just throwing me in telling me to figure it out by myself without a handbook (P03).

While no participant stated they did not want their family involved, a few of them spoke to the importance of being able to: “choose how much involvement my parents have” (P04):

A lot of times they would ask me if I wanted to bring my family, I guess into the mix, I don't know the word, but they would come to me first before even sending like a message to my family or something like that. And if I didn't want to, they would respect that (P05).

Sometimes, family involvement was welcome for certain interventions, but not others. For example, one participant explained: “Unless I wanted my parents there, unless I was comfortable with them being there, all of them [sessions] were just me and the healthcare provider” (P02).

Improving the Transition

Participants provided many suggestions about how to improve both the preparation for, and process of, transition into AMHS. Below, I provide a table with the recommendations, as well as quotes to substantiate them.

Recommendation	Quote(s)
Prior to discharge from CAMHS	
Obtain a list of their diagnoses, a summary of their care, and a plan with transition goals.	“There was no summary of like diagnosis, or what I need to work on, or do in the meantime. It’s more like if you need anything urgent call 911. Otherwise, just wait” (P03)
Facilitate a smoother process	
Meet with key providers ahead of transition	I feel like what would help me actually would probably meet with the person who I would be meeting with, so the person who would be running these groups if I met with them beforehand, just talking to them what to expect and all that (P02),
Have a specific person/team assigned to help	“But a worker [specifically to help with transition] would have been great. Because, like, even if they could help me practice on like, you know, this is what you have to do” (P03)
Receive more information about what to expect	“I feel like, if somebody, if somebody told me how it was actually going to be transitioning, then I wouldn’t, I feel like I wouldn’t be as upset” (P04) So, if you get to kind of have an idea of, you know, the type of people you’re going to be meeting and working with in the adult care system. It’s just kind of nicer to know what you’re expected, like to know what to expect sooner than later (P04)
Joint working between services	“I think that [joint working] sounds awesome” (P01).

Chapter 5: Discussion

In this chapter, I present a summary of the findings, a discussion of three key considerations, implications for nursing policy, practice, education, and research, strengths and limitations, and conclusions. The discussion points are: 1. Relating the Findings to the Theoretical Framework, 2. Inappropriately Managed Expectations, and 3. Factors Influencing Transition.

Summary of Findings

The purpose of this study was to explore young adults' transition from CAMHS to AMHS by describing their experiences and identifying facilitators, inhibitors, and gaps in care that affect their transitions. This qualitative study was guided by Thorne's (2016) Interpretive Description approach. Through convenience sampling I recruited six participants who were aged 17 to 19 years. Using conventional content analysis, I identified five categories and eight subcategories that helped to articulate the participants' stories: 1. Expectations, 2. Transition Should be a Gradual Process and not an Abrupt Change (Loss of Services and Co-occurring Transitions), 3. Factors influencing transition (Facilitators and Inhibitors), 4. Living the Transition (Differences in Care Philosophies, Transition is a Vulnerable Time, Support Systems, and Family Involvement), and 5. Improving the Transition.

Discussion Point One: Relating the Findings to the Theoretical Framework.

Meleis' (2010) middle-range transition theory contributed to the theoretical underpinnings of this study because it premises that transition is a process and not a change. The findings of my study are reflective of this view, such that participants spoke to elements of the theory through their descriptions of their experiences. Specifically, participants' stories of their transitions to AMHS correspond to Meleis' writings on the nature of transition, transition conditions, and patterns of response. Each of these is elaborated below.

Nature of Transition

The nature of transition includes the type, patterns, and properties of transition (Meleis, 2010). This element of Meleis' theory was evident within the *Transition Should be a Gradual Process and not an Abrupt Change* category, as well as the *Co-occurring Transitions* subcategory. The *types* of transition, as per the findings of this study, were *developmental* and *situational*. Specifically, youth were transitioning from adolescence into adulthood (i.e., developmental transition) and they were moving from one service to another (i.e., situational transition). While these were the primary types of transition, some participants were also transitioning into and out of employment, moving out on their own, graduating high school, and forming new relationships. Therefore, these transitions were *multiple, simultaneous*, and often *related*, which describe their *patterns*, according to Meleis (2010).

The five *Properties* of transition were also reflected in the participants' experiences. For example, some participants had *awareness* about their transition, but others did not, which affected their *engagement* in the transition process, such that those who were more aware were more engaged. The third property, *change and difference* were seen throughout the findings with some participants feeling comfortable about their shift in care, and others describing discomfort. The property *time span* was referenced by most participants when they explained that their transition was not fluid and gradual, but abrupt. The *critical points and events* included aspects of participants moving into adulthood, and most graduating high school or finding employment (Meleis, 2010).

Transition Conditions: Facilitators and Inhibitors

Facilitators and Inhibitors encompass *personal, community, and societal* conditions that may be facilitators or inhibitors to a healthy transition (Meleis, 2010). In terms of *Personal* conditions, participants stated they did not know the *meaning* of the transition or what to expect during it. This caused some to feel anxious or nervous, feelings that often continued during the transition process. Furthermore, participants articulated how being able to anticipate and prepare for their transition would be beneficial, however, most were not afforded this *preparation and knowledge* about what to expect. Finally, while *Cultural beliefs and Attitudes* were not explicitly explored, there is stigma around mental illness, and it is reasonable that beliefs and attitudes influenced the ways in which participants experienced both their mental illness and their care. (Meleis, 2010).

Community conditions were mentioned by participants who stated that while in CAMHS they felt they had an abundance of community resources, but as adults, they only knew of one service. This left them not knowing where to go for help. Importantly, participants described a loss of support from trusted healthcare professionals, school, and mental health hotlines – their ‘community’. Although *Societal* conditions were not elaborated upon, persons with mental illnesses are among the more oppressed, marginalized, and stigmatized populations in society, which can affect their experiences with care transitions (Benbow, 2009; Meleis, 2010).

Patterns of Response

Meleis (2010) stated that patterns of response, including *process* indicators and *outcome* indicators, are characteristics of healthy transitions. The principles underpinning the *process* indicators, *feeling connected, interacting, location and being situated, and confidence and coping* were discussed; however, the participants’ stories often reflected the absence of these. For example, participants did not feel connected with CAMHS post-transition, which led them to

offer suggestions about how to facilitate an ongoing connection with CAMHS during transition to AMHS to maintain their trusting relationships while developing new ones. Furthermore, instead of developing *confidence and coping*, participants stated sometimes utilizing negative coping strategies, such as self-medicating and substance use, during their transition period. Finally, *interacting* was also evident when participants explained that they wanted their family members involved in their transition *if* they could decide what their involvement looked like.

There are two *Outcome Indicators: mastery and fluid integrative identities*. As per Meleis (2010), when individuals have mastered the behaviors and skills necessary to manage their new environment or situation, they experience a healthy transition. *Fluid integrative identities* means forming a new identity after a transition (Meleis, 2010). Unfortunately, the experiences of participants in my study were not reflective of mastery nor fluid integrative identities, which is not surprising given the uncertainty and unease surrounding transition to AMHS described by the participants. It is possible, however, that a longitudinal study exploring transition prospectively would better capture these outcome indicators, and future researchers interested in this topic should consider such an approach (Calman et al., 2013).

Discussion Point Two: Managing Expectations

Participants in this study reported not knowing what to expect when they transitioned from CAMHS to AMHS or what would be expected of them. Assumptions were made by participants about what AMHS would be like, such as assuming they would be the same as CAMHS or being afraid that they would not be. Not knowing what to expect left some participants feeling worried or afraid about their upcoming transition, despite being told by CAMHS that it would be 'smooth'. Once the transition process started, it was often turbulent

with many challenges and inhibitors to overcome. This left participants feeling let down and abandoned when their experiences were different than expected.

Price and colleagues (2019) completed a systematic review with articles focusing on the transition experience from the perspective of young adults aged 14 to 25 years with a diagnosis of ADHD, before, during, and/or after transition to AMHS. They found that one major struggle associated with healthcare transitions is a lack of information about what can be expected during the transition process from one service to another (Price et al., 2019). Not having appropriate information resulted in their participants feeling ill-prepared for their transitions and let down. Furthermore, they expected that AMHS would have a fulsome understanding of their mental health history upon acceptance into care, which was rarely the case (Price et al., 2019).

Ensuring young adults have access to information, a thorough understanding about what is expected when transitioning out of CAMHS and/or into AMHS, as well as the differences between services is important (Mulvale et al., 2015). For example, in my study, participants did not know what to expect when it came to their ongoing care or whether they were accepted into AMHS. Butterworth and colleagues (2016), who looked at the experiences of 12 ‘care-leavers’ aged 18 to 22 years transitioning from CAMHS to AMHS in the United Kingdom, reported similar experiences. They found that once transition started, there was little to no communication between the mental health services and the young adults causing limited knowledge about what to expect in terms of their future care and uncertainties about acceptance into AMHS. Furthermore, Mulvale and colleagues (2015) found that upon acceptance into AMHS, the expectation of autonomy and independence, which is different from expectations in CAMHS, resulted in young adults dropping out of services post transfer of care. Given the importance of

ongoing care for people with mental illness, this point of vulnerability needs to be recognized and addressed, so that patients do not disengage from needed services.

Expectations are also different for healthcare professionals working in CAMHS compared to those working in AMHS (Manteuffel et al., 2008). AMHS healthcare professionals put more responsibility on the young adult to take charge of their care than in CAMHS, with less emphasis placed on family involvement. Once a young adult transitions into adult services, they are expected to function in their new adult roles with competence and without intensive support or guidance (Manteuffel et al., 2008). Healthcare professionals working in CAMHS are well-positioned to educate and inform patients about what to expect when switching care providers. Unfortunately, fragmented, and siloed care are realities of many health systems (Butterworth et al., 2016; Price et al., 2019). Strengthening information sharing between CAMHS and AMHS or offering opportunities for providers to better understand the different care contexts, might allow for clearer expectation setting with patients.

Importantly, as evidenced by my findings, CAMHS and AMHS are different, a fact also supported by literature on the topic (Mulvale et al., 2015). Poor transition stemming from communication breakdowns and inappropriately managed expectations is detrimental to the mental health and overall wellness of young adults requiring psychiatric care (Hergenroeder et al., 2015). For example, one participant in my study, who was involved with adult services for two years, was still uncertain about their future care at the time of the study. Transition planning, which is designed to prepare people for change, should continue through all stages of the transition process including in the beginning, during, and at the end of transition. As suggested by Schraeder & Reid (2017), transition support should continue for six to 12 months to ensure young adults have a healthy transition.

Discussion Point Three: Factors Influencing Transition.

One of the objectives of my study was to identify facilitators, inhibitors, and gaps in care that affect transition from CAMHS to AMHS. These were identified throughout the interviews, and include what participants found helpful and not, as well as what could be done differently to ensure a more positive transition experience. The inhibitors discussed below are: ‘Wait Times’, ‘Fragmented Care’, and ‘The COVID-19 Pandemic’.

Wait Times

One of the biggest challenges for the participants in my study was the amount of time they waited between discharge from CAMHS and initiation of AMHS. Long wait times negatively impacted their transition process and overall mental health because of three key reasons: First, a lack of resources available for individuals who no longer have access to CAMHS, but who are not yet accepted into AMHS; Second, being in a state of remission at the time of their transition and, therefore, not accepted into AMHS following discharge from CAMHS; and Third, experiencing a relapse of their mental illness because of fragmented care.

The above effects on mental illness due to poor transition to AMHS are similar to the findings of a study by Dimitropoulos and colleagues (2015). These authors used a grounded theory methodology to investigate the systematic facilitators and inhibitors associated with transitioning from CAMHS to AMHS for 15 young adults aged 17 to 21 years in Ontario, Canada. They found that 14 out of 15 participants experienced a relapse of their mental illness following discharge from CAMHS, and nine attributed their relapse to the lack of monitoring during the waiting period. Their findings also indicated that navigating care during the transition

period was difficult and that there needs to be a distinction between discharge and recovery to ensure young adults do not discontinue care prematurely (Dimitropoulos et al., 2015).

The wait times for participants in my study ranged from three to nine months for the initial assessment and an average of two months for a callback. To give context to the difficulties associated with wait times, I will discuss an example from one participant's experience. This participant reported waiting five months for an initial mental health assessment by AMHS and another three months for a follow-up and possible admission to hospital. They explained that during these eight months, they were not followed by their former CAMHS team, nor the referring physician or healthcare professional from AMHS who did the initial assessment. As per them, when they requested resources in the interim, the response was to just wait and call 911 if they needed immediate assistance. While wait times for mental health treatment may be perceived as a minor issue, the opposite is true (Moir & Barua, 2022). Wait times can cause serious consequences such as disengagement from mental health services, exacerbation of mental illnesses, substance use, suicidal ideation, and self-harm (Moir & Barua, 2022), which were reported by some participants in my study.

Long wait times for patients transitioning to new services is also evident in the literature, with researchers reporting similar – or longer – wait times (Butterworth et al., 2016; Leavey et al., 2019). For instance, Schandrin and colleagues (2016) completed a retrospective survey at Montpellier University Hospital exploring the transition from CAMHS to AMHS from the perspective of six child and adolescent psychiatrists and 14 adult psychiatrists. Another study by McNicholas and colleagues (2015) was completed in Ireland, which explored the predictors and the process of transition from CAMHS to AMHS from retrospective case notes of 62 former CAMHS users. These authors respectively reported wait times that were two to three months

(Shandrin et al., 2016) and six to seven months (McNicholas et al., 2015), with Shandrin and colleagues specifying that due to the long wait times, 48% of young adults discontinued care (Schandrin et al., 2016).

The Canadian Psychiatric Association [CPA] (2006) and Wait Time Alliance (Loebach & Ayoubzadeh, 2017) developed target timelines for assessment by psychiatric services based on classifications defined as *emergent*, *urgent*, and *scheduled*. The time target for the *emergent* classification is “Within 24 hours of the first episode psychosis, mania, major depression, and post-partum mood disorders” (Loebach & Ayoubzadeh, 2017, p.1). As per the Canadian Psychiatric Association (2006), this *emergent* classification implies that there is a danger to life, such as active suicidal ideation or acute mania, that requires immediate treatment. The response of the practitioner who evaluated and classified the individual as emergent is to facilitate an urgent referral to a hospital for an evaluation (CPA, 2006).

When classified as *urgent*, the individual is to be seen by psychiatric services “Within 1 week of the first episode psychosis, mania and postpartum mood disorders, and two weeks for major depression” (Loebach & Ayoubzadeh, 2017, p.1). This classification includes individuals with unstable conditions, who have the potential to quickly deteriorate and may require in hospital admission. The response at this level of classification involves an expedited consultation with a care service that has access to inpatient resources, while being monitored by their practitioner for fluctuations in their condition (CPA, 2006).

Lastly, the *scheduled* classification means that a person should be seen “Within 2 weeks of the first episode psychosis and four weeks for postpartum mood disorders and major depression” (Loebach & Ayoubzadeh, 2017, p.1). Individuals classified as such have stable symptoms with minimal dysfunction in their everyday life. Furthermore, the practitioner who

assessed the individual is not concerned about deterioration and may refer to appropriate mental health support services in the community (CPA, 2006).

In the Wait Times for Health Care in Canada Report (Moir & Barua, 2022) the median wait time from time of referral to delivery of treatment was 27.4 weeks (6.85 months), which was the longest wait time in this survey's 29-year history with a 195% increase from the year 1993 to 2022 (Moir & Barua, 2022). However, the shortest wait time by province was Ontario with a total wait of 20.3 weeks (5 months) (Moir & Barua, 2022). While these timelines exist, based on my study and previous research, these timelines are not often respected and/or followed.

Organizational factors might contribute to these delays in transition between services. McLaren and colleagues (2013) explored the organizational factors that facilitate or inhibit the transition from CAMHS to AMHS using an exploratory qualitative study of 34 health and social care professionals in London, England. From the findings, they suggested shared responsibility between CAMHS and AMHS for patients in between care services (McLaren et al., 2013).

Fragmented Care

Fragmented care occurs when there is a divide or disconnect between healthcare providers or services (MeetCaregivers, 2022). Fragmented care is evidenced when there is a lack of collaboration between CAMHS and AMHS or a lack of communication between services and young adults requiring them. Most participants in my study reported that their mental healthcare was fragmented. Some of the examples given by participants included: Lack of joint working and shared responsibility, insufficient communication, difficulty gaining access to AMHS and lack of transition planning. In a systematic review by Mulvale and colleagues (2015), consisting

of 12 articles mostly from the United Kingdom, the influence of care philosophies on transition for individuals aged 12 to 25 years was explored. The authors found that less than 5% of successful transitions between child/adolescent to adult mental health services had sufficient joint working, planning, continuity of care, or information exchange (Mulvale et al., 2015).

Joint Working. The term *joint working*, sometimes referred to as *parallel care*, involves multidisciplinary teams, such as CAMHS and AMHS, working together to provide care to patients (Butterworth et al., 2016; Leavey et al., 2019; Mulvale et al., 2015; Price et al., 2019). Lack of joint working is reported as a limitation by young adults, resulting in gaps in care. Participants in my study expressed a need for joint working between CAMHS and AMHS for several reasons: Maintaining a connection with former CAMHS provider, receiving continuity of care, and assistance with the application to programs in AMHS. These reasons reflect the findings of a qualitative thematic synthesis by Broad and colleagues (2017) who explored the experiences of 253 CAMHS users from 18 different studies. The authors concluded that young adults value continuity of care and joint working between CAMHS and AMHS. Furthermore, when young adults had the opportunity to receive joint working, they described it as a positive experience (Broad et al., 2017).

The most vulnerable time for discontinuation of services for individuals with mental illness is during transition because they are often waiting for services (Butterworth, et al., 2016; Price et al., 2019; Singh et al., 2017). Having joint working is shown to decrease discontinuation of services and high-risk behavior, while increasing empowerment and trust between young adults and mental health services (Broad et al., 2017; Dimitropoulos et al., 2015; Vyas & Singh, 2014). A ‘selective literature review’ (i.e., a study in which the authors purposefully selected the most important literature related to the research question) by Vyas and Singh (2014) discussed

the evidence of adolescence being a high-risk time, problems at the CAMHS and AMHS interface, and opportunities for change regarding the implementation of early intervention models. The findings suggest that lack of joint working and information exchange is so problematic for young adults, that it often results in discontinuation of care (Vyas and Singh, 2014). Price and colleagues (2019) contended that young adults who receive joint working feel more prepared for their transition, which results in a positive transition experience. While no participants in my study experienced joint working, some had community social support available to them, which provided mental health support throughout the transition process. Participants who had this support reported feeling more prepared than those who did not.

Joint working is often found to be a main criterion for a healthy transition (Butterworth et al., 2016; Leavey et al., 2019; Mulvale et al., 2015; Price et al., 2019; Singh et al., 2010; Singh et al., 2017). For instance, joint working is said to be a key component for continuity of care (Butterworth et al., 2016; Singh et al., 2010; Singh et al., 2017), a criterion for an *optimal* transition (Singh et al., 2010), and a facilitator to help foster a ‘mutual understanding’ between CAMHS and AMHS (Mulvale et al., 2015). While researchers state that joint working is necessary for a healthy transition and should be included in guidelines or policies, I was unable to locate literature exploring why joint working does not occur in practice. This represents an interesting knowledge gap for future research.

To improve the use of joint working, researchers suggest strategies such as joint planning and practicing independence (Butterworth et al., 2016), developing transition guidelines while recognizing the differing approaches (Mulvale et al., 2015), and having appointments with mental health professionals from both services being present (Leavey et al., 2019). Within joint-working arrangements, guidelines that help teams transition young adults from child-centered to

adult-oriented mental healthcare would be appropriate for use. These guidelines could be generalized, but modifiable to meet the individual needs, while keeping the main concepts in focus.

Communication. Another gap in care identified by participants in my study was the lack of information exchange between service interfaces (CAMHS and AMHS), as well as between these services and patients. Communication challenges are also evident in previously published studies. For example, Signorini and colleagues (2018) explored the challenges at the interface between CAMHS and AMHS using an online mapping survey. These authors suggest that providing CAMHS and AMHS professionals with a communication platform that includes the young adult and their family in the transition planning process, is paramount to a healthy transition (Signorini et al., 2018). Furthermore, Vyas and Singh (2014) asserted that young adults who switch services feel their transition is “poorly planned, poorly executed, and poorly experienced” (p.15), with lack of information exchange between services as a contributor. Poor information sharing practices result in patients making ill-informed assumptions about their care and treatment (Butterworth et al., 2016), disruption in care (Signorini et al., 2018), and an increased risk of disengagement from mental health services (Vyas & Singh, 2014). A notable example from my study was when a participant believed they were accepted into AMHS, despite not receiving confirmation of this.

While the reason behind poor information exchange is not proven, some authors suggest the foundation of the problem is the differing philosophical views between services (Leavey et al., 2019; Mulvale et al., 2015; Price et al., 2019; Signorini et al., 2018; Singh et al., 2017; Vyas & Singh, 2014). For example, Mulvale and colleagues (2015) stated that given how CAMHS are very supportive, family centered, and provide protective environments, their focus is different

from AMHS professionals who practice a more individualized approach. Additionally, Butterworth and colleagues (2016) found consistent communication concerns between AMHS and young adults for follow-ups and for those who were waiting for acceptance notifications. This same study found that very few participants experienced “good” communication between services during their transition from CAMHS to AMHS (Butterworth et al., 2016). Suggestions for improving communication, according to researchers interested in this area, include a less “condescending and intimidating communication style” (Butterworth et al., 2016, pp.144), a more caring approach by AMHS (Butterworth et al., 2016), and consistent use of transition planning involving the young adult and their family to ensure a clear understanding of their ongoing care (Manteuffel et al., 2008).

Central to high-quality and compassionate nursing care is effective communication (Bramhall, 2014). Effective communication during a vulnerable time, such as transitioning from CAMHS to AMHS, is crucial to assisting patients with informed decision-making regarding ongoing care and treatment. Some of the components of effective communication include compassion and empathy, however, it is difficult to clarify what compassionate care means and how it can be established in practice (Bramhall, 2014). Some of the barriers to effective communication by healthcare professionals include lack of time, stressful workload, fear, and anxiety about asking questions that may be difficult or sensitive, and not having the skills to effectively manage distress of patients and families (Bramhall, 2014). This last point is especially important because it underpins the need for communication skills to be taught to students in programs related to healthcare, such as nurses, physicians, and social workers (Bramhall, 2014; Chapman, 2009). Using effective communication skills has the potential to

decrease anxiety and improve coping for people adjusting to a new situation, such as transitioning from child-centered to adult-oriented mental healthcare (Bramhall, 2014).

Access to AMHS. The criteria to be accepted into AMHS are quite rigid and only people with a severe and persistent mental illness are often accepted (Butterworth et al., 2016; Price et al., 2019; Singh et al., 2017). To circumvent this rigidity, participants in my study were creative about their approaches to intake visits. For example, one participant stated that they felt lucky to be in a crisis at the time of their transition so that they would have a better chance of being accepted. Participants who were accepted into AMHS also described the difficulties accessing AMHS services. Some having to ‘settle’ on programs they didn’t feel would be beneficial or being rejected from programs due to substance use or not qualifying. Previous research illustrates how, due to the differing approaches between CAMHS and AMHS, the criteria for acceptance are vastly different (Butterworth et al., 2016; Singh et al., 2017; Mulvale et al., 2015). According to Mulvale and colleagues (2015), because CAMHS is more inclusive of patients with most (or all) mental health issues, transitioning patients might not meet the diagnostic criteria that are required by AMHS.

While previous studies have identified the difficulty patients have entering AMHS due to criteria, other studies have described additional influencing factors. First, some clinicians perceive that their patients will not be accepted into adult care and thus fail to refer them to adult services (Appleton et al., 2019; Eke et al., 2019; Mulvale et al., 2015). Second, patients have also reported difficulty receiving a referral from their physician (Butterworth et al., 2016; Price et al., 2019). Lastly, only those with a severe and persistent mental illness are routinely referred and accepted into AMHS (Leavey et al., 2019; Vyas and Singh, 2014). The findings of my study are similar to previous studies with two participants stating they were not initially referred by

CAMHS to AMHS, and instead were instructed to self-refer. These individuals reported difficulties navigating the admission process and one spoke to the vast amount of paperwork required. While these participants were mentally stable at the time of discharge from CAMHS, both reported feeling that they still needed ongoing mental health support.

A European study by Appleton and colleagues (2020) explored the experiences of 15 young adults who ‘fell through the cracks’ of the healthcare system, as well as their parents’ perspective during transition from CAMHS to AMHS. They found that people who were not ‘sick enough’ to have access to ongoing mental healthcare were not receiving the same quality of care after leaving CAMHS and entering AMHS. These authors discussed how mental health assessments completed by AMHS are commonly done in ways that left their participants feeling like the interactions were impersonal, short, and not fully capturing their need for ongoing care (Appleton et al., 2020).

It is well known that to qualify for care in AMHS, young adults need to have a severe or persistent diagnosable mental illness, as outlined in the DSM-V (Butterworth et al., 2017; Mulvale et al., 2015; Vyas & Singh, 2014). This means that being in a state of remission at the time of transition increases the risk of rejection by AMHS; it also makes it difficult for people with neurodevelopmental disorders (such as ADHD) to be accepted into AMHS (Butterworth et al., 2017). When young adults are not accepted into AMHS, they are told to access emergency services if they need help, or for parents to contact the criminal justice system if they need immediate assistance (Appleton et al., 2020; Moroz et al., 2020). As per Moroz and colleagues (2020) some of the barriers to accessing mental healthcare services in Canada include cost (e.g. having to pay for private mental healthcare), stigma, and not knowing where to go to access care.

Not having consistent access to a primary mental health provider can result in patients

presenting to emergency departments with new symptoms and more severe mental health issues (Singh et al., 2017). Moroz and colleagues (2020), found that young adults aged 20 to 29 years use the most emergency resources, compared to other age groups, often reporting that they do not have alternative options. Disengagement from services is common when transitions are poorly managed, and when individuals are not accepted into services they need (Appleton et al., 2019). When this arises, patients are more likely to use acute crisis services and their overall mental health declines (Butterworth et al., 2016).

COVID-19

One of the major inhibitors to transition to AMHS identified by four of the six participants was the COVID-19 pandemic. Three main challenges arose, which included difficulty navigating services, not being able to visit AMHS services ahead of time, and not having in-person meetings or groups. While these were expected and appropriate for safety (British Columbia Centre for Disease Control [BC CDC], 2021), the last point was especially difficult for one participant in my study who reported having phone and video conference anxiety. This participant needed to contact the adult crisis line before online meetings with AMHS and the interview with me. Another participant stated that the pandemic added "another layer" to an already stressful situation. While my study was done during the COVID-19 pandemic, this was not the focus of the study, and no questions were asked regarding the effect COVID-19 had on the transitions of participants. No previous published literature could be found on the transition from CAMHS to AMHS during the COVID-19 pandemic. Thus, no conclusions can be drawn based on previous research. However, there is emerging information on the effect COVID-19 had on the mental health of Canadians, which is discussed below, given the notable impact on the population of interest.

As per the Government of Canada (2022), due to feelings of isolation, loneliness, repeated lockdown measures, people are more at risk for developing anxiety and/or depression. Overall, the impact of COVID-19 on individuals has been negative, with more than seven out of 10 Canadians reporting the negative effect the pandemic has had on their mental health. Among Canadians in 2022, 15% screened positive for symptoms of anxiety and 19% for symptoms of major depressive disorder, with the highest prevalence amongst people aged 18 to 34 years. Furthermore, for people with a positive screen, they were 1.5 times more likely to report an increase in alcohol consumption and 2.5 times more likely to report an increase in cannabis use since the beginning of the pandemic, compared to those who screen negative (Government of Canada, 2022). Similar results were seen by the Centre for Addiction and Mental Health (2020), who found that 50% of Canadian reported a decline in their mental health and a significant increase in their stress level since the beginning of the pandemic.

In Canada young adults are experiencing a considerable increase in mental health concerns including an increase in stress and poor mental health due to the COVID-19 pandemic (BC CDC, 2021). In Toronto, Ontario, for example, there were substantial disruptions in mental health services and unmet support needs for people aged 14 to 28 years, and in Montreal, there were difficulties accessing health and social services for people aged 18 to 29 years (BC CDC, 2021). Clearly, the COVID-19 pandemic rendered youth with mental illnesses more vulnerable, while simultaneously stripping them of their needed services. Ideally, we will learn from this experience and create contingency plans to ensure proper support during times of unexpected disruptions in healthcare.

As the researcher for this study, I also felt that the COVID-19 pandemic inhibited some parts of my research. I found it difficult to form a rapport with participants online and had one

participant who found online modes of communication distressing. While this participant was encouraged to pause or reschedule to a time when they were more comfortable, they opted against this option. It is unclear whether their data would differ if they were collected in-person, when the participant might have felt more at ease. People who are feeling anxious are known to have intrusive feelings and thoughts that can be debilitating and impair concentration and increase distractibility, which might affect responses during an interview (Robinson et al., 2013). Furthermore, when the video option was used, I could only see the participants' faces, meaning that my ability to interpret their body language and non-verbal communication patterns was limited.

Implications for Practice

There are two main implications for practice: 1. the need for more comprehensive transition planning and 2. improved joint working'. These implications are discussed below from a nursing perspective.

Need for More Comprehensive Transition Planning

Most participants in my study reported disruptions in their care during their transition to AMHS and periods where they had no information about ongoing care. These findings are important because they highlight a persistent lack of proper discharge planning. Thankfully, most participants were in a state of remission upon discharge from CAMHS, though they still felt ongoing care was needed, and some participants spoke to having at least one relapse in their mental illness during their transition period.

Nurses, who use a holistic approach to care, are in a prime position to assist with transitioning from CAMHS to AMHS given their capacity to create and maintain therapeutic

relationships with their patients (Lockertsen et al., 2020). In a systematic review by Hayajneh and colleagues (2020), nurses were identified as foundational to proper discharge planning. The nurses in the included studies were responsible for many aspects of discharge planning, including: 1. identifying and assessing patients who need discharge planning, 2. working as part of an interdisciplinary team involving healthcare professionals, patients, and their families, 3. facilitating knowledge about and use of community resources, and 4. supporting patients and their families through discharge (Hayajneh et al., 2020). Lack of proper discharge planning leads to fragmented care, which is a challenge for young adults with mental illnesses. As such, more attention has been recently given to appropriate discharge planning (Xiao et al., 2019).

Interestingly, the way in which discharge planning is conceptualized varies from one interdisciplinary field to another (Xiao et al., 2019). With no consensus on what constitutes discharge planning, it is difficult to provide a clear definition within a mental healthcare context (Xiao et al., 2019). Authors writing on the topic describe discharge planning, generally, as a multidisciplinary process involving healthcare providers, the patient, and their family in the planning, implementation and evaluation from admission proceeding until the patient transitions to the next level of care (Gowda et al., 2019; Hayajneh et al., 2020; Xiao et al., 2019), and guidelines exist to guide the process for some illnesses. One example of a robust guideline is the guideline produced by The Joint British Diabetes Societies (2022). This document provides healthcare professionals with information about how to properly discharge and educate patients with diabetes and is shown to improve health outcomes post-discharge (The Joint British Diabetes Societies, 2022). While I did find one discharge guideline for patients with schizophrenia, the level of detail and structure to guide the process is not equivalent to what is available within the physical health context (Health Quality Ontario, 2016). People with mental

illness would benefit from better guidelines, consistently used in practice, to support their discharge from services, given that they often require life-long care that is divided into pediatric, adult, and geriatric landscapes.

Improved Joint Working

Initiating contact with AMHS after discharge from CAMHS can cause undue stress on young adults (Lockertsen et al., 2020), which was reported by some participants in my study. As part of the discharge planning mentioned above, nurses can facilitate the first contact with AMHS for their patients prior to CAMHS discharge. This would facilitate joint working between CAMHS and AMHS and improve the quality of care provided by making their transition experience fluid rather than fragmented (Paul et al., 2013). As previously discussed, joint working between CAMHS and AMHS offers an opportunity to improve transitions between these services. Currently, joint working is done haphazardly, and it is not part of typical mental healthcare agency ways of working. With the proliferation of online and virtual means to connect, there is an opportunity to increase joint working because healthcare professionals in different settings can easily attend appointments together to support their mutual patients. This represents a shift in care philosophy and delivery (and likely resourcing) and more research is needed to determine the most efficient way to implement joint working in this context.

Implications for Policy

There are two key implications for policy stemming from the findings: 1. need for adequate support and access to mental healthcare across the lifespan and 2. more community services for adults and increased funding focusing on mental health.

Need for Adequate Support and Access Across the Lifespan

According to Ontario Health (2022), due to the advances in medical technology, the life-expectancies of most (i.e., 90%) young adults in North America with chronic and complex disabilities see them living well into adulthood, making transitions from child services to adult services at age 18 years much more common. Due to the vulnerable age of transition, improper transition planning, and health system barriers, six quality standards were developed to help young adults with chronic and/or complex health conditions transition from child services to adult services (Ontario Health, 2022). These quality standards highlight the importance of early identification and assessing transition readiness. Strategies include: ongoing needs assessments; information sharing and support using developmentally appropriate information; having an individualized transition plan created with the young adult and their family; ensuring there is a designated person who coordinates the transition; facilitating an introduction to adult services before transitioning into their care; and confirming transfer completion, which is when the young adult remains connected to the designated healthcare professional and they feel their transition is complete. The quality statements within each quality standard are evidence-informed to reduce variation and gaps in care and designed to help improve transition programs already in place or to be used as tools to support quality improvements. In my study, participants made several recommendations on how to improve both the preparation for, and process of, transition into AMHS which are congruent with the quality standards. For example, prior to discharge from CAMHS participants wanted to obtain a list of their diagnoses, a summary of their care, and a plan with transition goals. Regarding the process of transition, these quality standards highlight some of the participant recommendations such as meeting with key providers ahead of time; having a specific person/team assigned to help; receiving more information about what to expect;

and joint working between services. Although these quality standards are transferable to some degree to young adults transitioning between mental health services, the participants of my study also spoke about needed increased access to community mental health resources, for example, which is not considered within this document. Tailored guidance might be needed for specific patient populations, like those with mental illness.

Participants in my study explained how they need support both during their transition from CAMHS to AMHS and throughout all phases of their lives. Having policies that ensure access to consistent mental health services across the lifespan would likely decrease disengagement from care and be beneficial for people as they progress from child to adult to older adult (Appleton et al., 2019; McDonagh, 2007). While policy statements have been created at national and international levels with the aim of setting the ‘gold standard’ for transitional care, these are often not adhered to in practice (McDonagh, 2007), which contributes to patients ‘falling through the care gap’ (Murcott, 2014). Adequate support from a healthcare professional and appropriate access to mental health services at all stages of life are particularly important for specific mental illnesses (Lockersten et al., 2020). For example, Lockertsen and colleagues (2020) explain that young adults with eating disorders struggle with the motivation to continue care and recover. When they encounter challenges that impede their access to mental healthcare, they are much more likely to discontinue treatment compared to persons with other psychiatric diagnoses (Lockertsen et al., 2020). Having mental health services that follow an individual through all stages of life would be ideal, however it might be difficult to ensure appropriate expertise in all relevant domains (i.e. pediatric illness, adult illness, and mental disorders common in older adults). Policymakers should explore the use of models that bridge transition points, thereby improving continuity of care and minimizing gaps in support.

More Community Services for Adults and Increased Funding Focusing on Mental Health

Some of the main challenges to transitioning from CAMHS to AMHS included a lack of adult community services – though increasing these would require a huge financial investment. According to Moroz and colleagues (2020), a lack of community-based mental health services causes a heavy reliance on acute care services, which are high-cost and straining on the healthcare system. While 80% of Canadians routinely use their family physician for their mental health needs, only 23% of family physicians report feeling comfortable meeting the mental health needs of their patients. Easily accessible community mental health services would be equitable, cost-effective, and beneficial for the mental health of Canadians. Unfortunately, these services are extremely underfunded with long wait times, often rendering the emergency department the only available option (Moroz et al., 2020).

In Canada (2015), only 7% of the total health spending targets mental health, despite the known prevalence of mental health issues in the Canadian population. Specifically, mental illness affects approximately 20% of all people, and in Ontario, mental illness accounts for 10% of the burden of disease (Centre for Addictions and Mental Health [CAMH], 2023; Moroz et al., 2020). In comparison, England (2014) invested 13% and France (2017) 15% of their total health spending to mental health initiatives (Moroz et al., 2020). Improving access and funding to community mental health services would not only benefit individuals with mental illness but would also contribute to a more sustainable healthcare system (Moroz et al., 2020).

Implications for Education

There are two key implications for education stemming from the results of this study: 1. improving knowledge of mental illnesses across the lifespan and 2. developing appropriate communication skills.

Improving Knowledge of Mental Illnesses Across the Lifespan

Participants reported that providers working in CAMHS were ‘hesitant to diagnose’ and, when they did receive a diagnosis, providers working in AMHS were not familiar with the disorder if it was one specific to the pediatric population (e.g., conduct disorder or oppositional defiant disorder). Some participants thought this might be because providers working in different domains do not necessarily learn about diagnoses less common to their patient population, implying that pediatric mental health providers would not know about adult and older adult illnesses or vice-versa. While our current mental healthcare system divides services into CAMHS and AMHS, providers working in both spaces require a sound knowledgebase about mental illnesses across the lifespan given that patients transition into and out of their care (Morsy et al., 2011; Murcott, 2014). Although the symptomology of childhood mental illnesses often differs from adult presentations (Collins & Munoz-Solomando, 2018), many disorders persist throughout one’s life, and childhood symptoms do not ‘turn off’ at age 18 years. Further, according to Collins and Munoz-Solomando (2018), who explain the notion of homotypic continuity – the idea that some mental illnesses seen in childhood or adolescents predict other mental illnesses later in life – it is imperative that providers are knowledgeable about mental illnesses generally, not simply those characteristic to certain ages. As transition to AMHS typically begins in late adolescents (16 to 17 years old) providers working with patients during this time likely help manage both pediatric and adult disorders, and/or symptoms that vacillate between what is common in children and adults. Ensuring up-to-date knowledge about mental illness across the lifespan would benefit patients and their transition experiences.

Developing Appropriate Communication Skills

Participants noted the difference in communication styles between CAMHS and AMHS,

as well as areas where communication could be improved. Open and approachable communication is pivotal to building rapport and therapeutic relationships (Appleton et al., 2019), and participants explained how feeling uncomfortable when discussing their mental health needs with healthcare professionals could lead to withholding information or misinformation that affected their care.

Communication is fundamental when forming professional relationships and is defined as “... a process during which information is shared through the exchange of verbal and non-verbal messages” (Bramhall, 2014, p.53). Communication is part of the entry-to practice competencies for registered nurses; specifically, that nurses will use communication skills informed by evidence to build professional relationships with patients that are compassionate and therapeutic (College of nurses of Ontario [CNO], 2019). Unfortunately, participants in my study had issues with the ‘cold’ and ‘business-like’ communication style used by AMHS professionals. They also explained how challenging it was to develop a rapport with multiple providers. For many people, their mental health is a sensitive topic, and having a mental illness can make them feel vulnerable (NICE, 2016). Communication skills must, therefore, be empathetic, compassionate, and understanding (CNO, 2019; Elmir et al., 2011). This study highlights the importance of embedding (or perhaps strengthening) education on therapeutic communication skills in nursing programs, including plenty of opportunities for nursing students to practice and apply them during practicums. While not reported by all participants, I learned that some felt that their interactions with AMHS were quite problematic. This led to unmet mental healthcare needs and perpetuated feelings of distrust, rejection, and abandonment. With more practice, nursing students become more proficient with therapeutic communication (Morsy et al., 2011), and this should be a focus of all programs.

Implications for Research

There are two key implications for research stemming from the findings of this study: 1. the use of tools to assess readiness to transition and 2. the effect of sex and gender on transitioning from CAMHS to AMHS.

Use of Tools to Assess Readiness to Transition

Participants' perspectives on their levels of readiness for AMHS were varied, with some feeling ready and others unprepared. This inconsistency across participants is reasonable, given that maturity and attainment of developmental milestones varies from person to person (Appleton et al., 2019). Currently, the structure of the healthcare system dictates when a person *must* transition out of pediatric services and, at age 18, patients can no longer access the child and youth care team – whether they are ready or not (Santosh et al., 2020). Short of re-inventing the healthcare system to allow for lifelong provision of mental healthcare, researchers should explore opportunities to embed more individualized approaches when possible.

In my study, half of the participants were made aware of their impending transition at their last CAMHS visit, causing them to feel scared and unprepared. Instruments and tools exist to assess patient's 'readiness', including readiness to transition within healthcare contexts and settings (Santosh et al., 2020). Zhang and colleagues (2014), for example, conducted a systematic review of ten different transition readiness tools for adolescents with a *medical* condition, assessing the reliability and validity of them. Based on their assessment, the Transition Readiness Assessment Questionnaire (TRAQ) appears to be the most psychometrically sound instrument. Using 33 items measured on five-point Likert scales, the questions focus on the skills related to managing medication, appointment keeping, tracking health issues, talking with providers, and managing daily activities (Zhang et al., 2014). While the authors concluded that

further validation of this tool is needed before it can be integrated into clinical practice, it offers a good starting point, though it is not specific to a mental health context (Zhang et al., 2014).

Literature on readiness tools for individuals with mental illness is sparse, however, I was able to find a tool on the topic developed and validated by Santosh and colleagues (2020) called The Transition Readiness and Appropriateness Measure (TRAM) The TRAM is designed to identify and help young adults with the challenges of transitioning from CAMHS to AMHS, and was created based on the input of young adults, parents, and healthcare professionals. The tool is holistic in nature and web-based, allowing it to be used in other countries, and although it shows promise, it is still in the early stages of research development (Santosh et al., 2020). Researchers and practitioners interested in this topic should explore the validity, implementation, and use of the TRAM for their setting.

Effect of Sex and Gender on Transitioning from CAMHS to AMHS

The terms *sex* and *gender* are often used interchangeably despite having different meanings. According to the Canadian Institutes of Health Research (2023), sex refers to the biological attributes of persons that are usually categorized as ‘male’ and ‘female’. Whereas gender is not confined to the binary male/female and instead refers to how people or groups perceive themselves and others. The transferability of research on the transition from CAMHS to AMHS would be enhanced if studies included a gender-based analysis approach. This would allow researchers to examine the similarities and differences between women, men, girls, boys, and gender-diverse people, which is important because society includes people of all genders, and a one-size-fits-all perspective might be flawed. Bringing these considerations into focus through research, improves the way in which we teach and practice, as well as formulate

programs and policies that are pertinent to the diversity of the Canadian population (Canadian Institutes of Health Research, 2023).

Given the emerging awareness of gender identity, the importance of inclusion, and using the pronouns people identify with, sex and gender are salient considerations for all research studies (Martin et al., 2020). In my study sex at birth was not collected, and my sample consisted of five participants who self-identified as women and one participant who self-identified as a man. The pronouns used were she/her, he/him, they/them, and she/they. Although stratifying my sample to look at differences between genders was not possible given the small sample size, anecdotally, I did not notice a difference in the self-reported mental health diagnoses, nor experiences based on gender. With a larger sample size, I might have revealed differences in the transition experiences of patients who identify as women, men, and otherwise. This information is important to ensure standardized approaches to transition are not solely reflective of one type of experience. To note, most literature on the topic includes the binary male/female perspective, which is problematic for the transferability of findings to real-world contexts.

Limitations

There are several limitations to consider when interpreting the findings of this study. First, the small sample size must be acknowledged. While 23 individuals consented to the coordinator giving me their contact information, most decided not to participate in the study. The main reason for this was that the interviews were taking place while they were preparing for their academic exams, highlighting an important consideration for recruitment of participants in this age range. Others cited that there was no in-person option for interviews due to the COVID-19 pandemic, which was expected though unfortunate. Second, the people who chose to participate in research studies might differ from those who do not; a phenomenon known as nonresponse or

volunteer bias (Polit & Beck, 2017). This type of bias is a limitation in most studies that use convenience sampling methods and the effects on my data are unknown (Polit & Beck, 2017). Third, the demographics for participants were similar, with all but one participant identifying as women and all identifying their ethnicity as white. This is important given the known inequalities in referral pathways for young adults within some ethnic groups who are seeking mental healthcare (Chui et al., 2021). Larger studies using a maximum variation approach to sampling could prioritize participants from diverse backgrounds and perspectives, potentially shedding light on nuances in experiences based on race, gender, ethnicity, and other forms of diversity. Fourth, the recruitment was conducted at one CAMHS setting, which limits the perspectives to those who received care from this location. It is likely that young adults transitioning from other CAMHS settings into adult care have variations in their experiences. Finally, this study was cross-sectional and retrospective, which did not allow me to follow participants forward through their transition to AMHS or afterwards. Having this longitudinal perspective would allow the process and outcome indicators in Meleis' (2010) theory to be more appropriately explored. Similarly, while the patient perspective is key to quality research in this domain (and therefore the lens I chose to study), the perspectives of healthcare professionals and family members should also be explored.

Strengths

There are several strengths of this study that should be acknowledged. First, despite the small sample size, I was able to collect rich data and identify recurring ideas and patterns (Polit & Beck, 2017). Second, investigator triangulation, used to enhance the credibility of the findings (Polit & Beck, 2017), was done by my thesis supervisor and I. Specifically, we independently and jointly analyzed the data, ensuring that the findings were true to the participants experiences

and not based on our biases or pre-existing views/values. Third, at the time of this study, no other studies were found that explored young adults' transition from CAMHS to AMHS during the COVID-19 pandemic, making this one of the first qualitative studies to do so. Fourth, much of the published literature highlights the inhibitors to transition, with little to no attention given to the facilitators. While I also explored inhibitors, the facilitators to a healthy transition were specifically sought and highlighted in the findings.

Conclusion

Mental illness in youth and young adults is a growing concern, which was amplified by the COVID-19 pandemic. Given the structure of mental healthcare in most countries, children and adolescents receive care through separate services than adults. Often, youth and young adults are discharged from CAMHS at a time when they are also experiencing social, educational, and developmental changes, making their smooth transition to AMHS important for their mental well-being. Some researchers have explored the transition from CAMHS to AMHS, however most work in this area privileges quantifiable information rather than the experiences of persons who have lived the phenomenon.

The findings of this qualitative study provide insight into the experiences of young adults who are - or have lived - the transition from CAMHS to AMHS from their perspectives. The participants' stories are useful to understand the physical and emotional challenges associated with shifting to adult services, and the recommendations provided by them can help to achieve a healthy transition in this context. Most notably, the participants of this study highlighted the confusion felt around the transitions in care and resulting impact on their mental wellness when gaps in service access exist. There is a need for improved communication between services and

proper education for patients and healthcare professionals about differences in care practices and philosophies in child/adolescent and adult services.

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4

Table 1

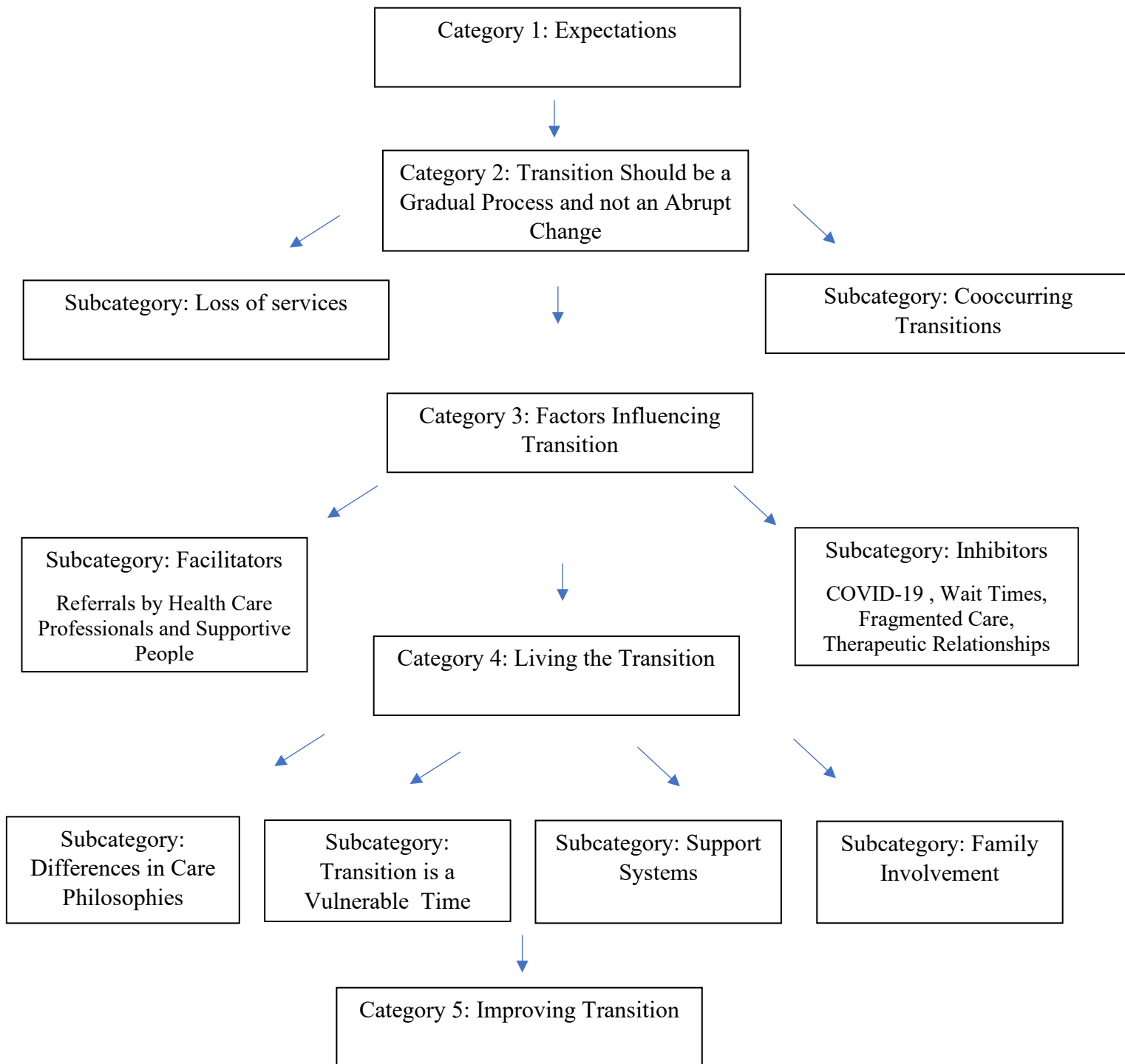
Participant Characteristics (n=6)

Characteristics	n=6
Age	
17	2
18	2
19	2
Pronouns	
She/Her	3
He/Him	1
They/Them	1
She/They	1
Ethnicity	
Caucasian (white)	6
Level of Education	
In High School	2
High School Completion	2
Adult Education	1
In University	1
Employment	
Unemployed	2
Employed (part time)	4
Living Arrangements	
Parent/Relative	4
Best friend & Parents	1
Boyfriend & Parent	1
Age of onset of mental health issues	
7-8	2
12-13	2
13-14	1
15	1
Age of diagnosis of mental health issues	
13-14	3
16-17	3
Diagnoses	
Depression	4
General Anxiety	3
Social anxiety	2
Eating Disorder	2
Borderline Personality Disorder Trait	2
ASD (autism spectrum disorder)	2
Agoraphobia	1
ADHD (Attention Deficit Hyperactive Disorder)	1
OCD (obsessive compulsive disorder)	1
Bipolar type 2	1

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Figure 1

Category Flow Chart



Note. Flow chart presents categories and sub-categories as presented in this thesis. ([Return to page 70](#))

Table 2

Facilitators

Facilitators	n	Quotes
Feeling independent in AMHS	2	<p>“You're an adult now, kind of feeling that I got from them-- it's more you are independent with it” (P02)</p> <p>“I definitely am wanting to stay more independent, being able to figure things out myself” (P01)</p>
Starting transition planning early	2	<p>“I was already 16, turning 17. So I was kind of glad that I had that extra time” (P06).</p> <p>“ I feel like it was an appropriate time (to start transition), because they weren't really sure how long it would take before I got an appointment with adult services.” (P02).</p>
Youth mental health hotlines	1	<p>“Another one would definitely be the helpline. Like, for example, the Youth Services Bureau YSB. Their help and chat center were very, very, very helpful. And also like, the Kids Help Phone, most of those they really helped me a lot” (P03).</p>
Being in a crisis at the time of transition	1	<p>“Well, the only thing that was helpful was me being in a crisis” (P03).</p>
Therapeutic activities through school	1	<p>“During our therapeutic activities (at school program), we would, at the same time, learn techniques or really learn to understand what it is what's happening inside our heads” (P05).</p>
Support offered through college	1	<p>“Now I'm having sessions with the college I'm going to and they have it's like sessions and tips and tricks to what to expect when you go to this college and the resources that they have to help you” (P05).</p>

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Table 3

Inhibitors

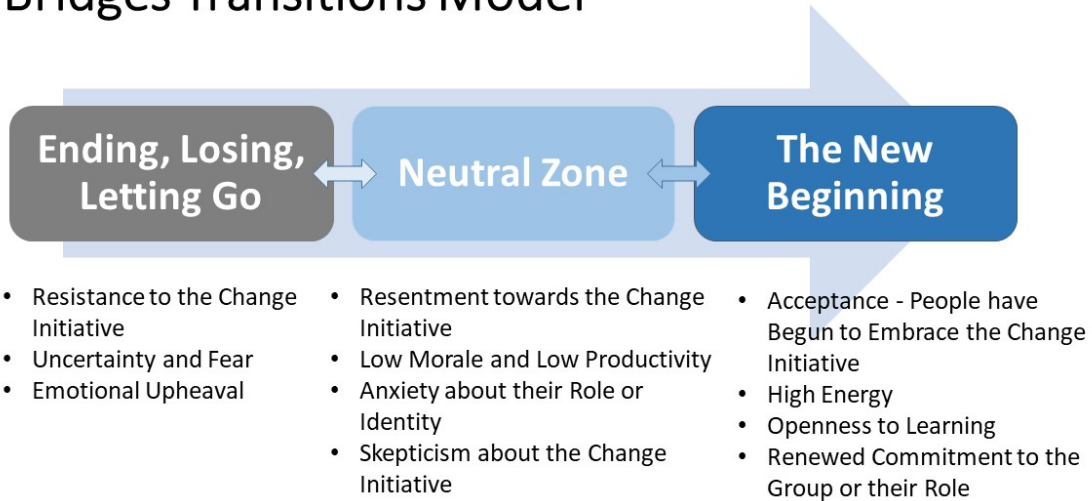
Inhibitor	n	Quotes
Not being able to visit AMHS services ahead of time	2	<p>“No, I think they're, they used to allow you to go look at some of the services. But I'm wondering, because of COVID, if they don't allow that anymore, I would have to look into that. But I thought that that would be helpful” (P01).</p> <p>“ I would really like to have like, just to go to the place and just see where it would happen and maybe meet the people in person” (P05)</p>
Feeling on your own	2	<p>“But I felt like I found myself feeling a lot more on my own in the adult care system” (P04).</p> <p>“You're on your own, you're an adult, you can deal with this on your own” (P03)</p>
Having phone and video chat anxiety	1	“Especially if you have social anxiety and phone anxiety. This is what you have to do step by step. Or like, if it was in person like you go in together, just trying to figure it out” (P03).
Lack of information	1	“Information would be awesome. I feel like more support transitioning. I feel, it feels like a handoff you know, like you're just given from one to another. That's like here, they're your problem now” (P03).
Group cancellations	1	“So, I started in the fall, and then they canceled the group because there weren't enough people” (P03).
Difficulty getting into adult services.	1	Getting into programs is extremely difficult, but also just waiting to hear back after an assessment, like you just ended up assuming, like, I guess I didn't get in (P04).

* Indicates that the inhibitor may be due to the COVID-19 and not a usual inhibitor to transitioning.

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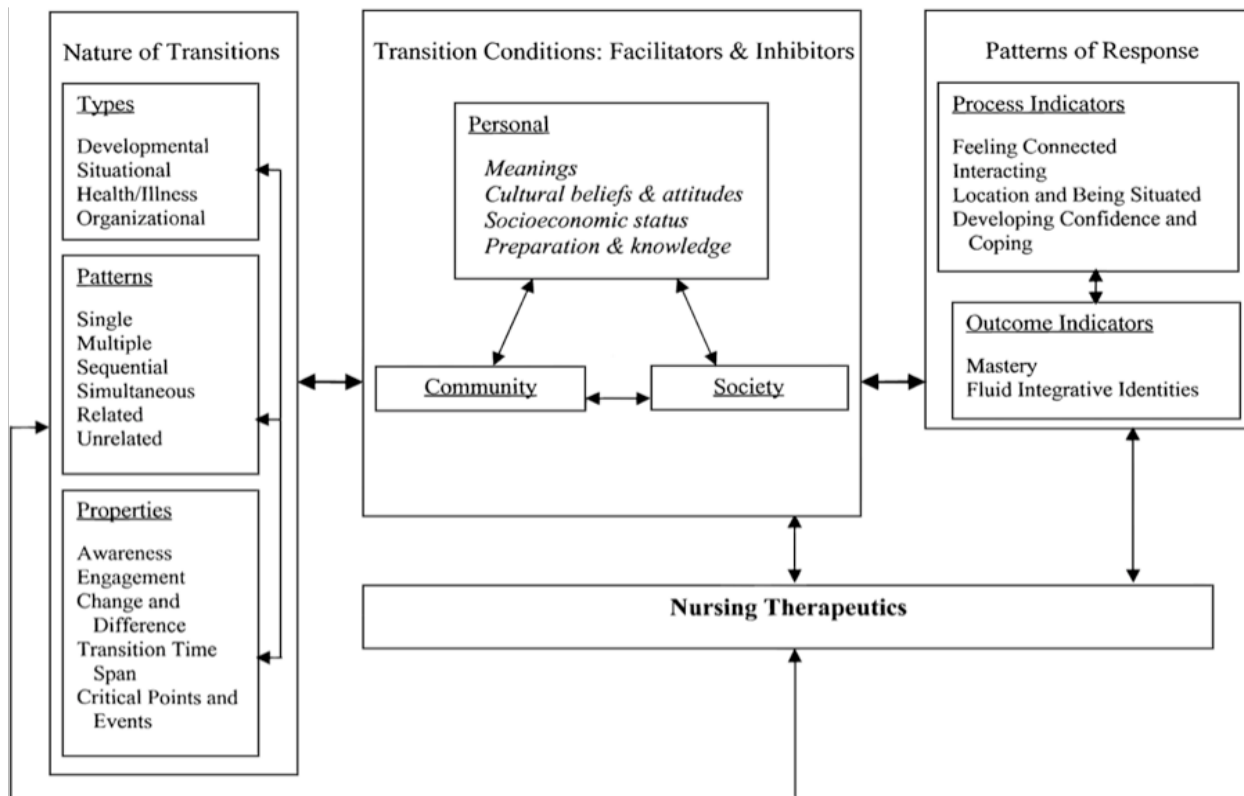
Appendix A:(Return to Previous Page)

Bridges Transition Model

Bridges Transitions Model

Appendix B:
(Return to Previous Page)

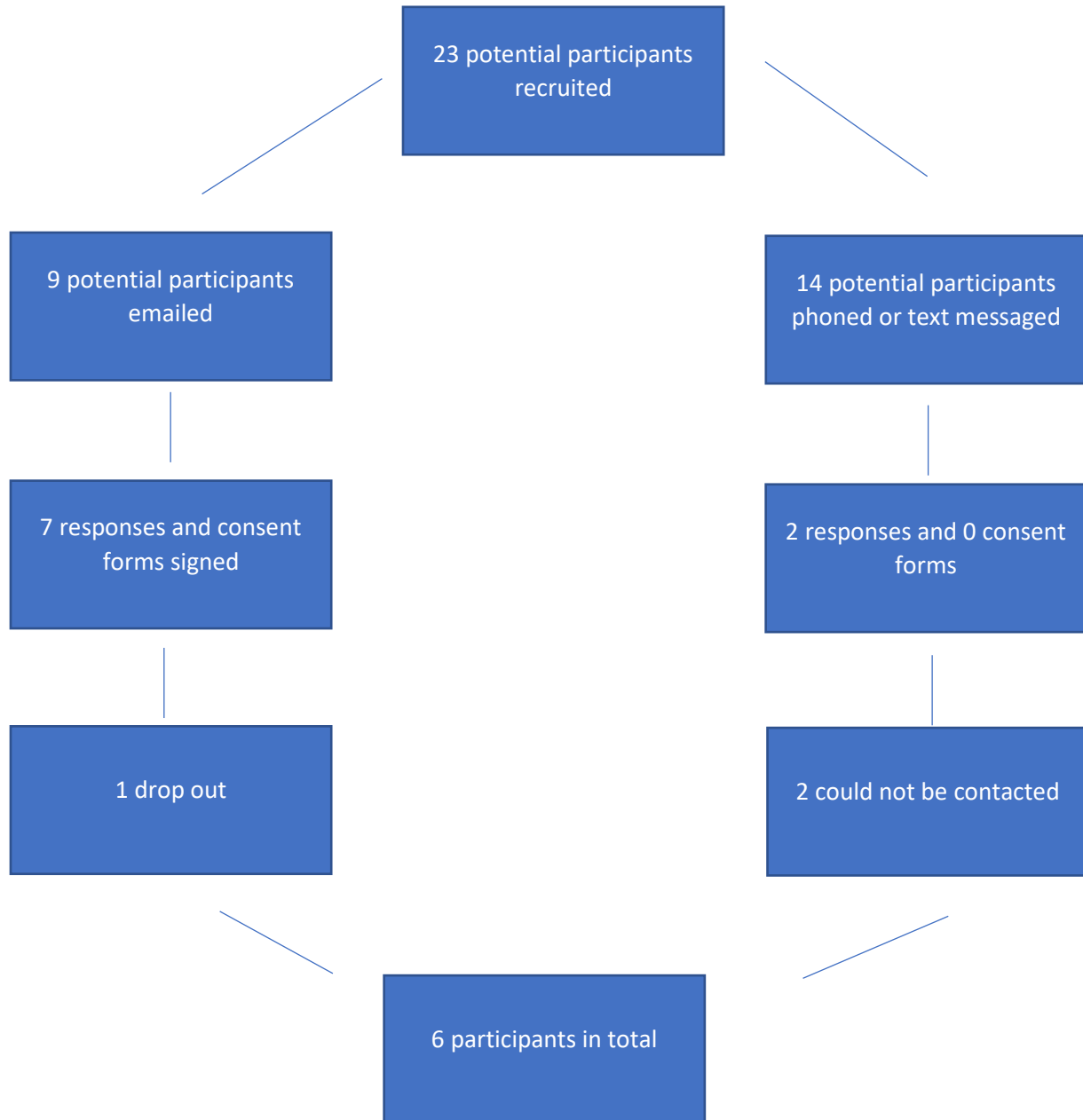
Meleis' Transition Model



Transitions: A Middle-Range Theory (Meleis et al., 2000)

Appendix C:
(Return to Previous Page)

Recruitment Flow Chart



Appendix D:

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Topic Guide (semi-structured interviews)

Demographic Data:

1. Hi, my name is Meagen, and I use her/she. How would you like me to refer to you?
(Name and pronouns). Is it ok for me to use the word 'you' when speaking to you?
Note: If the term "you" is not appropriate as per the participant I will ask what term is appropriate for use. If appropriate questions will be as follows.
2. How old are you?
3. How do you describe your ethnicity? (Ex. Caucasian, African American)
4. Are you in school? (What grade, how many credits left to complete)
5. Do you work right now? Have you in the past year? (Ex. Unemployed, working part-time/fulltime).
6. Do you live with someone? Who? (Ex. partner, family members) What kind of housing is it? (Ex. rooming house, own home, shelter).
7. How old were you when you started to notice your mental health concerns?
8. At what age were you diagnosed with a mental illness by a medical professional?
9. What are your diagnoses? (Primary vs. Secondary)

Interview Questions:

1. Can you tell me about your experiences with CAMHS? (Probe: First time you saw someone for mental health concerns)
2. What was it like when you learned that you would transition to AMHS (Probes: timing of when referral put in? When do you think it should have started?)

3. Can you tell me how you felt during the transition process? (If clarification needed:
When you met with the coordinator (Steve) and/or groups)
4. Can you tell me how you felt after the transition process? (If clarification needed: After
you left CAMHS)
5. Have you had an appointment with an AMHS worker yet?
6. Can you tell me about your experiences with AMHS? (Would you have found it
beneficial to have the coordinator with you at your first meeting).
7. What are some of the differences between CAMHS and AMHS?
(Probes: related to staff, culture, decision making, feeling understood, connected, feeling
judged)
8. What do you feel are some of the difficulties related to transitioning from CAMHS to
AMHS? (Probes: use tough parts instead of difficulties if issues with understanding,
feeling about provider, too many things going on, couldn't get there, didn't like the group
sessions).
9. What do you feel was helpful when transitioning from CAMHS to AMHS?
10. What do you think would have prepared you better for your transition?
(Probes: communication, parental support, meeting your new AMHS worker prior to
transition, booking an appointment with help, visit services ahead of time).
11. Did you feel ready/prepared to transition to adult services?
12. How would you describe your experience of transition as a whole?
Probes (aspects that are positive, negative, both)

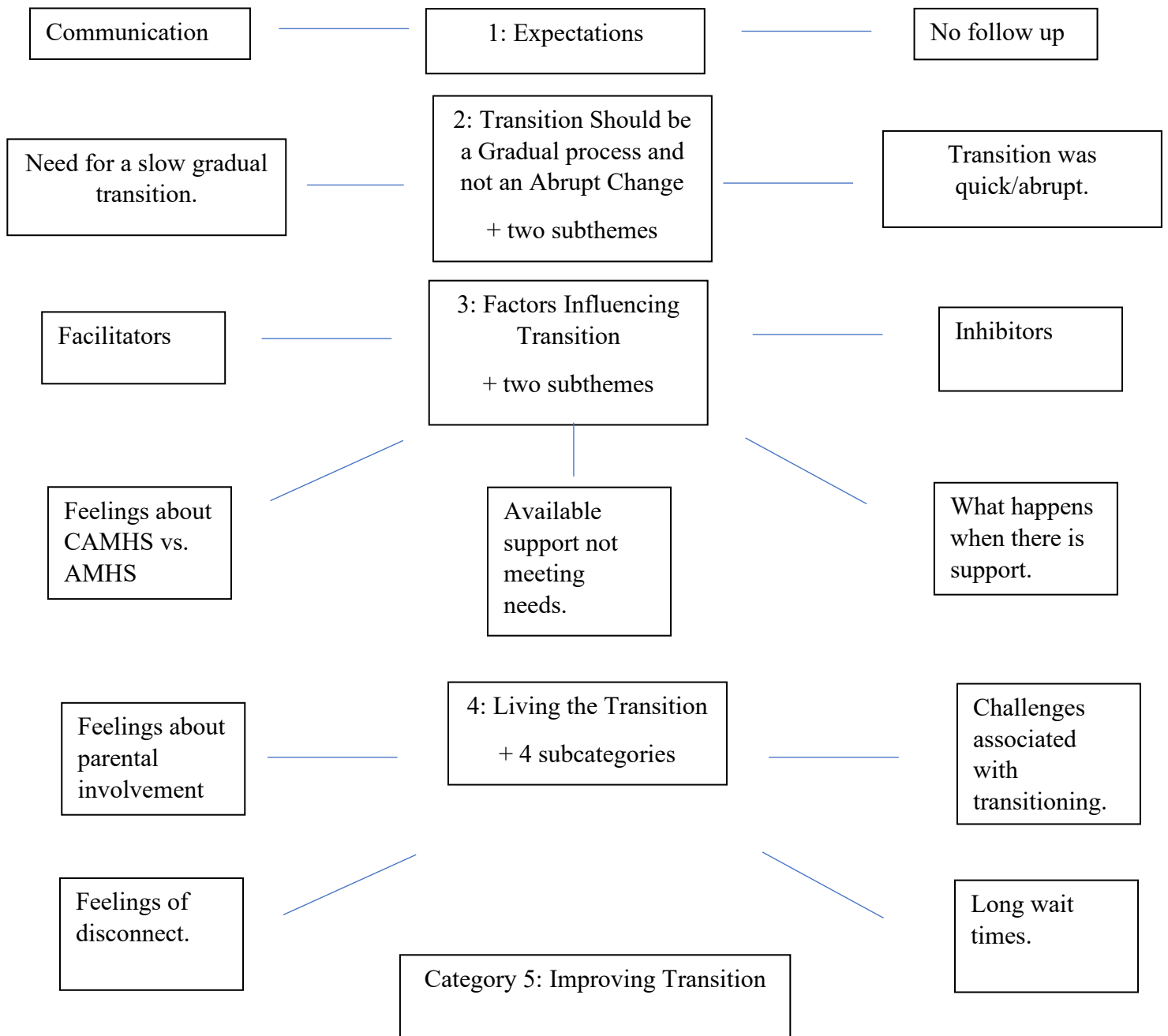
Transition Program Questions

1. Did anyone discuss transitioning with you in the program?

2. Was the transition process explained clearly? (If clarification needed: Did you know what to expect and how transition works?)
3. Did you participate in the CHEO mental health transitions group?
4. If you attended the group: What skills did you learn in the group session to better prepare you for transition?
5. Did the adult services you were referred to meet your needs?
6. Did you feel that you had a say in the decision making about what adult services you would be involved in?
7. Did you feel that your adult transitional plan was clear?

Appendix E:
 (Return to Previous Page)

Category Flow Chart



Appendix F:

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Information Sheet for Recruitment

Study title: Transitioning from Child/Adolescent to Adult Mental Health Services.

Dear, potential participants:

My name is Meagen McNeill, and I am a graduate student at the University of Ottawa in the Masters of Science in Nursing Program. I have worked as a nurse in the Emergency Department at the Children's Hospital of Eastern Ontario for the past 7 years. I have seen the increase in mental health issues that have occurred over the last several years and the gap between pediatric and adult mental healthcare.

I am conducting a study to explore young adults' transitions from Child and Adolescent Mental Health services (CAMHS) to Adult Mental Health Services (AMHS). The objectives are to describe the transition from CAMHS to AMHS from the perspective of patients and to identify barriers, facilitators and gaps in care that affect transition.

Participation in this study is voluntary. If you are interested in participating, the study would involve a one-time interview lasting approximately 60-90 minutes and will help find answers to these questions. The interview will be on a date and time that is convenient for you, once we have discussed the study, answered your questions, and you feel comfortable providing your consent.

Steve Dumouchel, who is the Coordinator for Transitional Mental Health Services for Youth at CHEO, contacted you because you meet our study inclusion criteria. The study findings will provide us with a more complete picture of the transition process from CAMHS to AMHS for those with a mental illness, including information about what makes an optimal transition and what is needed throughout the transition process. Information from the study might also help improve services offered at CHEO.

As compensation for your time, \$20 will be e-transferred to you after the interview. If you choose to withdraw from the study at any time, you will still receive this compensation, provided you leave an up-to-date email. If you experience distress as a result of study participation, you can contact the Ottawa and Region Distress Centre to speak with a mental health professional at 613-238-3311.

Thank you for taking the time to read this information and I hope to speak with you about your experiences.

Sincerely,

Meagen McNeill, RN, BScN

Appendix G:

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Informed Consent Form

Informed Consent Form

Study Title:

Transitioning from Child and Adolescent Mental Health services to Adult Mental Health Services.

Principal Investigator:

Meagen McNeill

INTRODUCTION

You are invited to participate in the above-mentioned research study due to a diagnosis of depression and/or generalized anxiety disorders and are in the process of transition or have already transitioned from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS). This consent form provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

Please take your time in making your decision. You may find it helpful to discuss it with your friends and family.

Taking part in this study is voluntary. You have the option to not participate at all or you may choose to leave the study at any time. Whatever you choose, it will not affect the usual medical care that you receive outside the study.

IS THERE A CONFLICT OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to explore young adults' transitions from Child and Adolescent Mental Health Care to Adult Mental Health Care. The specific objectives are:

1. To describe the transition from Child and Adolescent Mental Health Services to Adult Mental Health Services from the perspective of patients.
2. To identify barriers, facilitators, and gaps in care that affect transition from Child and Adolescent Mental Health Services to Adult Mental Health Services from the perspective of patients.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about twelve people will take part in this study, from research sites located in Ottawa, Ontario, Canada.

WHAT WILL HAPPEN DURING THIS STUDY?

You will be asked to participate in an interview. The interview will take between 60-90 minutes to complete and will take place either over the phone or through a video chat forum. You will be asked to provide information about your experience during your transition from CAMHS to AMHS. The information you provide is for research purposes only. If you feel uncomfortable about a question you can choose not to answer if you wish. Some questions may cause some emotional stress, especially if experiences during your transition were negative. If you do experience emotional distress, the interview can be rescheduled, and you will be provided with appropriate resources such as the Ottawa and Region Distress Centre so you can speak with a mental health professional. A follow-up phone call will also be done for all participants to answer any questions and allow for comments. You will be audio or video recorded depending on whether phone or video chat is used throughout the duration of the interview.

HOW LONG WILL PARTICIPANTS BE IN THE STUDY?

Your participation in this study will last for the duration of the interview and a follow-up phone call within 24-48 hours after the interview.

CAN PARTICIPANTS CHOOSE TO LEAVE THE STUDY?

You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. If you choose to withdraw from the study, you are encouraged to contact the research team.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the research team know. However, this would also mean that you withdraw from the study. If you decide to leave the study, you can ask that the information that was collected about you not be used for the study. Let the research team know if you choose this.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

There are no medical risks to you from participating in this study but taking part in this study may make you feel uncomfortable while discussing your experiences. You may refuse to answer questions or leave the interview at any time if you experience any discomfort. Your participation in this study will entail that you reveal personal information which may cause you to feel emotional or psychological distress. You have received assurance from the researcher that every effort will be made to minimize these risks such as ensuring your comfort level when speaking to the researcher, offering to reschedule interviews and offer resources if needed as well as a follow-up call.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You may not receive direct benefit from participating in this study, but it gives you an opportunity to express your experiences and needs. We hope that the information learned from this study will help other people with mental health issues have an optimal transition from CAMHS to AMHS in the future. Your participation in this study will help to provide insight into what young adults need to feel prepared for this. By choosing to participate in this study, the information you provide may enable positive change in the way the transition process is done in mental healthcare.

HOW WILL PARTICIPANT INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the research team will only collect the information they need for this study. Records identifying you will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document. Authorized representatives of the following organizations may look at

your original (identifiable) medical records at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The research ethics board who oversees the ethical conduct of this study
- This institution and affiliated sites to oversee the conduct of research at this location

Information that is collected about you for the study (called study data) may also be sent to the organizations listed above. Your name, address, email, or other information that may directly identify you will not be used. The records received by these organizations may contain your disclosed identifiers e.g., participant code, initials, sex, and date of birth. This research study is collecting information on race and ethnicity as well as other characteristics of individuals because these characters may influence how people respond and because there are substantial disparities in the health status between ethnic and racial groups. Providing information on your race or ethnic origin is voluntary.

Communication via e-mail is not absolutely secure. We do not recommend that you communicate sensitive personal information via e-mail. The video/audio recordings will be stored in a secure location and viewed only by members of the research team. The recordings will be kept until they have been transcribed (turned into written records) and then they will be destroyed. Any information that may indicate that you are being harmed or at risk of harm would not be kept confidential and instead be disclosed to appropriate authorities. All data collected in this research will be kept for a maximum of ten years in an encrypted file in a locked facility at the University of Ottawa. After the retention period has ended, all data will be destroyed. The use of virtual platforms, like any internet communication or storage and retention of information, involve privacy risks around access and disclosure of information. However, there are safeguards in place to reduce these risks (e.g., account registration, meeting passwords, disposal of records or devices on which information is stored).

The results of this research may be published in scientific journals and be presented to an audience at multiple times. If the results of this study are published, your identity will remain confidential. Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. If you would like a copy of the results upon completion of the study, please contact Meagen McNeill. If at this time you are not comfortable with the presentation of your information you will be invited to work with the research team to find a solution that works for you.

WHAT IS THE COST TO PARTICIPANTS?

Participation in this study will not involve any additional costs to you or your private healthcare insurance. The interviews will be scheduled at your convenience to ensure there are no costs such as childcare or missing work.

ARE STUDY PARTICIPANTS PAID TO BE IN THIS STUDY?

If you decide to participate in this study, you will receive \$20 by e-transfer as a thank you for your participation. If you choose to withdraw from the study at any time, you will still receive this amount, provided you leave an up-to-date email.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please let me, Meagen McNeill know, and I will send you a copy of the results. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is protected and respected.

By signing this form, you do not give up any of your legal rights against the researcher, nor does this form relieve the researcher of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

WHOM DO PARTICIPANTS CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, you can talk to the research team, or the person who oversees the study at this institution. That person is:

Meagen McNeill

Amanda Vandyk

Name

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study. That person is a member of the CHEO Research Ethics Board:

Cheo Research Ethics Board

613-737-7600 ext.3272

Name

Telephone

SIGNATURES

- All of my questions have been answered,
- I understand the information within this informed consent form,
- I allow access to related personal health information as explained in this consent form,
- I do not give up any of my legal rights by signing this consent form,
- I agree that my participation in this interview will be audio recorded for research purposes,
- I understand that the interviews will be conducted using Zoom, Teams or Skype that offer Advanced Encryption Standard, but have privacy risks associated with its use.
- I agree to take part in this study,

Signature of Participant

Printed Name

Date

Signature of Person Conducting
the Consent Discussion

Printed Name & Role

Date