“I always think about if I ever have a child that has to go through it [transition to adult healthcare], I wouldn't want them to have the same experience that I did.” – YA08

"Improving the Transition From Pediatric to Adult Healthcare:
Recommendations From Young Adults with Lived Experience"

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ABSTRACT

Background: With advancements in modern healthcare, an increasing number of youth with complex care needs now survive into adulthood. As healthcare service demands increase for this population, challenges exist for how to best facilitate meeting their high resource needs, particularly as they experience transitions in care. For young adults with childhood-onset chronic conditions (e.g., T1 diabetes, autism, and mental health conditions) and/or complex care needs, the transition from pediatric to adult healthcare is a critical time for both their overall life course and health outcomes. Throughout and following this transition, young adults are vulnerable to deteriorating outcomes, such as a decline in health status. Most studies exploring how to enhance service delivery outcomes focus on perspectives other than the young adults themselves. Seeking input from young adults directly about their experiences with health services is a key step towards improving service delivery. **Objective:** The aim of this dissertation was to better understand the experiences and service improvement recommendations of young adults with chronic conditions and/or complex care needs who transitioned from pediatric to adult healthcare services. **Methods:** A scoping review and qualitative descriptive research study were used to explore the recommendations and experiences associated with the transition from pediatric to adult healthcare, from the perspectives of young adults who have experienced this transition. **Results:** Recommendations identified in the scoping review included: 1) improving continuity of care; 2) facilitating patient-centred care; 3) building strong support networks; and 4) implementing transition education

preparedness training. In the qualitative descriptive study, prevailing themes for improving the experience of YAs in transition from pediatric to adult healthcare services included establishing: 1) continuity of care; 2) improved access to supports; 3) transition readiness; and 4) a patient-centred care team. **Conclusion:** Results from this dissertation will inform research, practice, and policy. The recommendations of young adults with chronic conditions and/or complex care needs present policymakers, healthcare providers, researchers, young adults, and families with practical transition service improvement strategies and actions.

DEDICATION

This work is dedicated to the brave young adults who took time from their busy lives to share recommendations for improving transitions in care, thereby helping to make a difference for others.

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List of Abbreviations

AAC	Adolescent Autonomy Checklist
AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
ACP	American College of Physicians
ADA	American Diabetes Association
ADAPT	Adolescent Assessment of Preparation for Transition
ADHD	Attention Deficit Hyperactivity Disorder
AHRQ	Agency for Healthcare Research and Quality
ASD	Autism Spectrum Disorder
CAHMI	Child and Adolescent Health Measurement Initiative
CAPHC	Canadian Association of Paediatric Health Centres
CCN	Complex Care Needs
CF	Cystic Fibrosis
CFPC	The College of Family Physicians of Canada
CHC	Children's Healthcare Canada
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institute of Health Research
CMA	Canadian Medical Association
CPS	Canadian Paediatric Society
CPSA	College of Physicians and Surgeons of Alberta
EMR	Electronic Medical Record

FMEC	Future of Medical Education in Canada
GNB	Government of New Brunswick
ICF	International Classification of Functioning, Disability and Health
IHI	Institute for Healthcare Improvement
IOM	Institute of Medicine
JBI	Joanna Briggs Institute
MCC	Medical Council of Canada
NB	New Brunswick
NBHC	New Brunswick Health Council
NICE	The National Institute for Health and Care Excellence
NBACL	New Brunswick Association for Community Living
NBMS	New Brunswick Medical Society
OECD	Organisation for Economic Co-operation and Development
PCC	Patient-Centred Care
PRESS	Peer Review of Electronic Search Strategies
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RHA	Regional Health Authority
SCD	Sickle Cell Disease
TRAQ	Transition Readiness Assessment Questionnaire
WHO	World Health Organization
YA	Young Adult

Chapter 1: Introduction

The purpose of this dissertation is to explore the lived experiences and recommendations of young adults (YA) with chronic conditions and/or complex care needs (CCN) for improving transitions from pediatric to adult healthcare. This dissertation follows the general format for an articles-based thesis and includes five chapters: an introductory chapter, three publishable manuscripts, and a concluding chapter (Morris & Tipples, 1998). Chapters two through four in this articles-based dissertation present stand-alone manuscripts written for targeted peer-reviewed journals. The current chapter presents: an introduction, the background, objective, and context for this doctoral research; the predisposition of the researcher; the guiding philosophical framework; and the adopted interdisciplinary approach. This chapter concludes with descriptions of how each chapter fits within the overall framework of the dissertation.

Background

Advances in healthcare have resulted in record numbers of YAs with childhood-onset conditions and/or complex care needs (CCN) living well into adulthood and thus requiring ongoing healthcare services (Brenner et al., 2018; Cohen et al., 2018; Goodwin et al., 2020). CCN represent an array of health and social care needs in the presence of a recognized condition, with or without a diagnosis (Brenner et al., 2018). Regrettably, YAs presenting with a variety of different conditions and CCN report high levels of stress and low levels of preparedness as they navigate new and unfamiliar adult healthcare services (Andrade et al., 2017; Travis et al., 2020; Varty et al., 2020). Typically, YAs are required to leave pediatric care around the age of 18 during a complex time when life transitions arise concerning education, employment, health, and relationships (Canadian

Association of Paediatric Health Centres [CHC], 2016; Cheak-Zamora & Teti, 2015; Viktorsson et al., 2022; White et al., 2023; Wood et al., 2018). This transfer to the adult health system is a one-time event and is signaled by the completion of services received from pediatric care (Canadian Association of Paediatric Health Centres [CHC], 2016). It is important to note that the age of transfer for adult healthcare ranges depending upon factors such as the region (e.g., ages 16-19 in Canada, and ages 18-21 in the US) and the YA's developmental ability (Toulany et al., 2022; White et al., 2023).

The transfer event is one component within the overall process of transitioning from pediatric to adult healthcare. The transition process represents a broader period (e.g., ages 12–26) and is categorized as a purposeful and planned process (Blum, 2002). It involves the movement from child-centred to adult-oriented care, and includes pre- and post-transfer stages (Blum, 2002; Schmidt et al., 2020; White et al., 2023). Supporting YAs with the services required for a successful transition to adult healthcare during this critical developmental period can have lasting effects throughout their life course (Goralski et al., 2017; Harris, 2010; Murray et al., 2020). However, many YAs experience barriers during their transition from pediatric to adult healthcare services as a result of discontinuities in care, lack of transition planning and programming, gaps in acquiring self-management skills, and a knowledge deficit among healthcare providers (Khetarpal et al., 2022; Ryan et al., 2023; Schraeder et al., 2021).

Barriers to Transitions in Care

Addressing the hurdles faced by YAs when leaving pediatric care is challenging for YAs, their families, and service providers due to a wide-ranging scope of barriers, which span across sectors and settings (Butler, 2021; Gray et al., 2018). These

difficulties during the transition to adult healthcare have been attributed to: (a) fragmentation in care (Charlton et al., 2017; Government of New Brunswick, 2021a); (b) a lack of transition planning and programming (Khetarpal et al., 2022; Lebrun-Harris et al., 2018; McKay, 2019), (c) a lack of self-management skills (Cassidy et al., 2022; Ryan et al., 2023), (d) a lack of healthcare provider training (Schraeder et al., 2021; Splane et al., 2023), and (e) a need for more input from YAs with lived experience (Okumura et al., 2022; Sobota et al., 2015; White et al., 2023).

Fragmentation in care. As YAs leave pediatric care, they are confronted with many changes to service delivery when they transition to the adult healthcare system (Canadian Association of Paediatric Health Centres, 2016; Canadian Institute for Health Information [CIHI], 2020; Langmaid et al., 2020). YAs, who would have received pediatric care and supports, in some cases for 18 years from one primary care provider, find themselves trying to navigate what can be a confusing adult system, post-transfer. This transition can involve transferring to new providers to meet their adult needs (Canadian Association of Pediatric Health Centres, 2016).

Unfortunately, these YAs may be unable to find equivalent services within the adult system (Glauser, 2018; White et al., 2023; Withers & Green, 2019). Moreover, when these YAs do transfer to healthcare providers within the adult healthcare system, research suggests they encounter resource and personnel limitations (Ontario Health, 2022; Philbin et al., 2017; Singh & Tuomainen, 2015; Steinway et al., 2017). For example, when appointments are secured, they can be shorter in duration (Kvarnström et al., 2021; Schraeder et al., 2021), families may no longer be involved as they once were (Kerr et al., 2020; National Institute for Health and Care Excellence, 2016), and

the new healthcare providers may lack detailed information about the YA's prior medical history (Chouteau & Allen, 2019; Philbin et al., 2017; White et al., 2023). Compounding matters, many healthcare providers also lack flexible funding and payment structures for transition planning (McManus et al., 2018; Toulany et al., 2022).

In addition to these challenges, YAs can also experience an unanticipated loss of health insurance due to aging out of their family's plan (Butler, 2021). Loss of insurance can severely impact YAs' ability to afford or access quality care (e.g., maintaining costly prescriptions or professional services such as psychologists) (Moroz et al., 2020). Disruption of such services throughout the transition process can lead to: (a) discontinuity of care (Jarvis et al., 2021; Sheehan et al., 2015; Toulany et al., 2019); (b) reduced medication adherence (Butler, 2021; Campagna et al., 2020); (c) increased ER visits and hospitalizations (Butler, 2021; Shepard et al., 2018; Vaks et al., 2016); and (d) increased mortality (Calhoun et al., 2019; Kakkar et al., 2016; Varty et al., 2020).

Lack of Transition Planning. Transition planning is a process that should begin in early adolescence around the age of 12 with youth and their families and continue until the YA can successfully manage their conditions within the adult healthcare system (e.g., demonstrates self-management behaviours) (Betz et al., 2021; Mahan et al., 2017). Adequate planning for the transition from pediatric to adult healthcare is referenced by several clinical guidelines for healthcare transitions (Betz, 2017; Canadian Association of Paediatric Health Centres, 2016; National Institute for Health and Care Excellence [NICE], 2016; Lestishock et al., 2020; White et al., 2023). Indeed, best practice guidelines recommend that both health and social care providers should consider each

YA's individualized needs and that structured planning should occur during meetings with the YA, their family, and the various providers involved in their care (Colver et al., 2018; Lestishock et al., 2020; National Institute for Health and Care Excellence, 2016; Toulany et al., 2022). Transition planning programs are generally designed to assess patient self-management, develop transition readiness, create health summaries, and may offer additional resources (e.g., educational sessions, tools) (Canadian Association of Paediatric Health Centres, 2016). These programs exist in a variety of settings; however, a recent scoping review found that hospitals and medical institutions with an academic focus were amongst the most common (Doucet et al., 2022).

Despite clinical recommendations advocating for this structured transition planning, barriers remain to adopting this practice and many YAs still lack access to formalized transition programming (Brandon et al., 2019; Butler et al., 2021; Khetarpal et al., 2022; Lebrun-Harris et al., 2018; Mubanga et al., 2017; Nadarajah et al., 2021; Varty et al., 2020). Difficulty in providing structured transition programming may be linked to a lack of financial support from within the clinical and healthcare systems (Hobart & Phan, 2019; Nadarajah et al., 2021; Stepien et al., 2021). For instance, providers may face challenges while conducting transition planning due to a lack of billing support for these activities (Hobart & Phan, 2019; Schraeder et al., 2021). Moreover, in the US, healthcare providers may encounter restrictions in billing certain aspects of transition planning, such as preparing or updating the care plan, due to a lack of established codes that are reimbursed by payers (McManus et al., 2020). Overcoming barriers to securing funding for transition programs targeted at YAs with chronic conditions (e.g., mental health) and/or CCN, has been attributed to extensive political

advocacy campaigns and can be bolstered with evidence of programming evaluation outcomes (McGorry et al., 2022).

When transition planning activities do occur, several practice-based challenges exist (Colver et al., 2018; Cleverley et al., 2020). One such barrier is that healthcare providers have reported concern over spending time creating transition planning documents when these plans may not be adopted by other healthcare providers (Colver et al., 2018). An added barrier includes a lack of evidence and policies describing ways that primary care providers could be directly involved with the transition planning process, particularly with YAs requiring mental health services during this transition (Cleverley et al., 2020; Steinway et al., 2017). Specifically, an identified gap in the planning process is the absence of a well-defined framework outlining the roles and responsibilities for each member of the care team in areas such as patient education (Hobart & Phan, 2019). Indeed, a recent position paper regarding youth and YAs with cancer reported that challenges exist in accessing services, such as transition planning, for this population, and these challenges were exacerbated by a shortage of specialized centres offering age-appropriate, multi-disciplinary care (Ferrari et al., 2021). Moreover, concern exists about how healthcare providers can integrate the transition planning process into their full clinical workloads (Cleverley et al., 2020; Nguyen et al., 2016). Given challenges such as these, research generally indicates that few youth receive transition planning support from healthcare providers (Centres for Disease Control and Prevention, 2022; Lebrun-Harris et al., 2018).

A lack of access to transition programming may also be impacted by geography. For example, youth and YAs with type 1 diabetes and epilepsy living in rural

communities reported a lack of services or less comprehensive services during transition to adult healthcare, compared to those living in larger cities (Jacobs, 2020; Perry et al., 2012). Further, one study suggested that due to insufficient infrastructure and financial resources for health services for youth and YAs in rural areas, that alternative service settings such as school-based or community healthcare should be considered (Jacobs, 2020). By and large, it is evident that youth and YAs continue to struggle with barriers during this transition process (Malik-Soni et al., 2022; Margolis et al., 2017; Rich, 2017; Roberts et al., 2020).

Lack of Self-Management Skills. Beyond receiving the appropriate healthcare provider supports and resources, managing one's own health condition(s) has been considered an essential outcome for YAs transitioning to adult healthcare (Toulany et al. 2022; White et al., 2023). This self-management can include skills such as adhering to prescribed medication regimens and booking medical appointments (Betz et al., 2021; Lozano & Houtrow, 2018). Regrettably, studies have demonstrated that many youth and YAs do not acquire these necessary skills for self-management, leaving some to rely on their family members to support and manage their healthcare (Betz et al., 2021; Schuiteman et al., 2020).

Furthermore, these deficits in knowledge and skills related to self-management and self-advocacy can lead to increases in mortality and morbidity (Frederick et al., 2017; Margolis et al., 2017; Town et al., 2023). As such, the development of patient self-management skills should be a key part of transition programs and practice (Canadian Association of Paediatric Health Centres, 2016; Stewart et al., 2017). Of course, it must be noted that some YAs with chronic conditions and/or CCN must rely

on continued care management support from their caregivers into adulthood due to an incapacity for making their own healthcare decisions (Redley et al., 2013).

Lack of Healthcare Provider Training. In addition to YAs expressing challenges in effectively overseeing their own care, healthcare providers also identify a corresponding deficit in their own knowledge and training on managing the needs of YAs as they transition into adult healthcare services (Canadian Association of Paediatric Health Centres, 2016; Malik-Soni et al., 2022). Care providers attribute this gap in their knowledge to a lack of formalized training concerning transitions in care during their pre- or post-licensure training (e.g., residency placements, continuing education credits) (Schraeder et al., 2021). A recent Canadian study featuring feedback from primary healthcare providers reiterated that this knowledge gap on transitions in care further resulted in lack of knowledge surrounding available professionals and services to assist youth and YAs (Schraeder et al., 2021). Consequently, due to a lack of provider familiarity about services for youth and YAs with chronic conditions and/or CCN, these patients may miss out on acquiring resources (e.g., community-based services) (Schraeder et al., 2021). Important content areas identified by providers for these training programs include YA development, childhood-onset diseases, and healthcare transition processes (Canadian Association of Paediatric Health Centres, 2016; Cooley et al., 2011; Toulany et al., 2022; Tsang et al., 2022; White et al., 2023). Moreover, in alignment with current guidelines, it is recommended by healthcare providers that this training should be accessible to all healthcare providers across different settings involved with transitional care (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022).

Current Transition Guidelines

To address the barriers that have been identified when transitioning from pediatric to adult healthcare, clinical guidelines specific to this transition period are beginning to emerge throughout the world (Canadian Association of Paediatric Health Centres, 2016; Lestishock et al., 2020; Pape & Ernst, 2022). For instance, in the U.K., evidence-based transition recommendations for health and social work professionals are available from the National Institute for Health and Care Excellence (National Institute for Health and Care Excellence, 2016). Their guidelines were developed by an evidence review committee formed of health and social care providers, service users, and family members or carers (National Institute for Health and Care Excellence, 2016).

In the United States, the AAP/AAFP/ACP released joint report guidelines updating pediatric-to-adult health services recommendations in *Supporting the health care transition from adolescence to adulthood in the medical home* (Cooley et al., 2011; White et al., 2023). The peer-reviewed report was developed by AAP/AAFP/ACP members, healthcare providers (e.g., internal medicine-pediatrics), allied health providers, along with YA and family experts in transitions in care (White et al., 2023). This report supplies best practices on transition planning for youth and YAs, transition barriers, and quality improvement outcomes (White et al., 2023).

In Canada, Children's Healthcare Canada developed transition guidelines to provide guidance and resources to stakeholders, such as healthcare providers, on the transition process from pediatric to adult health services (Canadian Association of Paediatric Health Centres, 2016). Other pediatric institutions have also produced their

own organization-specific guidelines and committees (BC Children's Hospital, 2023a; Boston Children's Hospital Social Work Transition Committee, 2023; IWK Health Centre, 2023; SickKids, 2021). Children's Healthcare Canada (CHC) published their transition guidelines in 2016 in a document titled: *A guideline for transition from paediatric to adult healthcare for youth with special healthcare needs: A national approach* (Canadian Association of Paediatric Health Centres, 2016). This national guideline was developed in consultation with a multi-disciplinary team, including youth, YAs, and their families (Canadian Association of Paediatric Health Centres, 2016). These recommendations were informed by research findings, along with expert opinion (Canadian Association of Paediatric Health Centres, 2016). A corresponding website featuring the CHC guidelines was also developed for clinicians, patients, and their families (Canadian Association of Paediatric Health Centres, 2016).

Evidence-based transition guidelines developed by CHC offer a structured framework for improving patient healthcare (Canadian Association of Paediatric Health Centres, 2016). Their findings and recommendations targeted transition improvement initiatives at both the patient and clinical level, with the overarching goal to influence long-term health system outcomes (Canadian Association of Paediatric Health Centres, 2016). The three principal areas of recommendations they provide include (a) person-centred care; (b) clinical care; and (c) systems-related suggestions (Canadian Association of Paediatric Health Centres, 2016).

When examining the evidence, the CHC (2016) committee identified 19 main recommendations (within the three categories above) for improving transitions from pediatric to adult healthcare services. These recommendations focus on patient-centred

care, such as: (a) respecting their choices; and (b) addressing the various needs of patients (e.g., physical, mental health, lifestyle, educational, and financial) (Canadian Association of Paediatric Health Centres, 2016). CHC guidelines further indicate that transitions can be improved in clinical practice when healthcare providers: (a) build their capacity for engaging and educating YAs and families; (b) partake in collaborative communication between pediatric and adult healthcare providers, such as sharing patient medical summaries on transfer to adult services; (c) conduct structured transition planning activities; (d) assess transition readiness; and (e) prioritize care coordination for youth with CCN and their families (Canadian Association of Paediatric Health Centres, 2016). CHC systems-level recommendations included: (a) adopting written transition policy; (b) developing efficient health information systems to improve cross-sector communications; (c) establishing transition champions; (d) ongoing transition education for stakeholders; (e) collecting mixed-methods data for improving clinical practices; and (f) involving YAs, families, and policymakers to identify transition enablers and barriers (Canadian Association of Paediatric Health Centres, 2016).

To support the activities of healthcare providers in adopting CHC guideline recommendations, decision makers are encouraged to facilitate the adoption of EMRs into health service settings (Canadian Association of Paediatric Health Centres, 2016; Disabato et al., 2015; Wiemann et al., 2015). Decision makers and clinicians are also encouraged to assist patients with access to primary care supports throughout the transition process and to help in their transition preparedness (e.g., self-management skills) (Canadian Association of Paediatric Health Centres, 2016; Davidson & Doyle, 2021; Toulany et al., 2022). For these recommendations to be implemented during

patient-provider interactions, healthcare providers in both pre- and post-licensure programs are encouraged to partake in ongoing education about transitions in care (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022; White et al., 2023). Importantly, decision makers, care providers, and researchers are encouraged by CHC to develop innovative ways to support the transition of youth throughout their journey into adult healthcare services (Canadian Association of Paediatric Health Centres, 2016). For those seeking transitions in care guidelines that are institute-specific, SickKids in Toronto, Canada, has prescribed ways that pediatric and adult clinicians can facilitate the transition process (SickKids, 2021). Notably, their *Guidelines for transition from pediatric to adult care* specify the competencies that youth and YAs (ages 10–18) should acquire before the final transfer to adult healthcare (e.g., awareness of their medications) (SickKids, 2021).

In 2022, the Canadian Paediatric Society (CPS) produced clear clinical recommendations in *A call for action: Recommendations to improve transition to adult care for youth with complex health care needs* (Toulany et al., 2022). The CPS position statement, developed by clinicians and an Adolescent Health Committee, calls for early transition planning and care support, the establishment of a transition plan, and ensuring sustained support for YAs after their transition to adult healthcare (Toulany et al., 2022). To achieve successful transitions, the CPS advises that the transition process should be continuous and coordinated, entail a stepwise and individualized plan, and involve an integrated and patient-centred approach that is developed collaboratively with pediatric and adult care providers (Toulany et al., 2022). The CPS also encourages new educational initiatives to be developed to increase the capacity of care for youth and

YAs in diverse clinical settings (Toulany et al., 2022). Furthermore, they reiterate the importance of transitions in care training for care professionals and call for them to receive appropriate remuneration for their services (Toulany et al., 2022). Above all, Toulany et al. (2022) highlight the urgent need for professionals from across sectors to improve the integration of care services so youth can avoid disengagement from health services and negative health outcomes.

Transition Resources and Services

To address the challenges YAs may encounter during the transition from pediatric to adult healthcare, a variety of transition programs and resources are now available (Marani et al., 2020; Moons et al., 2021). Recent programs and models developed to improve transitions in care outcomes (e.g., access to services) are typically structured so youth or YAs interact with a multidisciplinary team which may include diverse supports, such as transition program facilitators and educational workshops (Malik-Soni et al., 2022; Marani et al., 2020; Moons et al., 2021; Schmidt et al., 2018). The aims of these programs may involve improving patient education levels for managing their health condition, assessment of transition readiness, and opportunities for peer support (Cleverley et al., 2020; Johnson et al., 2020; Maddux et al., 2020; Schmidt et al., 2020). Usually, these programs focus on addressing the needs of patients having one primary chronic condition and are often offered in healthcare settings, such as outpatient clinics or within pediatric hospitals (Gauci et al., 2022; John et al., 2022; Johnson et al., 2020).

Such programs and corresponding tools for enhancing the continuity of care during transitions are unfolding throughout North America. For example, the Got

Transition® clinical program is a transition resource developed in the United States which is endorsed by the AAP/AAFP/ACP for healthcare providers, youth, YAs, and their families (Got Transition, 2022; White et al., 2023). The federally supported Got Transition® program offers a structured approach to improve the integration process of youth into YA healthcare, known as the Six Core Elements™ (White et al., 2020). The Six Core Elements™ framework (transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer completion) provides important resources for clinicians to focus on patient milestones and outcomes throughout the entire transition process, from pediatrics to adult healthcare integration (Cleverley et al., 2020; White et al., 2020). As of now, this framework has not yet undergone validation (Got Transition, 2022). To further avoid discontinuities in the transfer of information as youth and YAs leave pediatric services, a recently proposed program involves a joint visit with the pediatrician, adult healthcare provider, and transferring YA to ensure these communications are shared in a continuous way (Colver et al., 2019; Corsello et al. 2021; Pape & Ernst, 2022; White & Greenberg, 2022). The Telehealth Toolkit, a resource for clinicians developed by Got Transition®, is designed to improve communications during a YA's dual visit with their pediatric and adult healthcare providers (White & Greenberg, 2022).

Surrey Place, a centre composed of satellite locations in Toronto, Canada, specializing in programming for youth and YAs (ages 12–21) with intellectual and developmental disabilities, has developed a medical summary template to support this transfer of information (Surrey Place, 2019). The template is called the SHARE Transition Plan Health Care Toolkit (Henze et al., 2019; Surrey Place, 2019). The

province of BC has also adopted the ON TRAC program for youth or YAs (ages 12–24) with chronic conditions and/or CCN, and their families or caregivers (BC Children's Hospital, 2022). This program offers a toolkit and resources focused on developmentally appropriate care aimed to enhance continuity when transferring to adult healthcare (BC Children's Hospital, 2022). The program incorporates a readiness checklist along with a multidisciplinary care plan (BC Children's Hospital, 2022). Alberta Health Services also offers the Well on Your Way transition program, which features a website to teach youth, YAs, and their families how to manage their healthcare needs and prepare for the transfer to adult healthcare (Alberta Health Services, 2022). The program prompts youth to bring someone to their healthcare appointments for support, based on their preference (Alberta Health Services, 2022).

Of late, transition planning resources are expanding to include online portals where patients can securely access their own medical records. YAs owning their medical details can facilitate continuity of care while mitigating medical file loss due to the fragmented electronic documentation systems of various providers (i.e., healthcare clinics, health authorities, or provincial boundaries). Just TRAC It!, which is part of the ON TRAC Transition, is one example of a continuous record (BC Children's Hospital, 2023b). Created by BC's Children's Hospital, it allows youth and YAs (e.g., ages 16–18) to share their pediatric medical history (Han et al., 2021). The tool, housed on the patient's smartphone or tablet, was developed by the Partners in Care Youth Advisory Council (BC Children's Hospital, 2023b). Another example is the Ontario SickKids hospital's MyChart, which allows patients to share their medical history (SickKids, 2022b). The SickKids transition program has also developed a tool named the MyHealth

3 Sentence Summary to help coach youth to communicate their medical history, treatment plan, and concerns to discuss during the initial visit in adult health services (SickKids, 2022c).

Transition planning can be further facilitated by healthcare providers developing the proper knowledge and skills related to caring for YAs with chronic conditions and/or CCN (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022). Indeed, transition programming resources now exist to improve the transitions in care competencies of health providers. For example, healthcare providers may attend related learning opportunities with reputable institutions, such as the University of British Columbia's Mainpro accredited online program Transitioning to Adult Care for Youth with Chronic Health Conditions and Disabilities or Health Services for Children with Special Needs' Health Professional Education modules (Health Services for Children with Special Needs, 2023; University of British Columbia, 2022).

Along with improving transition planning, a designated support person (e.g., 'champion' or 'transition coordinator') is another solution that transition programs have implemented to help YAs navigate through the transition process (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022). Such designated persons can offer support with care coordination, planning, education, navigation, as well as emotional and administrative support (Annunziato et al., 2013; Dimitropolous et al., 2019; Hillis et al., 2016). For instance, Toronto's SickKids hospital offers a navigation service for patients with supervision from their Social Work Department (SickKids, 2022a). The role of a transition coordinator has also been trialed in Alberta at a clinic for youth (aged 17) and YAs (aged 18) having type 1 diabetes which resulted in improved

clinic attendance; yet ER visits and hospitalizations for diabetic ketoacidosis occurred at the same rate in the usual care and intervention groups (Butalia et al., 2021).

Finally, peer support is another type of programming that can focus on improving transitions in care. Peer support programs represent an emerging area of interest and can be offered in a formally structured way for youth and YAs by health clinics or community health organizations (Canada's Drug and Health Technology Agency, 2023; Halsall et al., 2021; MacDonald et al., 2019). A systematic review assessing peer support interventions for youth and YAs (up to age 18) with chronic conditions and/or CCN found that peer supports improved the behavioural and emotional health outcomes of youth and YAs with chronic conditions (Kohut et al., 2014). Bomba et al. (2017) report that peer transition programs could help youth and YAs (15–27 years) with chronic conditions in acquiring valuable information about medical issues. It is important to note that most peer support research and recommendations to date have focused on specific health conditions, such as cancer, type 1 diabetes, and schizophrenia (T1DM) (Ashrafi et al., 2021; Cassano et al., 2008; Chien et al., 2019). For instance, in the US, YAs with type 1 diabetes participated in a psychologist-led peer support group over a span of five months (Markowitz & Laffel, 2012). Although the pre- and post-intervention analysis did not reveal significant differences in glycemic control, the study did discover a noteworthy reduction in diabetes distress levels among participants (Markowitz & Laffel, 2012). Overall, the efficacy of peer support programs for youth and YAs having conditions such as mental and behavioral health issues, as well as various chronic physical conditions, remains in

its early stages of exploration (Canada's Drug and Health Technology Agency, 2023; Gopalan et al., 2017; Zimmerman et al., 2022).

Despite the existence of these training modules, national guidelines, programs, and resources for YAs, their families, and healthcare providers, this population continues to experience difficulty navigating this transition (Dimitropolous et al., 2015; Kokorelias et al., 2023; MacNeill et al., 2022). Recent studies reaffirm that YAs continue to struggle with securing continuous healthcare services post-pediatrics, accessing developmentally appropriate care, and developing the skills needed for post-transfer success to adult healthcare (Calleja et al., 2020; Malik-Soni et al., 2022; Murray et al., 2022; Ryan et al., 2023). Further, providers express a gap in receiving necessary transitions in care training (Schraeder et al., 2021; Splane et al., 2023).

With the recent release of transitions in care guidelines by bodies such as the CPS and the CAPHC, clinicians and decision makers now have clear suggestions for how to improve continuity of care, bolster access to services, and refine the knowledge and skills of both YAs and their providers for managing transitions (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022). However, the existing discrepancy between these guideline recommendations and observed practices suggests a potential shortfall in current guideline implementation. Indeed, outstanding questions remain as to why barriers persist for YAs, attributed to factors such as care fragmentation, inadequate access to transition programming, ongoing gaps in self-management skills for YAs, and knowledge deficiencies among providers concerning transitions in care. The disparities between these expert recommendations and the current state of transition-related services and resources underscore the need for a

thorough investigation into these issues. To help overcome these barriers, further research is needed from the perspectives of YAs with lived experience to better understand their requirements for optimizing transitions in care service delivery.

YAs Lived Experiences

Although this trend is shifting, evidence suggests that considerable research on transitions to adult healthcare has been derived from the experiences of care providers and clinicians (Betz et al., 2013; Gray et al., 2021; Morsa et al., 2018; Okumura et al., 2015; Pape & Ernst, 2021; Schraeder et al., 2020). However, YAs may identify and prioritize issues differently from other stakeholders (e.g., their clinicians) (Gibson-Scipio et al., 2015; Morsa et al., 2017). For example, generalized studies examining YAs seeking healthcare, including one study on type 1 diabetes (Balfe et al., 2013), emphasize YAs desire to establish emotional connections with their care provider during appointments. However, the provider, due to time limitations during an appointment, may be focused on other aspects of the visit such as processing biomedical information and symptom management (Balfe et al., 2013; Viktorsson et al., 2022). Gathering firsthand perspectives from individuals who have interacted with healthcare services, commonly referred to as research participants with lived experience, is increasingly recognized for its benefits in healthcare research (Breault et al., 2018; Cadel et al., 2022). Capturing insights from patients regarding their experiences not only serves to amplify the voices of those seeking care, but also enables health systems to enhance the overall quality of their services (Cadel et al., 2022). Furthermore, interviewing YAs who have gone through this transition process to hear about their experiences can help: (a) sustain and increase the active involvement of YAs with adult healthcare services (Bombard et al., 2018; Hislop

et al., 2016); (b) inform and improve transition interventions (Betz et al., 2013; Schraeder et al., 2021); and (c) develop transition policies (Committee on Improving the Health, Safety, and Well-Being of Young Adults et al., 2015; Dave et al., 2023; Lachance & Canas, 2018; Steinway et al., 2017). In addition to research participation, a recent study on improving healthcare transitions suggested that acquiring direct input from YAs when developing research on transitions in care is also critical to improving outcomes such as YA experiences and healthcare utilization (Okumura et al., 2022). Moreover, designing primary health services that are informed by YAs with chronic conditions and/or CCN can help organizations to achieve improved service (Allen et al., 2022; Lee, 2019). Overall, capturing the recommendations of YAs with chronic conditions and/or CCN, based upon their recent transition from pediatric to adult services, is a necessary step towards improving service delivery outcomes.

Dissertation Objective

As the number of youth with chronic conditions and/or CCN transitioning to adult healthcare grows, healthcare providers find themselves grappling with how to best meet the service delivery needs of this population (Betz et al., 2023; Brenner et al., 2018; Toulany et al., 2022). In response to this rising challenge, transition models and programs have been developed to improve outcomes (Beaudry et al., 2019; McGorry et al., 2019; Mora et al., 2020; Vaks et al., 2016). Regrettably, despite new models and research initiatives aimed at improving transitions from pediatric to adult healthcare, poor outcomes continue to be reported by YAs (e.g., higher rates of emergency department visits, disengagement with health services) (Garvey et al., 2022; Murray et al., 2022; Tsang et al., 2022). Although several studies have explored improving these transitions in

care, many YAs with varied chronic conditions (e.g., physical disabilities, neurodevelopmental, rheumatic diseases) have been unable to gain access to structured programming as they transition from pediatric to adult healthcare for numerous reasons, such as a lack of dedicated clinics (Fergus et al., 2022; Johnson et al., 2021; Shanahan et al., 2021). Moreover, when it comes to research on improving service delivery during transitions, many of the recommendations come from the voices of care providers, as opposed to the voices of youth or YAs with lived experience (Gray et al., 2021; Johnson et al., 2021; Morsa et al., 2018). Thus, there is a need to further explore and understand YA experiences and recommendations to improve their transitions in care, as articulated directly by the YAs themselves (Betz et al., 2023; Gabriel et al., 2017; White et al., 2023). Indeed, given that YAs continue to experience barriers to transition (Calleja et al., 2020; Malik-Soni et al., 2022; Murray et al., 2022), further investigation is warranted. Specifically, there is a keen interest in understanding if there are certain contextual factors (e.g., geographic location) that impact YAs experiences transitioning from pediatric to adult healthcare services. The aim of this dissertation is to better understand the experiences and service recommendations of YAs with chronic conditions and/or CCN who have transitioned from pediatric to adult healthcare services, as viewed from the perspective of the YAs themselves. The overarching research question for this dissertation is: *What are the experiences of young adults with chronic conditions and/or CCN who transferred from pediatric to adult healthcare and what are their recommendations on how to improve this transition in care?*

Context: Manuscripts One and Two

The content within manuscripts one and two feature settings that reflect an international context. Specifically, the scoping review protocol (Chapter 2) and scoping review (Chapter 3) included studies that presented the recommendations of YAs on their transition experiences from within North American and European healthcare settings. Therefore, many of the studies from the scoping review were set in healthcare systems classified as either universal or mixed (e.g., publicly, and privately funded) (Canadian Institute for Health Information, 2023; International Society for Pharmacoeconomics and Outcomes, 2023).

Context: Manuscript Three

While the content in manuscripts one and two feature settings that reflect an international context, the content in manuscript three reflects the perspective from a small Canadian province. As such, the barriers to transition occurring within these settings may be region-specific, stemming from differences in the levels of resources and healthcare infrastructure, such as staffing and the range of services available. The setting for the primary study (Chapter 4) was New Brunswick (NB), a small Canadian province where just over half of the population lives in rural areas (Statista, 2022). Canada has a universal and publicly funded healthcare system (Medicare) which is administered by each province (Government of Canada, 2019). The healthcare system within NB is composed of two Regional Health Authorities (RHAs) called Horizon Health Network and Vitalité Health Network. Horizon Health Network supports the central and southern portions of the province (12 hospitals and 28 health centres/clinics), and Vitalité Health Network supports the northern and southeastern areas (11 hospitals and

9 health centres) (Horizon Health Network, 2023a; Vitalité Health Network, 2023a). Both RHAs offer a range of healthcare programs and services (e.g., acute care, mental health services, ambulatory care, and public health) (Horizon Health Network, 2023a; Vitalité Health Network, 2023a).

Complexities can arise during the provision of health services to youth, YAs, and their families when receiving care through NB's health networks. Some challenges in receiving healthcare can be attributed to youth with chronic conditions and/or CCN typically aging out of pediatric care (before the ages of 17–18) during this period of transition (Horizon Health Network, 2023b). For those patients aged 18 and under, NB does not have a pediatric hospital; therefore, youth and their families requiring tertiary or specialized healthcare are required to travel out of the province to receive services. Typically, children in NB are referred to the IWK Health Centre (Halifax, NS) when specialized healthcare is required, with a referral from an NB-based care provider (e.g., pediatrician). At times, these patients may also be required to travel to other provinces, such as Quebec, to receive specialized care related to oncology treatments, eating disorders, and cardiac surgeries (Nadarajah et al., 2021; Splane et al., 2023; Vitalité NB, 2023).

Beyond these issues, service delivery providers in NB also experience challenges due to a lack of funding and problems that emerge with dual-linguistic budgeting and service delivery (New Brunswick Medical Society, 2021). As Canada's only officially bilingual province, the services delivered to residents must follow the rules identified within the Official Languages Act (Public Legal Education and Information Service of NB, 2005). By law, healthcare organizations can choose what language they

wish to perform their daily operations, yet patients must be made an active offer by healthcare staff for the services they receive to be provided in the language of their choice (Public Legal Education and Information Service of NB, 2005). With this context in mind, healthcare operations in NB are described as a "collection of silos" (p.4) having fragmented human resources, technology, and information systems (NB Department of Health, 2020).

To date, resources and supports remain limited for YAs with chronic conditions and/or CCN transitioning from pediatric to adult healthcare in NB (Charlton et al., 2017). To illustrate the scope of this underserved population, one government study on chronic disease management in NB reported that 58% of youth aged 12 to 17 had at least one chronic condition (e.g., asthma) (NB Department of Health, 2010). In addition, the 2023 NB Student Wellness survey reported that 56% of youth and YAs (ages 12–18) indicate having symptoms of anxiety and depression, with many of these students not knowing where to go for services (NB Health Council, 2022; 2023). These numbers reflect a substantial proportion of YAs now requiring integration into adult healthcare services. Compounding this issue, healthcare in NB has experienced a "crisis" due to care provider shortage and lengthy wait times for receiving access to primary care, specialist care, and mental healthcare, coupled with an increase in demand for services (Government of New Brunswick, 2021b, p. 4; Lamrock, 2022; Moir & Barua, 2022; Morrison & Peterson, 2017; New Brunswick Health Council, 2018, 2020; New Brunswick Medical Society, 2019; Ross et al., 2015). Moreover, NB has the third longest average wait time in Canada to access treatment after a referral from a primary healthcare provider (e.g., 53 weeks) versus other provinces, such as Ontario (e.g., 21

weeks) (Moir & Barua, 2022). Indeed, the issue of timely access to services was recently identified by the NB Health Council as a struggle for youth from all NB regions; however, wait times appear to be shorter in more-urban centres (NB Health Council, 2022).

Unlike other Canadian provinces, such as British Columbia and Alberta, NB (where data collection for the primary research study took place) lacks provincial transition policies and guidelines that detail ways for improving access to adult healthcare. Indeed, no strategy or transition specific services presently exists for coordinating healthcare transitions between pediatric and adult services in NB (Charlton et al., 2017; Splane, 2021), although federal guidelines are available (Children's Healthcare Canada, 2018; Toulany et al., 2022). An exploration of programs, coupled with consultations with experts in the field, confirmed the absence of formal programs in NB that support the transition from pediatric to adult healthcare. The exception to this gap in transition services is a pediatric-focused oncology navigator in NB. Their role remains predominantly limited to supporting clients under the age of 17. However, they do continue to assist patients above that age; yet only in circumstances where the YA requests support in areas such as the transition from high school to university (M. McGibbon, personal communication, Mar. 21, 2022). NB also has educational and vocational planning for a subset of young people (ages 16–30) with mobility disabilities which is offered in NB through Ability NB (Ability NB, 2017). Vocational and educational support planning is also offered to YAs with intellectual disabilities through the NB Association for Community Living (NBACL) (NB Association for Community Living, personal communication, March 8, 2022). However, all YAs with chronic

conditions and/or CCN would benefit from varied transition supports, such as those provided in primary care. This lack of targeted programming further widens the service provision gap for YAs leaving pediatric care. Indeed, structured transition interventions, as found in other jurisdictions, are associated with improvements in medication adherence, healthcare utilization, self-care, and quality of life (Gabriel et al., 2017; Schmidt et al., 2020). This suggests that original research is urgently needed to take place in NB to help decision makers and clinicians prioritize what specific actions (e.g., interventions or transition programs) can address service delivery obstacles for YAs in NB, given its unique context (Splane, 2021).

Predisposition of the Researcher

As a frame of reference for readers, it should be noted that the findings as presented within this dissertation were guided by this researcher's unique experiences and perspective. As such, it is important for readers to interpret these manuscripts with an appropriate context for understanding how these works reflect my underlying "views, values, and beliefs about the research design" (Holmes, 2020, p.2). To explain how my worldview has impacted this research process (Savin-Baden & Major, 2013), I describe below my personal influences.

First, it should be acknowledged that I am a middle-class mother with cherished people in my life having chronic conditions and/or CCN who are in the transition process from pediatric to adult healthcare. As such, I draw upon my lived experiences with navigating the publicly funded Canadian health and education systems. Second, as a first-generation post-secondary graduate, I have obtained degrees in the following areas: Bachelor of Science in Kinesiology (UNB), Bachelor of Public Relations (MSVU),

Master of Education for Healthcare Professionals (UNB), and am a PhD Candidate in Interdisciplinary Studies (UNB). Third, as for vocation, I spent many years of my career working in private healthcare where I supported allied health professionals in chronic disease management. I have also taught youth of all ages in the public sector, including YA university learners (UNBSJ MBA program). In addition, I worked as a Certified Kinesiologist where I focused on improving the health and well-being of youth and adults. My professional background includes Lean Six Sigma Black Belt quality improvement and leadership training from Harvard ManageMentor. Finally, I have worked at UNB's Centre for Research in Integrated Care as a research assistant, which has allowed me to contribute to projects focused on reducing care fragmentation (e.g., families in transition) and improving health outcomes.

All these experiences have provided me with numerous opportunities to interact with pediatric and adult healthcare specialists, primary care providers, allied health members, and families, to discuss the stressors and service gaps experienced by youth and YAs. In March 2019, after attending the inaugural Harvard Medical School conference on improving the treatment for YAs with chronic conditions during transitions, it was clear that youth/YAs, families, and care professionals urgently want to improve patient experiences and service delivery. My hope is that findings from this research will contribute towards this worthy aim.

Overall, I believe that patients should be at the centre of service improvement initiatives. I believe their missing voices on transition services may pinpoint why poor outcomes remain during transition (e.g., disengagement with the health system), despite research efforts in the last 15 years. In a positive move, the Canadian Association of

Paediatric Healthcare Centres has developed national guidelines for the transition from pediatric to adult healthcare, in collaboration with YAs (Canadian Association of Paediatric Healthcare Centres, 2016). However, the outstanding questions remain as to why YAs continue to experience poor transitions and how could these experiences be improved. This outcome suggests problems with guideline implementation, which clearly indicates that further exploration is needed to understand how to address this challenge. Hence, I propose patient recommendations are key for identifying service improvement initiatives intended for engaging YAs. Let us listen and act on what they say. For if we do not, we will continue to fail in breaking the cycle of disservice and disengagement for YAs with chronic conditions and/or CCN.

Philosophical Framework

Beyond my personal experiences, this dissertation's body of research is also influenced by underlying philosophical perspectives regarding ontology, epistemology, and methodology. It is important to describe these philosophical assumptions underlying this research so readers can gain more context for how decisions were influenced and made throughout this research process (Jackson, 2013). Denzin and Lincoln (2011) define ontology as the study of what can be known about the real world. The ontological assumption guiding this research is relativism. Relativism adopts the position that no single universal standard exists for understanding concepts such as truth and reality (Baghramian, 2001). Consequently, the world consists of multiple individual realities influenced by context (Mills et al., 2006). In other words, each individual constructs their own reality (Scotland, 2012). Relativism implies that reality is subjective and based on individual experiences (Guba & Lincoln, 2005). Relativism impacts this study since

the perspectives and reality of each YA interviewed will be considered. Inherently this means each participant will develop their own interpretation and meaning of the phenomenon of transitioning from pediatric to adult healthcare (Parahoo, 2014). This researcher adopted a relativist approach since it allowed the opportunity to explore and present a cluster of participant viewpoints, while also treating each YA interviewed as having an individualized perspective based upon their lived experience (Given, 2008). Capturing the experiences of many YAs with chronic conditions and/or CCN representing experiences of service delivery from various communities and contexts both internationally and in NB is important so that our primary study findings can provide policymakers with a robust range of recommendations (National Institute for Healthcare Research, 2023).

The epistemological stance for this work is subjectivism. Epistemology represents the philosophical approach to how knowledge can be created as it relates to the connection between 'what can be known' and the 'knower' (Denzin & Lincoln, 2011). Thomas et al. (2020) assert that researchers bring their own influence when conducting studies. Accordingly, as a researcher, I took a subjective approach to how knowledge was created in all three manuscripts within this dissertation, which explored the lived experiences of YAs with chronic conditions and/or CCN. Adopting a subjective approach impacted this dissertation in more than one manner. First, it emphasized the experiences of each of my participants, and second, it enabled me to critically reflect on the subjective experience I brought to this research process (Bradshaw et al., 2017). By reflecting on my subjective experience, I was able to take the appropriate measures for sustaining the rigour and trustworthiness of the data. For instance, to avoid bias during data analysis, I

had other experienced researchers explore the data coding in both my scoping review and primary study during analysis to validate consistency in data interpretation (Campuslabs, 2020).

In terms of methodology, I followed the JBI methodology for scoping reviews and a qualitative descriptive design for a cross-sectional research study. Scoping reviews are used to present a broad overview of the evidence on a set topic (Peters et al., 2015; Tricco et al., 2016). JBI methodology, in particular, is appropriate for mapping the extent of the knowledge in a complex field, such as when reporting on the recommendations of YAs with chronic conditions and/or CCN as they transition from pediatric to adult healthcare (Peters et al., 2020; Watson et al., 2011). JBI methodology for scoping reviews is a systematic process for identifying and charting literature based on predetermined inclusion criteria and research objectives which produces a comprehensive summary relevant to audiences such as researchers and policymakers (e.g., review findings highlight areas for future inquiry) (Munn et al., 2018; Peters et al., 2021). In conducting the scoping review, a subjective approach also was applied to this knowledge synthesis. As such, the interpretation of this data was shaped by my individual experiences and knowledge (Crotty, 1998; Thomas et al., 2020). However, transparent methodological and reporting guidelines were applied throughout the review process to ensure the results reflected rigour in data analysis, interpretation, and reporting (Peters et al., 2021).

A qualitative descriptive design was selected for the primary study because it provides a comprehensive description of participant perspectives and highlights the voices of participants (Colorafi & Evans, 2016). Qualitative descriptive research supports developing a deeper understanding of the individual human experience in its unique

context (Doyle et al. 2020). Moreover, qualitative descriptive designs are appropriate for understanding the experiences of participants with a phenomenon that is poorly understood and/or information is sought on interventions (Doyle et al., 2020; Kim et al., 2017). This research design first prioritizes acquiring the literal descriptions from participants (Bradshaw et al., 2017). Once these descriptions are gathered, analysis and interpretation of how participants ascribe meaning to events can then occur (Bradshaw et al., 2017; Sandelowski, 2010).

By following this approach, the data produced remains close to the surface, meaning the interpretation of participant's experiences is kept to a minimal level (Bradshaw et al., 2017). This approach provided the flexibility for themes to emerge organically during data analysis (Bradshaw et al., 2017; Kim et al., 2017). This approach is common in qualitative health service delivery research, as it enables health pratitioners and policymakers to receive study findings that are presented in a straightforward way that is relevant to their informational needs (Sandelowski, 2000, 2010). Thus, as it applies to our qualitative descriptive study, this design is well suited for understanding the "what and where" of events and how transitions in care services can be improved (Kim et al., 2017). As well, this approach aligns with this researcher's aim to develop an understanding and describe the lived experiences of YAs transitioning from pediatric to adult healthcare (Bradshaw et al., 2017). Overall, adopting relativist and subjective positions are methodologically congruent with qualitative descriptive research design and supports my aim as a researcher to understand the healthcare experiences of patients along with the direct implications and impact on a healthcare setting, such as NB (Colorafi & Evans, 2016).

It is important to note that both studies discussed within this dissertation were intentionally designed without a predefined theoretical framework. The deliberate exclusion of a theoretical framework was a strategic decision, attributed to the exploratory nature of both studies (Bradshaw et al., 2017; Kim et al., 2017), and to the methodology chosen for each study. For example, given the exploratory nature of the scoping review and the qualitative descriptive design, utilizing theory with predefined coding frameworks during data analysis had the potential to limit the organic emergence of themes (Bradshaw et al., 2017; Elliott, 2018; Kim et al., 2017). During data analysis, capturing emergent codes from the participant's own voices, without the need for adherence to a predefined coding framework, was necessary to ensure the comprehensive consideration of all recommendations from YAs in addressing our research question (Elliott, 2018).

Interdisciplinary Approach

An interdisciplinary study is an approach to addressing research questions where insights from more than one discipline can help to produce a more comprehensive understanding of the topic (Repko et al., 2019). As such, interdisciplinary research projects are designed to integrate insights and theories from the literature representing multiple disciplines (Repko & Szostak, 2020), which can lead to many benefits. For example, approaches to health service improvement that embeds research and perspectives from complementary disciplines can provide "rich, innovative, and relevant data for public health intervention" (Kivits et al., 2019, p. 1061). Moreover, acquiring perspectives from across several disciplines can lead to a fuller understanding of complex

challenges (Jacob, 2015; Klein & Newell, 1998), whereas a single disciplinary approach could overlook new opportunities for healthcare improvement (Smye & Frangi, 2021).

Interdisciplinary projects differ from other types of research, namely multidisciplinary projects (NC State University, 2023). While both may be composed of individuals representing different disciplines (e.g., in healthcare), research conducted in the latter approach takes place when researchers from different disciplines work in an independent manner on a common research problem or question (NC State University, 2023). On the contrary, the individuals working on interdisciplinary projects engage in an interchange of information and experiences beyond their individual disciplines with the set research aim of developing integrated knowledge (Ding et al., 2020; Morton et al., 2015). Indeed, interdisciplinary approaches have been encouraged by renowned health institutes, such as the National Institutes of Health (NIH), for their dynamic capabilities in producing innovative solutions for overcoming societal challenges (National Institutes of Health, 2023; Jones, 2010). Hence, to best achieve this dissertation's aim of capturing YA experiences and recommendations for improving service delivery, an interdisciplinary approach was used.

This dissertation drew on research from various fields, including (a) nursing; (b) health sciences; and (c) health services delivery. The bodies of literature from these disciplines and insights from my supervisory team, reflecting perspectives from nursing sociology, and psychology, were pivotal for addressing how to explore the experiences and recommendations of YAs with chronic conditions and/or CCN who transferred from pediatric to adult healthcare and to identify ways to improve service delivery (e.g., interventions). Specifically, analyzing the literature from these disciplines was

foundational for understanding the research problem under study (Dossanova et al., 2016). To first illustrate how a nursing lens was applied to this dissertation, a brief context about the discipline of nursing is needed. Nursing aims to follow the health and well-being of patients through all developmental stages, across settings, and in collaboration with other providers (Canadian Family Practice Nurses Association, 2023). Nurses provide assessment, screening, education, and chronic disease management to improve health outcomes (Canadian Family Practice Nurses Association, 2023). Nursing research involves the scientific inquiry of developing knowledge for improving nursing practice and health policy, along with the health of individuals (American Association of Colleges of Nursing, 2023). Priority areas for nursing research include the promotion of health and facilitating access to services with the overall goal of improving health outcomes (American Association of Colleges of Nursing, 2023; Canadian Nurses Association, 2023). My Ph.D. co-supervisor, representing the profession of nursing, provided informational guidance to further my understanding of the nursing field. For instance, when faced with a variety of choices for selecting what terms to use throughout this dissertation, her insight helped me to determine what language is most accepted and applied within the discipline of nursing. This support received in language selection was helpful in creating content within these manuscripts that can be familiar to audiences seeking tangible recommendations for improving transitions in care, such as healthcare providers and policymakers. A nursing lens was also applied to this dissertation through frequent guidance from the nursing literature (e.g., CINAHL databases). This nursing literature informed the background, discussion, and implications sections for all manuscripts in this dissertation (Betz et al.,

2013). Also, nursing resources were frequently consulted to better understand the concepts recommended by the YAs presented within these manuscripts.

The second discipline underpinning this dissertation is health sciences. Health sciences involve the study of all aspects of health and disease, with the aim to develop allied health knowledge, technology, and interventions for improving the healthcare of patients (Nature Portfolio, 2022). As such, the research aims of health sciences aligned with the desired outcomes of this dissertation's aim, which was to explore the experiences of YAs with chronic conditions and/or CCN and to determine tangible actions for enhancing the quality of healthcare provided during transitions in care. The discipline of health sciences impacted the development of this dissertation as represented through (a) the literature cited in these manuscripts, (b) the informational guidance provided by a pediatrician to aid my understanding of pediatric medicine (e.g., for the purpose of writing practical finding implications), and (c) the educational sessions I attended to improve my knowledge on transitions. Fittingly, as part of the publication process for this dissertation, a manuscript was peer reviewed by experts representing the specialty of pediatrics and transitions in care, which brought new perspectives to this project. By attending the Harvard Medicine conference on optimizing treatment and transition for YAs with chronic conditions (March 2019) I learned about resources that were also recommended by combined internal medicine and pediatrics specialists (e.g., Got Transition and the TRAQ assessment tool) (Johnson et al., 2021). These evidence-based tools were ultimately presented in this dissertation.

The third discipline informing this dissertation, health services delivery, focuses on a composite of actions from across all levels of the health system and structures that are required to enhance service delivery performance while improving the health of populations (World Health Organization, 2000; 2010). This discipline also focuses on the activities that policymakers and healthcare administrators are engaged with, such as their processes for making decisions within the health system (World Health Organization, 2021). Settings for the delivery of these services can include hospitals, health centres, mobile health clinics, and community health organizations (van Olmen et al., 2010).

Research around health services delivery focuses on healthcare outcomes (e.g., utilization, cost, quality), and the organization of health services (Greenberg & Dimick, 2017). Insights gained from the field of health services delivery also influenced this research by providing details about ways that health services can be structured and organized, as evidenced in the content of the literature included within this dissertation. A substantial amount of the background information and literature in Chapters two to four were derived from journals focused on health services delivery. For example, I conducted a literature review for the primary study (Chapter 4) to determine what mixed methods studies have been conducted on improving transitions. Searching this peer-reviewed health service delivery research was necessary to pinpoint the scope of research gaps that exist on transitions and to highlight areas for future research. A healthcare decision-maker (SH) with a background in health services delivery research was consulted throughout the dissertation for input and insights. For example, I reached out to SH to better understand the current structure and organization of service delivery for youth and YAs with chronic conditions and/or CCN as they transitioned from

pediatric to adult healthcare in NB. SH's perspective as a decision-maker provided a necessary expert opinion to support how the recommendations derived within this dissertation could be feasibly adopted into an NB-based service delivery setting (S. Henry, personal communication, January 5, 2022). For instance, SH provided the knowledge necessary for understanding the current organization of healthcare services in NB and what healthcare service delivery issues exist for youth as they age out of pediatric care (e.g., gaps in the current structure of service delivery, such as a lack of transition programs and clinics, along with matters pertaining to private health insurance) (S. Henry, personal communication, January 5, 2022). Further, I consulted the literature on healthcare services delivery in NB for youth and YAs with chronic conditions and/or CCN (Charlton et al., 2017; Dubé et al., 2019; Splane et al., 2023; Vitalité Health Network, 2023b). During my Ph.D. studies, I took a course on Healthcare Administration and Management in Canada from Athabasca University. Lessons learned from that course included developing a deep understanding of the complex decisions that healthcare administrators must often face when having scarce resources. This information helped me to understand that administrators must structure services based on limited resources and reaffirmed that patients' voices can help health leaders to understand what services matter most to ensure that patients, such as YAs with chronic conditions and/or CCN, may experience optimal benefits from those same services.

As mentioned previously, my Ph.D. supervisory committee guiding this dissertation included a co-supervisor with a background in the discipline of nursing. In addition, my supervisory committee included members with a background in sociology

and psychology. As such, their lenses were incorporated throughout this dissertation. Their insights, feedback, and experiences, arising from their diverse backgrounds and experiences working on interdisciplinary projects, were an integral part of the development and rollout of this research. Further, as part of the committee guiding this research, a YA with lived experience with transitioning from pediatric to adult healthcare played a vital role as a member of this research project, a concept commonly referred to as 'patient engagement' (Manafo et al., 2018). Early consultation from this YA provided an important perspective for ensuring this research was established in a patient-oriented manner (Canadian Institutes of Health Research, 2019). This YA engaged with the project by reviewing the proposal for this research and offered meaningful suggestions to improve the design of this project (e.g., feedback in areas such as methods and recruitment) (van Overbeeke et al., 2020). While preparing the primary study findings for publication, a YA with lived experience will be invited to suggest ways in which the findings from this dissertation can be shared. This YA will also be consulted for knowledge translation activities related to this overall research (e.g., presentations and social media) package. By engaging YAs as part of the research team through tasks such as refining questions, and interviewing YAs with chronic conditions and/or CCN to learn more about their lived experience with the transition process, this dissertation aims to achieve a greater understanding of this population's experiences. With the development of a robust knowledge translation plan, it is hoped that the findings from this dissertation will prompt action by decision or policymakers, ultimately leading to real change in the delivery of healthcare services for YAs in NB. For example, the experiences and

recommendations from these YAs can inform a transitions in care strategy which is long overdue in NB (Canadian Institutes of Health Research, 2014, 2019).

Format for Dissertation

This dissertation is formatted following an articles-based approach (Baggs, 2011). This dissertation has an introductory chapter; three published or publishable manuscripts; and a concluding chapter. The format for this dissertation was selected to expedite the dissemination of timely research findings along with their implications for clinical practice and service delivery (Lewis et al., 2021; Smaldone et al., 2019). An additional reason for using this approach was to create a learning opportunity to develop the required skills for publishing in academic journals (Lewis et al., 2021). The following sections include descriptions of the three manuscripts in my dissertation (two published and one in preparation for publication), including how they address the research problem under study. Specifically, manuscripts one and two mapped the literature on YA experiences and recommendations for improving transitions. Manuscript three provided research findings on the lived experiences and recommendations of YAs who have transitioned to adult healthcare services in an Atlantic Canadian province.

As the first author of the three manuscripts, I had the lead research role in the development of the manuscripts at all stages, from conception to final approval. For manuscript one, I developed the research question and helped to develop the search strategy. I planned all steps of the protocol (i.e., determining the population, concept, context, and inclusion criteria), drafted this work, and provided critical revisions. As the research lead for manuscript two, I coordinated and performed title and abstract screening; coordinated and conducted all data synthesis and analysis; interpretated

findings; drafted this work; and provided critical revisions. A JBI trained librarian (AG) helped developed the search strategy for manuscripts one and two and performed title and abstract screening for manuscript two in accordance with the JBI methodology requirements for conducting a scoping review with a minimum of two reviewers (Peters et al., 2015). As the lead researcher for manuscript three, I refined the research question; developed the methodology (which included developing a semi-structured interview script); conducted data collection, transcription, and analysis; drafted this work; and performed critical revisions. My supervisory team (SD, AL, LM) provided conceptual support and suggested revisions to all three manuscripts (e.g., critical review of draft data analysis). The first manuscript has been published in the *Healthy Populations Journal*, the second was accepted for publication with the journal *BMJ Open*, and the third is in the process of being submitted for publication to the *Canadian Journal of Family and Youth.* The manuscript styles vary to meet the requirements of specific journals.

Story of the Research Process

The three manuscripts (described above) were each designed as part of a stepwise approach to address this dissertation's overarching aim to understand the experiences and service improvement recommendations of YAs with chronic conditions and/or CCN who have transitioned from pediatric to adult healthcare. Manuscripts one and two, a JBI scoping review protocol and full review, were first conducted to broadly map the literature (e.g., peer-reviewed or grey) on the experiences and recommendations of YAs on improving the transition from pediatric to adult care. This first step explored the current state of the literature, to identify research patterns and gaps in the experiences and recommendations of YAs with chronic conditions and/or CCN transitioning to adult

healthcare (Codina & Lopezosa, 2021). This review reaffirmed that gaps exist in identifying solutions to improve transition planning and transfer for YAs. Further, the review highlighted the need to explore in greater detail strategies for improving the transition process from YAs who have experienced this transition. Although the scoping review revealed several current recommendations for improving the transition from pediatric to adult healthcare, it is apparent that many of these recommendations have not been consistently put into practice, particularly across the Canadian provinces (McKay 2019; Nadarajah et al., 2021). In order to explore localized barriers to transitions in care and YA perspectives on ways to improve transitions in care services, I conducted a primary research project focused on transitions in care in NB. I employed a qualitative descriptive study to explore the experiences and recommendations of YAs with CCNs transitioning from pediatric to adult care in NB, which provided a better understanding of the specific ways YAs can improve their outcomes throughout this transition. Thus, manuscript three was a necessary next step to address, in detail, this dissertation's research objective for improving our understanding of YA experiences and recommendations (i.e., to inform a NB based transitions in care strategy). Findings from manuscript three provide a clear picture to the reader for how this study builds upon the prior research in novel ways. These novel findings and their implications are highlighted throughout manuscript three and discussion chapters within this overall research package. Taken together, the knowledge derived from the three manuscripts provide robust evidence on the experiences, recommendations, and practical implications for improving transitions in care for YAs with chronic conditions and/or CCN to audiences urgently

seeking to avoid deteriorating health outcomes. The sections below provide a summary of the objectives for all chapters within this dissertation.

Chapter 2, manuscript one, "Improving the Pediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs: A Scoping Review Protocol," aimed to comprehensively map recommendations on how to improve the transition from pediatric to adult healthcare based on the experiences of young adults (aged 18–30) with CCN. The protocol outlined a scoping review of peer-reviewed and grey literature, following the JBI scoping review methodology. This paper guided the scoping review that was conducted for the second manuscript.

Chapter 3, Manuscript two**,** "Improving the Pediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs: A Scoping Review," aimed to identify recommendations within the literature on how to improve the transition from pediatric to adult healthcare from the perspective of YAs who have gone through the process. The review was conducted in accordance with JBI methodology for scoping reviews. We searched MEDLINE (Ovid), CINAHL (EBSCO), PsycINFO (EBSCO), and EMBASE (Elsevier) databases, and conducted a grey literature search for relevant material. This scoping review focused on the recommendations of YAs with chronic conditions and/or CCN who have transitioned from pediatric to adult healthcare, in any setting (e.g., hospital, clinic, or community) and across all sectors (e.g., health, education, and social services). This paper contributed to the development of my primary study by reaffirming the gaps that YAs experience during transitions in care. This review also highlighted that gaps remain in identifying solutions for addressing how to improve transition planning and the transfer of care. This suggested the need to explore more detailed strategies for improving the transition planning process, as voiced by those who have experienced the transfer to

adult healthcare services to improve practice guideline recommendations for YAs with chronic conditions and/or CCN.

Chapter 4, manuscript three, "Improving the Transition from Pediatric to Adult Care: Recommendations from Young Adults with Lived Experience," presents findings from a qualitative descriptive study exploring the experiences and recommendations of young adults with lived experience to improve the transition from pediatric to adult healthcare services in an Atlantic Canadian province. This study aimed to better understand the experiences of YAs with CCN who have transitioned from pediatric to adult healthcare services. A qualitative descriptive design was used to describe the experiences of YAs (aged 19-30) from NB, Canada. Results from this study will inform policy and lead to the development of necessary service delivery improvement strategies. Applications from these findings offer promising results for enhancing the experiences of future youth transitioning from pediatric services.

The closing chapter of this dissertation offers readers an overall discussion about the research findings from this dissertation on improving the transition from pediatric to adult healthcare services for YAs with chronic conditions and/or CCN. This discussion includes a summary of recommendations from each manuscript on enhancing transition services along with implications for: (a) future research initiatives; (b) education and resources for YAs and their families; and (c) policy and practice improvements for clinical healthcare providers.

Conclusion

Given that the number of YAs living with chronic conditions and/or CCN continues to grow, research on improving service delivery for this vulnerable population is urgently needed (NB Health Council, 2016; Public Health Agency of Canada, 2019;

Schmidt et al., 2020; White et al., 2023). Despite the development of clinical transitions in care guidelines, greater understanding is needed to identify where these service gaps continue to exist and what strategies and policies need to be developed and implemented to address these gaps. Capturing the recommendations of YAs with lived experience can act as a first step toward planning transitions in care practice and delivery improvements. Moreover, understanding patient experience represents a useful foundation for designing future research with the aim of improving healthcare outcomes (Allen et al., 2022).

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Chapter 2: Manuscript One

Title: Paediatric to Adult Transition as Experienced by Young Adults with Complex Care Needs: A Scoping Review Protocol

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Abstract

With advancements in modern medicine, an increasing number of youth with complex care needs survive into adulthood. As service demands increase for this group, challenges exist on how to best facilitate meeting their needs as they transition from pediatric to adult health care. There is growing evidence of young adults describing their transition experiences and suggesting improvements to the design and delivery of these services. By synthesizing the existing literature, an increased understanding can be gained about the recommendations of those who have recently transitioned from pediatric to adult health care, thus improving both patient experiences and outcomes. This scoping review aims to comprehensively map recommendations on how to improve the transition from pediatric to adult health care based on the experiences of young adults with complex care needs. This study protocol outlines a scoping review of peer-reviewed and grey literature, following the Joanna Briggs Institute (JBI) scoping review methodology. Literature will be identified using a comprehensive search strategy developed by a JBI-trained librarian. Papers involving primary studies with recommendations of young adults recently transitioned from pediatric to adult care will be included. Search strategy results will be screened by two independent reviewers and included studies will have duplicates removed and charted according to a modified PRISMA flow diagram. Working with the Centre for Research in Integrated Care at the University of New Brunswick, knowledge translation activities will involve targeted communication channels to a variety of knowledge users, such as researchers, clinicians, and policymakers.

Keywords: pediatric to adult transition, transition experience, complex care needs, scoping review, quality improvement, patient engagement

Introduction

Young adulthood (YA) is a complex time when life transition dilemmas arise concerning education, employment, health engagement, and relationships (Al-Yateem, 2012; Cheak-Zamora & Teti, 2015; Viktorsson et al., 2022; Vincent, 2017; Wood et al., 2018). It is an important life development stage since it "determines the young adult's position within society" (de Jong-Gierveld, 2001, p. 98). Due in part to modern healthcare advances, a high number of young adults are living with chronic conditions in North America (Cohen et al., 2011; Kaufman, 2007; Pinzon et al., 2006). Youth with medical complexities are also more likely to survive into adulthood (Cohen et al., 2011; Kaufman, 2007; Wise, 2004). As a result, Chamberlain and Kent (2005) reinforce the urgent need to study and implement effective services for youth transitioning from pediatric to adult healthcare to set them on a path for optimal life outcomes. When healthcare transition interventions are delivered in a structured and informed way, improvements in patient experience, healthcare outcomes, and population health can result (Schmidt et al., 2020). A synthesis of research is required to understand the transition process from pediatric to adult healthcare from the perspective of young adults with complex care needs, specifically their recommendations on how to improve transition policies and practices. While youth from this population represent only a fraction of those transitioning from pediatric to adult healthcare, they encounter more challenges with the process (White et al., 2023), and thus their recommendations may contribute to transition process improvements for other populations.

To date, reviews on the transition from pediatric to adult services have largely reported on the experiences of youth through the lens of caregivers and healthcare providers, overlooking the voices of the young adults who have experienced transition in care (Betz et al., 2013; Morsa et al., 2018; Okumura et al., 2015). Capturing insights from young adults is reported as helpful when designing programs intended for improving transitions in care (Panek-Hudson et al., 2021).

The transition from pediatric to adult healthcare is categorized as the purposeful and planned process that involves the movement from child-centred to adult-oriented care systems (Blum, 2002; Schmidt et al., 2020; White et al., 2023). This transition process can be challenging for youth with chronic conditions and/or complex care needs (CCN). CCN are defined as "multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. CCN are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by healthcare structure" (Brenner et al., 2018, p. 1647). As a result of these complexities, youth with chronic health conditions are significant users of health care resources (Pinzon et al., 2006). Examples of conditions associated with CCN include diabetes, cerebral palsy, epilepsy, spina bifida, and mental health conditions (e.g., depression, anxiety, mood disorders) (Brenner et al., 2018; New Brunswick Health Council [NBHC], 2017). In North America, approximately 15-18% of youth have at least one chronic condition and/or complex care needs (Berry et al., 2011; Pinzon et al., 2006; Voorheis et al., 2020).

Evidence suggests that improving the transition experience of young adults with CCN is challenging, since this population often faces service provision gaps and barriers

to accessing healthcare (Anderson et al., 2018; Gray et al., 2018; Nelson, 2016). Understanding the healthcare experiences of this population is a crucial first step in driving healthcare improvement (Luxford & Sutton, 2014). White et al. (2023) suggest more research is needed regarding healthcare transitions with a focus on the experiences of youth, young adults, and families, as well as examining transition outcomes from a population health perspective. Currently, very little research focuses on the perspectives of young adults with various CCN when making recommendations for improvement in the transition process. To our knowledge, there is no comprehensive review focused uniquely on capturing improvement recommendations from the lens of young adults with CCN who have recently transitioned from pediatric to adult healthcare.

Given the growing body of literature on YA transition, a number of systematic reviews have been conducted in the following transition areas: (a) healthcare for youth with special healthcare needs (Bloom et al., 2012); (b) care of children and youth with type 1 diabetes (Nakhla & Daneman, 2012); (c) evaluation of research on adolescents and emerging adults with special healthcare needs perspectives (Betz et al., 2013); (d) continuity of care applications to transition research and clinical practice using the International Classification of Functioning, Disability and Health (ICF) framework for youth with chronic health conditions (Nguyen et al., 2018); and (e) meta-synthesis of experiences when transferring from pediatric to adult wards within a hospital setting (Fegran et al., 2014).

The reviews published to date have limited areas of scope, such as focusing only on the outcomes of transition (e.g., adherence) (Nakhla & Daneman, 2012), concentrating on transition models or systems issues (Nelson, 2016), exclusively

focusing on Organisation for Economic Co-operation and Development (OECD) free economic market country settings (Rich, 2017), or being restricted to one patient population or sector (e.g., autism patients in the context of higher education (Vincent, 2017). Overall, the literature suggests great interest in expanding the presence of youth and young adult voices in research (Weil et al., 2015; Woodgate, 2022). For instance, a review by Betz et al. (2013) includes the perspectives of adolescents and young adults. However, this proposed review will focus on exploring YAs transition experiences and differs from Betz et al. (2013) since it will include current studies that exclusively feature perspectives of young adults who have already experienced the transition process to adult services, rather than significant adolescent representation. Betz et al.'s (2013) study evaluates research on healthcare transition for youth with special healthcare needs.

The current scoping review will expand on previous reviews and provide an overview of recommendations on the transition process from the perspective of young adults across geographic locations and study types. The primary objective of this review is to comprehensively map recommendations on how to improve the transition from pediatric to adult healthcare based on the experiences of young adults with CCN. It is important to study this period of transition, given that youth experience disjointed and difficult shifts from pediatric to adult healthcare (Hopper et al., 2014). If left unaddressed, this problem will grow rapidly as the number of young adults with CCN continues to expand (Cohen et al., 2018). The results of this scoping review will address a literature gap and inform future research by producing a clear portrait of synthesized evidence related to improvement recommendations for young adults with CCN transitioning from pediatric to adult healthcare.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2020), as it is recommended to use standardized guidelines in the design and reporting of scoping reviews to ensure reproducibility and robustness. A preliminary search of CINAHL, PubMed, and the JBI Database of Systematic Reviews and Implementation Reports was conducted, and no current or ongoing reviews with the same objective on this topic were identified. In brief, the steps within the JBI scoping review framework are the following: (a) defining and aligning the objective and question/s; (b) developing and aligning the inclusion criteria with the objective/s and question/s; (c) describing the planned approach to evidence searching, selection, extraction, and charting; (d) searching for the evidence; (e) selecting the evidence; (f) extracting the evidence; (g) analyzing the evidence; (h) presenting the results; and (i) summarizing the evidence in relation to the purpose of the review, making conclusions, and noting findings (Peters et al., 2020). The following sections describe in detail how the review will adhere to JBI's approach.

Step One: Defining the Review Question

To align with the study objective, the scoping review will address the following question: What are the recommendations of young adults (aged 18-30) with CCN who recently transitioned from pediatric to adult healthcare on how to improve the transition experience?

Step Two: Developing the Inclusion Criteria

The inclusion criteria will consider population, concept, context, and types of evidence sources (Peters et al., 2020).

Population

The focus of our scoping review is on the experiences of young adults with CCN who have transitioned from pediatric to adult healthcare. Young adult will be defined as individuals aged 18–30 years. We will accept various terms used in the literature regarding young adults (e.g., emerging adult, adolescent, young man, or young woman). Studies will be excluded if their descriptions include experiences of young adults under the age of 18 or above the age of 30, given that many young adults enter adult services by age 18, and transition programs worldwide are completed by the age of 25 (Fegran et al., 2014; Got Transition, n.d.; Kaufman, 2007; Nakhla & Daneman, 2012; Rich, 2017). The decision to cap the population at age 30 will prevent participant recall bias by avoiding lengthy time since their transfer to adult healthcare. The review is not specific to any CCN, condition, sex, ethnicity, or other demographic variables.

Concept

The main study concept is transition experience recommendations from pediatric to adult healthcare. Transition to adulthood from the pediatric system is defined as the "purposeful and planned movement of young adults with chronic physical and medical conditions" (Blum et al., 1993, p. 570), and encompasses emotional, mental, and behavioural health. Recommendations based on these types of transition experiences must be present in the study to be included and be from the perspective of young adults themselves; studies discussing only experiences without any recommendations will be excluded.

Context

This review will consider transition experience suggestions of young adults with CCN in all settings, such as hospitals, clinics, or community-based settings, as well as across all health sectors. Studies will be excluded if they focus solely on intra-institutional transfer (e.g., intra-hospital). There will not be any additional exclusion limitations placed on this review, as the intent is to explore pediatric to adult healthcare transition experiences.

Types of Sources

This scoping review will consider all primary research studies that use a qualitative design. Mixed methods design will only be considered if a qualitative design is included. Systematic reviews that meet the other inclusion criteria will be excluded from the review; however, the references will be hand searched for relevant articles. Grey literature, such as unpublished primary studies and/or evaluation reports, will also be considered for inclusion in this scoping review. Studies published in English, and from around the world, will be considered for inclusion.

Step Three: Developing the Search Approach

The search strategy follows a multiphase approach and will aim to locate both published and unpublished primary studies. During the first phase, an initial limited search was conducted in MEDLINE (Ovid) and CINAHL (EBSCO) to identify text words in the titles and abstracts as well as index terms from relevant articles. During this process, a librarian (AG) developed a full search strategy for MEDLINE by testing search terms, and only those that yielded unique results were included. The search strategy was externally peer-reviewed by a second librarian (AM) using the Peer Review

of Electronic Search Strategies (PRESS) guidelines (McGowan et al., 2016). Searches will be conducted using a combination of database index terms and text words, limited by title/abstract. English language limits will be applied; publication date will not be limited. A full search strategy for MEDLINE (Ovid) is provided (see Appendix A). A final search strategy will be adopted for each database.

Step Four: Searching for Evidence

The databases to be searched include MEDLINE (Ovid), CINAHL (EBSCO), PsycInfo (EBSCO), and Embase (Elsevier). A process to locate sources of unpublished studies and grey literature will be developed using best practices (Bonato, 2018). This will include searching the first 10 pages of Google and Google Scholar and using relevant keywords to search Dissertations and Theses (ProQuest), institutional repositories, and relevant conference proceedings.

Step Five: Selecting the Evidence

Following the search, all identified citations will be collated and uploaded into the EndNote citation manager with duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria using Covidence review management software. Next, the full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for the exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion between the two reviewers, or with a third reviewer when needed. Relevant reviews will be tagged within Covidence to search their reference lists. The reference

lists of all included studies will be hand-searched for additional studies. The results of the search will be reported in full in the final report and presented in a modified Preferred Reporting Items for Systemic Reviews and Meta-analyses (PRISMA) flow diagram (Tricco et al., 2018). Any deviations from the study protocol will be tracked and reported in the final manuscript.

Step Six: Extracting the Evidence

Data will be extracted from included papers by the two independent reviewers using a Microsoft Word data extraction tool developed by the reviewers. Extracted data will include specific details about the population, concept, context, study methods, and key findings relevant to the scoping review objective. A draft of the extraction table is provided (see Appendix B). This will be modified and revised as necessary during the extraction of included studies. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the two reviewers will be resolved through discussion, or with a third reviewer as needed. Authors of research articles and other sources of literature may be contacted to request additional or missing data where needed.

Step Seven: Synthesizing the Evidence

Data extracted from included papers will be presented in a tabular form (Peters et al., 2020). The table will feature results (e.g., specifying participant subgroup conditions and improvement recommendations, year of publication, research methods, and study purpose). Data will be synthesized based on types of recommendations (e.g., health service need) which will then be pulled together into corresponding themes using qualitative content analysis. Results will be accompanied by a clear explanation of classification criteria.

Step Eight: Presenting the Results

The data extracted from relevant published and unpublished literature will be presented in a tabular form that is aligned with the objective of this scoping review (e.g., recommendations). Data displayed will include the author and year of publication, country of origin, type of literature, research design, methods, population(s), sample size, setting, sector, and transition recommendation(s).

Step Nine: Summarizing the Evidence

A narrative summary will accompany the tabulated data and will describe how the results relate to the review objective and question.

Patients and Public Involvement Statement

Patient opinions from a patient health advisory group will be consulted to design a collaborative strategy for disseminating finding results.

Results/Discussion and Dissemination

This scoping review aims to expand transition improvement research by synthesizing recommendation evidence from young adults with CCN as experienced by those who have already transitioned. Further insights into patient suggestions for improving their care will be uniquely captured in this process. To our awareness, this is the first scoping review to focus on capturing the improvement recommendations of patients who have CCN from the perspective of young adults who have recently transitioned from pediatric to adult healthcare. A limitation of this review is that it will not assess studies for quality; scoping reviews do not involve assessing included studies for measures of rigour (Peters et al., 2015). Also, limitations may exist regarding the number of databases searched and will be addressed by explicitly acknowledging that

searching other databases may have identified additional relevant studies. Searching four subject databases will help address selection bias, and database selection was guided by the topic. A search of the grey literature will also be conducted to identify additional articles. The search strategy consists of terms appropriately describing the research question and was peer reviewed by another JBI-trained librarian. Due to limited resources for translation, articles published in languages other than English will be excluded.

A strength of this study is by not having inclusion or exclusion criteria restrictions on specific young adult conditions, sex, ethnicity, or other demographic variables, study results will be of interest to readers from various health backgrounds and disciplines.

Recommendations

Recommendations from young adults can guide knowledge users, such as researchers, clinicians, and policymakers, toward overcoming health transition service inequities. Synthesizing recommendations from youth with a variety of chronic conditions has proven a useful tool for policymakers when addressing health consequences for large populations (Arim et al., 2015). A recent systematic review by Barnert et al. (2019) reinforces the pressing need to develop population health outcome measures (e.g., improving health access) for youth with medical complexities. To fulfill this research need, implications from this review will produce specific ways to improve population health service delivery and indicate key areas for future research directions. Policymakers from all health sectors involved with transitions from pediatric to adult healthcare will be encouraged to incorporate results from this review into their quality improvement planning and policy initiatives. Review findings will be disseminated through conference proceedings and a peer-reviewed publication.

Author Note

All authors (MC, SD, AL, and AG) provided critical revisions to the work. This included reading and approving the final manuscript. The views expressed in this study reflect the authors' own perspective. The authors declare no conflict of interest. Not commissioned; externally peer reviewed. We would like to thank Alison Manley, Health Sciences Librarian with Horizon Health Network, for peer-reviewing the search strategy for this scoping review.

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Chapter 3: Manuscript Two

Title: Improving the Transition from Pediatric to Adult Healthcare: A Scoping Review of Recommendations of Young Adults with Lived Experience

Cassidy, M., Doucet, S., Luke, A., Goudreau, A., & MacNeill, L. (2022). Improving the transition from paediatric to adult healthcare: A scoping review of recommendations of young adults with lived experience. *BMJ Open,* 12, e051314. https://doi.org/10.1136/bmjopen-2021-051314

Note: Minor adjustments have been made to this manuscript compared to the original publication to reflect consistency in language use for the reader (e.g., "patient-centered care" will be spelled "patient-centred"). Please be advised that minor changes occurring in this chapter, such as updates to references, are not reflected in the published version of the manuscript. The numbering of tables and figures has also been adapted for reader clarity and proper sequencing. The formatting of this article has been adapted from the original publication to APA 7 style. Primary Author Contribution: MC drafted this work, conducted data screening and analysis, provided critical revisions, and approved the final manuscript. Copyright for this article falls under the Creative Commons Attribution Non-Commercial (CC BY-NC 4.0) license. For full copyright information, please refer to Appendix K.

Abstract

Objective: The goal of this review was to identify recommendations within the literature for how to improve the transition from pediatric to adult healthcare from the perspective of young adults living with chronic conditions and/or CCN who have gone through the process. **Design:** This review was conducted in accordance with JBI methodology for scoping reviews. **Search Strategy:** We searched MEDLINE (Ovid), CINAHL (EBSCO), PsycINFO (EBSCO), and EMBASE (Elsevier) databases, and conducted a grey literature search for relevant material. The databases were searched in December 2019, and re-searched June 2020 and September 2020, while the grey literature was searched in April 2020. This scoping review focused on the recommendations of young adults with chronic conditions who have transitioned from pediatric to adult healthcare, in any setting (e.g., hospital, clinic, or community), and across all sectors (e.g., health, education, and social services). **Results:** Eighteen studies met inclusion criteria for this review. These studies included young adults with 14 different chronic conditions, receiving healthcare services in North America (67%) and Europe (33%). Young adults' recommendations for improving the transition from pediatric to adult healthcare (n=# of studies reporting this theme) included: improving continuity of care (n=12); facilitating patient-centred care (n=9); building strong support networks (n=11); and implementing transition education preparedness training (n=7). **Conclusion:** Review findings can benefit service delivery by addressing important barriers to health, education, and social services for youth transitioning to adult healthcare.

Strengths and Limitations of the Study

1. This is the first scoping review to focus on capturing the improvement recommendations of patients who have chronic conditions through the lens of young adults who have transitioned from pediatric to adult healthcare.

2. The search strategy included robust databases with peer-reviewed and grey literature, with no restrictions on the condition, sex, ethnicity, or other demographic variables of the young adult.

3. Non-English studies were excluded; thus, eligible studies may have been missed.

4. Given the nature of scoping reviews and as per scoping review guidelines, the quality of included studies was not assessed.

Background

In the past, living beyond their 20th birthday was an unattainable goal for many children and youth with chronic conditions; however, the survival rate has increased to over 90% in recent decades (National Institute of Health, 2009; Pinzon et al., 2006; Whitehouse et al., 2013). These survival trends extend to multiple childhood-onset conditions, such as congenital heart disease, cystic fibrosis (CF), and rheumatic diseases (Mackenzie et al., 2014; Stephenson et al., 2015; Woo & Petty, 2011; Zomer et al., 2013). Many of these children and youth with chronic conditions have complex care needs that require more medical, social, and/or educational support (Brenner et al., 2018; Cohen et al., 2018; Kaufman et al., 2007). As a result, there is a new generation of patients entering adulthood with chronic conditions, which gives rise to unprecedented health system impacts (Cohen et al., 2018; Cohen et al., 2011; Kaufman et al., 2007).

Despite growing interest in improving health outcomes for Young Adults (YAs) with chronic conditions transitioning from pediatric to adult healthcare, difficulties continue to be reported due to inadequate transition services and a lack of programming (Canadian Association of Paediatric Health Centres, 2016; Jivanjee & Kruzich, 2011; Ontario Health, 2022). For example, the 2019-20 National Children's Health survey indicated that 81% of youth in the USA failed to receive services to facilitate this transition process (Child and Adolescent Health Measurement Initiative, 2020). Furthermore, many YAs lack a plan for continued assistance beyond pediatrics and the skills to self-manage their varied care needs (Anderson et al., 2018; Ferris et al., 2015; Gray et al., 2018; Lozano & Houtrow, 2018). For YAs, this lack of transition preparedness, coupled with the loss of long-term services and supports provided by pediatric and social care providers, can lead to gaps in care and disengagement with adult services (Coyne et al., 2019; Jivanjee & Kruzich, 2011; National Institute for Health and Care Excellence, 2016).

Indeed, poor transitions to adult healthcare have been associated with increased morbidity and mortality in several childhood-onset chronic conditions such as type 1 diabetes, HIV, lupus, and kidney disease requiring transplant (Felsenstein et al., 2015; Foster et al., 2015; Kakkar et al., 2016; Kapellen et al., 2018). For example, reports on patients with spina bifida indicate worsened health status post-transfer to adult services (Sawyer & Macnee, 2010). As well, morbidity and mortality rates for sickle cell disease were found to rise sharply during the emerging adult age category (aged 20–24) compared to youth (aged 15–19) (Hamideh & Alvarez, 2013; Kayle et al., 2019). Moreover, decreased adherence to medications and treatment during this transition can

lead to declining health status and quality of life for many YAs living with a range of chronic conditions (Ersig, 2019; Foster, 2015; Nakhla & Daneman, 2012; Pai & Ostendorf, 2011). These complications are not only detrimental to the individuals' health, but also costly for both the patient and the healthcare system.

Two recent scoping reviews have examined healthcare related to pediatric to adult transitions for YAs with CCN. Burke et al. (2018) focused on the availability of transitional healthcare services for young people with arthritis and epilepsy and Williamson et al. (2017) examined the lack of healthcare access for youth with intellectual and developmental disabilities (Burke et al., 2018; Williamson et al., 2017). Compiling the service delivery preferences of these YAs could be extremely useful for designing practical service improvement initiatives for this population (e.g., Institute for Healthcare Improvement's [IHI] 'Model for Improvement') (Betz et al., 2013; Gray et al., 2018; Institute for Healthcare Improvement, 2021; Institute of Medicine, 2018; Langley et al., 2009; O'Hare et al., 2019). As such, gathering findings through conducting a scoping review is a key first step in identifying important service delivery priorities in the areas of health, education, and social services for youth transitioning from pediatric to adult healthcare. Mapping the current literature on recommendations for transitions from pediatric to adult healthcare, as voiced by young adults, will help identify service delivery gaps (e.g., transition planning and transfer) and create direction for future systematic reviews and research.

Objective

The primary objective of this scoping review was to comprehensively search the literature for recommendations to improve the transition from pediatric to adult

healthcare, based on the transition experiences of young adults' (aged 18-30) with chronic conditions and/or complex care needs.

Review Question

1. What recommendations have been reported in the literature on how to improve the transition experience from pediatric to adult healthcare from the perspective of young adults living with chronic conditions and/or complex care needs aged 18- 30, who have transitioned to adult healthcare services?

Methods

Study Design

This review was conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2020). Data was analyzed using qualitative content analysis (Hsieh & Shannon, 2005). For additional information on the review methods, refer to the published protocol (Cassidy et al., 2021). A preliminary search of CINAHL, PubMed, and the JBI Database of Systematic Reviews and Implementation Reports found no current or ongoing reviews with the same objective (JBI, 2018).

Patient and Public Involvement Statement

Patient opinions from a patient health advisory group will be consulted to design a collaborative strategy for disseminating finding results.

Search Strategy

The systematic search process, as outlined in Table 3.1, aimed to locate both published and unpublished studies. An initial limited search was conducted in MEDLINE (Ovid) and CINAHL (EBSCO) to identify text words from titles and abstracts, as well as index terms from relevant articles. During this process, a librarian (AG) developed full search

strategies (Appendix A) and searched all databases listed in Table 3.1. A grey literature search was conducted and is fully described in Appendix A. Database searching occurred on 20 December 2019, with searches re-run on 2 June 2020 and again on 23 September 2020; grey literature was searched on 21–24 April 2020.

Table 3.1

Search Strategy and Inclusion and Exclusion Criteria

Search Strategy	
Sampling strategy	• Externally peer-reviewed by a second librarian using PRESS guidelines. Databases were searched Dec 20, 2019, June 2, with a final update Sept 23, 2020.
Types of studies	• English language academic journals. No date limits were used.
Databases searched	• MEDLINE (Ovid), CINAHL Full-Text (EBSCO), PsycINFO (EBSCO), and EMBASE (Elsevier).
Additional sources and search methods	• Grey literature; Google; Google Scholar; Conference proceedings EMBASE (Elsevier); Dissertations and Theses (ProQuest); hand searching of select youth health journals; hand searching the reference lists of included studies; "Cited by" feature through Scopus (Elsevier) and Google Scholar to locate more recent publications citing studies in this review.
Inclusion criteria	• All primary research studies using a qualitative design. Mixed method designs were included only if accompanying a qualitative design. • All categories of chronic health conditions and complex care needs were included. Complex care needs were defined as health and social care needs in the presence of a recognized condition, with or without a diagnosis (Brenner et al., 2018). • YAs were defined as young adults aged 18-30. We accepted various terms used in the literature referring to young adults provided they fell within the parameters of age 18-30 (e.g., emerging adult, adolescent, young man, or young woman).
Exclusion criteria	• Systematic reviews. • If descriptions included young adults' experiences above the age of 30, given that many young adults transition programs worldwide are completed by the age of 25. • According to JBI methods, the team excluded quantitative studies given the research aim was to capture YA recommendations in their own descriptive words.

Inclusion Criteria

Participants

This scoping review focused on the recommendations of young adults living with chronic conditions and/or complex care needs who have transitioned from pediatric to adult healthcare. Specific inclusion criteria are shown in Table 3.1.

Concept

The main study concept was recommendations to improve the transition experience from pediatric to adult healthcare. Transition to adult healthcare from the pediatric system was defined as the planned process of moving young adults from pediatric care through to the transfer and integration into adult healthcare and encompasses concepts such as mental and behavioural health (Schmidt et al., 2020; White et al., 2023).

Context

This review considered recommendations to improve the transition experience of young adults living with chronic conditions and/or complex care needs in all settings (e.g., hospital, clinic, or community), and across all sectors (e.g., health, education, and social services). Studies were included only if they captured YA verbatims using open-ended language (e.g., via qualitative or mixed methods studies). Studies were excluded if they focused solely on intra-institutional transfer (e.g., intra-hospital), lacked a qualitative component, or if recommendations were not identified as a primary outcome.

Study Selection

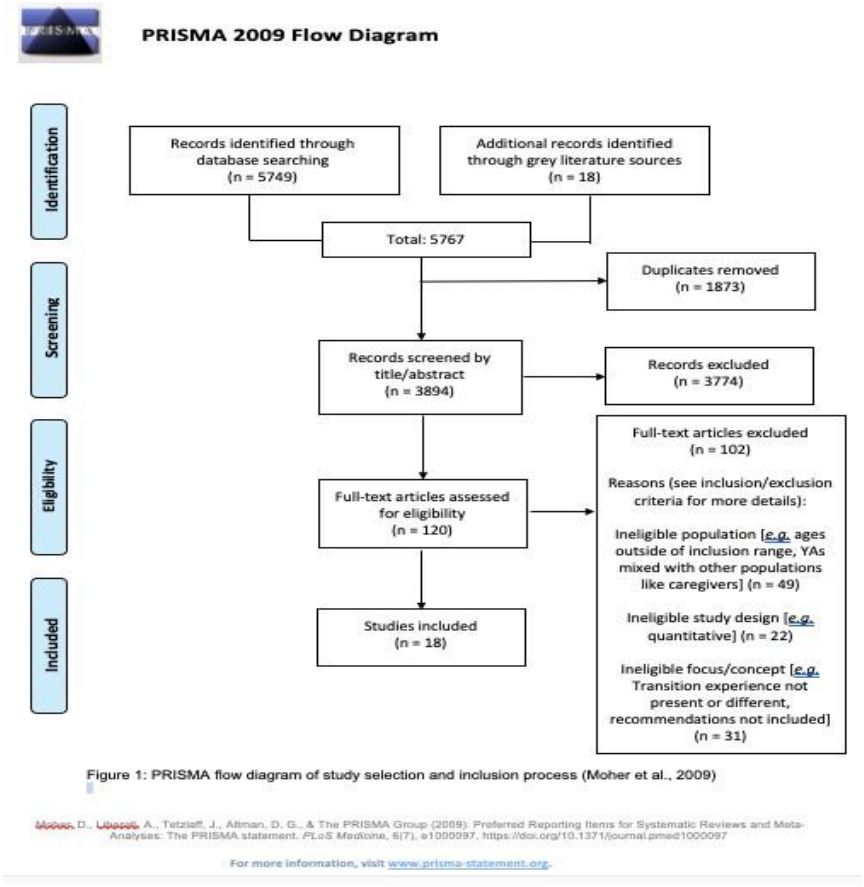
Search results were first collated and uploaded into the citation manager, Endnote version X8.2 (Clarivate Analytics, PA, USA), and then uploaded to Covidence (Veritas

Health Innovation Ltd, Melbourne, Australia), a screening and extraction tool for systematic reviews. Both tools were used to remove duplicates. Two independent reviewers (MC and AG) then screened titles and abstracts for assessment against the inclusion criteria. The full texts of selected citations were retrieved and assessed in detail against the inclusion criteria by two independent reviewers. This data extraction tool was developed by the reviewers (see Table 3.2). Any disagreements between reviewers were resolved through discussion. When full text was not available (e.g., conference abstracts), a decision was made to contact authors for further information (e.g., if the text met the majority of pre-defined inclusion criteria and was missing one key piece of evidence).

Results

The initial search strategy identified a total of 5749 records. After title and abstract screening, 120 remained for full-text review. A total of 18 studies met the final inclusion criteria for this review. Figure 3.1 presents a modified PRISMA flow diagram that presents the number of records identified, included, and excluded, as well as the reasons for exclusions (see Figure 3.1) (Moher et al., 2015).

Figure 3.1



Included studies were published between 2011 and 2019. Two-thirds of the articles were from North America, with 44% from the USA (n=8) and 22% from Canada (n=4). The remaining articles were from Europe (n=6). Over 83% of the articles (n=15) involved transitions from pediatric tertiary care settings. Studies describing adult services included healthcare (n=17) and educational settings (n=1). The 17 studies that took place within healthcare settings varied with regard to organizational structure, policies, and funding models. Therefore, it was not possible to conduct direct comparisons of service provider responsibilities and resources or compare transitions between different levels of care across countries and settings. All studies included YAs with chronic conditions (e.g., T1 diabetes, HIV, neuromuscular,

organ transplant, mental health, cardiac, spina bifida); however, the complexity of conditions and healthcare needs were not consistently described and could not be accurately captured. Therefore, for the remainder of the results and discussion, we will refer to the population as YAs with chronic conditions, rather than YAs with chronic conditions and/or complex care needs.

Our review included all primary research studies using a qualitative design. Mixed method designs were included only if accompanying a qualitative design (qualitative methods =13; mixed methods =5). A total of 18 articles reported recommendations on how to improve the transition from pediatric to adult healthcare as voiced by YAs living with chronic conditions who have completed the transition process themselves. Content analysis was used to synthesize the recommendations from YAs about transition improvements across the included studies. YA recommendations were synthesized into four major areas: improving continuity of care (n=12); facilitating patient-centred care (n=9); building strong support networks (n=11); and implementing transition education preparedness training (n=7). A table summarizing the studies' major areas of recommendations is presented in Table 3.3 with full citations presented in Appendix C.[1-18]

Table 3.2

Data Extraction

Author & Year	Country	Sample (Ages/ Sex)	Health Conditions	Transition Setting	Study Design: Method/Aim or Purpose
Ådnanes and Steihaug (2016),[1]	Norway	N=9; Ages 18–30; F(8) M(1)	n=5: Severe mental illness (e.g., PTSD); n=4: Personality disorder	Pre-transfer pediatric care: Primary care. Post-transfer adult care: Health clinics/facilities (mental health).	[Qualitative: Interviews] Capture experiences and views about treatment and care, with a focus on (dis)continuities and episodes.

Bryant *et al.* (2011),[2]	United States	N=14; Ages 19–25; F(8) M(6)	Chronically ill youth with hemoglobinopathy	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Qualitative (descriptive phenomenology): Interviews] Describe the transition experience, expectations, and concerns of (CIYH) who transitioned to adult care.
Chandra *et al*. (2015),[3]	United States	N=12; Ages 18–23; F(8) M(4)	Chronic liver disease and/or liver transplant	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Mixed Methods: Survey] Assess patient/parent perspectives after their transfer process to adult care to develop a more effective transition program; and acquire improvement suggestions for facilities and pediatric caregivers.
Grivetta *et al.* (2012),[4]	Italy	N=7; Ages 19–27; F(4) M(3)	HIV+ youth	Pre-transfer pediatric care: Infectious disease department Post-transfer adult care: Health clinics/facilities	[Qualitative: Interviews] Identify obstacles and areas of improvement in HIV patients' healthcare transition and nursing process implications.
Huang et al. (2011),[5]	United States	N=10; Ages 18–25; F(6) M(4)	n=4:T1D; n=3: IBD; n=3: CF	Pre-transfer pediatric care: None provided Post-transfer adult care: Health clinics/facilities	[Qualitative: Focus groups] Examine the transition process from pediatric to adult care services from the perspectives of YAs with chronic disease and pediatric and adult care providers.
Kakkar *et al*. (2016),[6]	Canada	N=25; Ages 19–25; F(15) M(10)	HIV perinatally infected youth	Pre-transfer pediatric care: None provided Post-transfer adult care: Health clinics/facilities	[Mixed Methods: Questionnaire] Determine outcomes after transition to adult care amongst HIV+ youth; and document transition process experiences, identify barriers to successful transition and process improvements.
Kerr *et al*. (2018),[7]	Ireland	N=8; Ages 18–24; F(3) M(4)	Neuromuscular conditions	Pre-transfer pediatric care: None provided Post-transfer adult care: Health clinics/facilities	[Mixed Methods (realist evaluation): Interviews] Develop theory about interventions, and organizational and human factors that help/ hinder successful child to adult services transition, drawing on experiences and knowledge of YAs with life-limiting conditions, their parents/carers, and service providers.
Kola *et al.* (2015),[8]	United Kingdom	N=6; Ages 19–25; F(2) M(4)	n=3: Dyslexia; n=1: Epilepsy; n=1: Epilepsy & CP; n=1: Quadriplegic CP	Pre-transfer pediatric care: Medical services Post-transfer adult care: Educational centre	[Qualitative (interpretive phenomenology): Interviews] Explore the lived experiences, perceptions, and challenges of chronic neurological condition YAs, undergoing transition from adolescence to adulthood.
Lindsay *et al.* (2016),[9]	Canada	N=12; Ages 19–25; F(8) M(4)	Spina bifida	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: None provided	[Qualitative (descriptive): Interviews] Explore youth and parent experiences of a new transition model for youth with spina bifida, compared young adults with spina bifida who did not participate.

Lindsay *et al.* (2017),[10]	Canada	N=4; Ages 20–28; M(4)	Duchenne Muscular Dystrophy	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Qualitative (interpretive): Interview] Explore enablers and barriers of clinicians, young men, and parents in transition from an adult DMD clinic within a pediatric hospital to an adult health facility.
Margolis *et al.*, (2017),[11]	United States	N=33; Ages 19–27; F(4) M(29)	Chronic Granulomatous disease	Pre-transfer pediatric care: None provided Post-transfer adult care: Health clinics/facilities	[Mixed Methods: Survey] Identify strengths and barriers to transition from pediatric to adult care; and determine strategies to enhance the transition process.
Plevinsky, Gumidyala and Fishman (2015),[12]	United States	N=29; Ages 18–30	Chron's disease or ulcerative colitis	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Mixed Methods (qualitative phenomenology): Survey] Understand transition of YAs with (IBD), the impact of the paediatric patient– provider relationship; and what determines the adult patient–provider relationship.
Asp, Bratt and Bramhagen (2015),[13]	Sweden	N=16; Ages 19–24; F(11) M(5)	Congenital Heart Disease	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Qualitative (descriptive): Interviews] Explore the experiences of YAs with CHD after transfer from the pediatric cardiac clinic to adult congenital heart disease clinic.
Dimitropoulos *et al.* (2015),[14]	Canada	N=15; Ages 18–21; F(15)	Eating disorders	Pre-transfer pediatric care: Specialized tertiary program Post-transfer adult care: Therapy/group programs	[Qualitative (grounded theory): Interviews] Identify systemic facilitators and barriers of transferring YAs with eating disorders from pediatric to adult and mental health services.
Valenzuela *et al*. (2011),[15]	United States	N=10; Ages 24–29; F(7) M3)	Behaviorally acquired HIV	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Providers in multi-settings	[Qualitative: Interviews] Describe experiences of youth with HIV transitioned to adult care, to identify difficulties encountered, and to explore improvement areas.
Garvey *et al.* (2014),[16]	United States	N=26; Ages 23–29; F(16) M(10)	T1D	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Qualitative: Focus groups] Explore transition experience from pediatric to adult diabetes care reported by post-transition (T1D) emerging adults, with focus on care transfer preparation.
Iverson et al. (2019),[17]	Norway	N=11; Ages 19–23; F(5) M(6)	T1D	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Qualitative (explorative): Interviews] Explore how YAs with (T1D) experienced the transition from paediatric to adult care services.
Ritholz *et al.* (2014),[18]	United States	N=26; Ages 23–29; F(16) M(10)	T1D	Pre-transfer pediatric care: Hospital centre/clinic Post-transfer adult care: Health clinics/facilities	[Qualitative: Focus groups] Explore perceptions that (T1D) emerging adults have of their patient-provider relationships across the transition from pediatric to adult care.

Table 3.3

Included Studies Major Areas of Recommendations

Improving continuity of care	Improving communication and collaboration	Huang *et al*. (2011),[5] Kerr *et al*. (2018),[7] Margolis *et al.* (2017),[11] Valenzuela *et al*. (2011),[15]
	Participating in a warm handoff	Asp *et al.* (2015),[13] Dimitropoulos *et al*. (2015),[14] Garvey *et al. (*2014),[16] Grivetta *et al.* (2012),[4] Iverson *et al*. (2019),[17] Kakkar *et al*. (2016),[6] Kerr *et al*. (2018),[7] Lindsay *et al.* (2016),[9] Margolis *et al.* (2017),[11] Ritholz *et al.* (2014),[18] Valenzuela *et al*. (2011),[15]
	Implementing a point person	Asp *et al.* (2015),[13] Garvey *et al. (*2014),[16] Grivetta *et al.* (2012),[4] Iverson *et al*. (2019),[17] Kerr *et al*. (2018),[7] Lindsay *et al.* (2016),[9] Valenzuela *et al*. (2011),[15]
Facilitating patient centered care	Listening	Ådnanes and Steihaug (2016),[1]
	Providing developmentally appropriate information	Ådnanes and Steihaug (2016),[1] Asp, Bratt and Bramhagen (2015),[13] Garvey *et al.* (2014),[16]
	Including YAs in care decisions	Ådnanes and Steihaug (2016),[47] Kerr *et al*. (2018),[7] Dimitropoulos *et al*. (2015),[14] Valenzuela *et al*. (2011),[15]
	Shifting to 'Patient-first' care	Asp *et al.* (2015),[13] Ådnanes and Steihaug (2016),[1] Iverson *et al*. (2019),[17] Lindsay *et al.* (2016),[9] Ritholz *et al.* (2014),[18]
Building strong support networks	Nurturing relationships with care providers	Asp, Bratt and Bramhagen (2015),[13] Ådnanes and Steihaug (2016),[1] Grivetta *et al.* (2012),[3] Iverson *et al*. (2019),[17] Kerr *et al*. (2018),[7] Lindsay *et al.* (2016),[9] Margolis *et al.* (2017),[11]
	Increasing family/caregiver involvement	Chandra *et al.* (2015),[3] Kerr *et al*. (2018),[7] Plevinsky *et al.* (2015),[12]
	Improving access to peer support	Bryant *et al.* (2011),[2] Huang *et al*. (2011),[5] Margolis *et al.* (2017),[11]
Implementing transition education preparedness training	Increasing education for youth	Asp *et al.* (2015),[13] Chandra *et al.* (2015),[3] Dimitropoulos *et al*. (2015),[14] Garvey *et al. (*2014),[16] Lindsay *et al.* (2016),[9] Margolis *et al.* (2017),[11]
	Increasing training for care providers	Lindsay *et al.* (2017),[10] Garvey *et al. (*2014),[16]

1.0. Improving Continuity of Care

Several studies reported that YAs recommended improving the transition from pediatric to adult services by receiving organized and coordinated care throughout the transition from pediatric to adult healthcare [4, 5, 6, 7, 9, 11, 13, 14, 15, 16, 17, 18]. It was recommended that this continuity in care should include professionals across all settings, and this cohesive process must begin far in advance of final transfer to adult services [5, 7, 11, 15]. Specifically, YAs recommended: 1) improving communication and collaboration; 2) participating in a warm handoff; and 3) implementing a point-person.

1.1.Improving Communication and Collaboration

Improving communication and collaboration refers to the way information is exchanged between healthcare providers and youth to improve the transition experience. YAs report that care should be seamless in nature and is improved with the implementation of communication tools (e.g., integrated health records). It was recommended that this communication and collaboration occur amongst inter-agency health professionals, their staff, as well as YAs and their families. This improved communication would help foster understanding of shared goals and roles [5, 7, 11].

Specifically, YAs wanted to be more engaged in this communication process while under pediatric care, such as by having opportunities to practice asking more questions to understand decisions about their healthcare [11]. YAs overwhelmingly expressed preferences to begin early transition discussions (e.g., at age 15) with their providers and families [7, 11, 15]. One young adult said, "…Start at a young age, just to let them know that it's [children's services] going to come to an end" (p.130) [7]. Another participant

said, “Have the doctor tell parents to talk to their kids at age 15 or 16 [about beginning the transition process communications]” (p. 719) [11].

1.2. Participating in a Warm Handoff

A ‘warm handoff’ is an in-person interaction with providers, the youth, and their family that occurs during the transfer process from pediatric to adult healthcare. This process is intended to be positive and friendly in nature and can occur in different settings as a bridging technique between pediatric and adult healthcare [9, 13]. YAs experienced discomfort and ‘insecurity’ during this transition due to a lack of familiarity with their future adult healthcare environment [13]. During the pre-transfer period, YAs wanted to meet their new providers and staff, visit the physical location(s) of their new provider(s) (e.g., by means of a tour), and begin any onboarding processes (e.g., scheduling a first appointment) [4, 7, 9, 11, 13, 14, 15, 16, 18]. As one YA suggested, “…having somebody say ‘OK, this is [...] where things are […] This is where the waiting room is.’ Instead of that first appointment where you’re meeting your doctor” (p. 195) [16]. Of note, YAs provided numerous ways this in-person meeting could occur, such as connecting together at the last pediatric appointment or having the pediatrician attend the first visit in adult healthcare [4, 6, 13, 17]. As stated by participants, “The adult provider should participate in the last visit at the pediatric outpatient clinic” (p. 726) [17] or, “...an opportunity to visit the adult outpatient clinic before the transition” (p. 726) [17].

1.3. Implementing a Point Person

The importance of identifying a key person to facilitate the transition process and serve as a bridge between pediatric and adult healthcare frequently emerged as a recommendation from YAs [4, 6, 7, 13, 15, 17]. YAs often felt disoriented about where

and how to access the information they required to participate in adult services [7, 16]. As such, a transition coordinator role was identified as a potential solution to address unmet needs and to facilitate guidance and plan care coordination across sectors from health, education, and employment [4, 7, 9, 15, 17]. As suggested by one YA, "How about one of the nurses, like every Monday night call all the incoming young adults?" (p. 195) [16]. Registered nurses were most often suggested for this position as transition coordinators [4, 16, 17]. Physicians were also suggested as care professionals who could help youth as they transition from pediatric to adult services [4]. One YA reaffirmed the benefits of a designated role stating, "if there was one person that could find it all out for you and then give all the information to you at once, that would be helpful" (p.131) [7].

2.0. Facilitating Patient-Centered Care

Numerous studies reported that YAs prefer healthcare providers to be focused on individualized patient needs and preferences [1, 7, 9, 13, 14, 15, 16, 17, 18]. YAs want this healthcare to be delivered in a respectful and emotionally intelligent manner. By providing healthcare through these methods, patient-provider relations were strengthened [1, 7]. These dynamic interactions between healthcare providers and youth produced the following specific recommendations: 1) listening to YAs; 2) providing developmentally appropriate information; 3) including YAs in care decisions; and 4) shifting from parent-focused care to patient-focused care.

2.1. Listening to YAs

Listening, according to YAs, refers to being heard and responded to with understanding [1]. YAs expressed that their concerns were not taken seriously, or actively listened to, which made them feel their needs were not being addressed by their

healthcare provider [1]. As a point of emphasis for improving healthcare transitions, one YA advised that doctors should prioritize "listen[ing] to the patient" (p. 100) [4]. Another YA participant highlighted the impact of ineffective listening in stating, "[...] I was not understood, because they are 100 percent certain that I have a [borderline personality] disorder. They took this as a starting point in their treatment; what I said had no importance, and I wasn't believed either" (p. 4) [1]. Participants also reinforced the importance of, "being understood, respected, and taken seriously" (p. 4) [1].

2.1. Providing Developmentally Appropriate Information

This recommendation reflects that youth wanted to understand information about their clinical condition [13]. This goal was hindered when YAs felt communication was not tailored to their health literacy level [13]. YAs preferred providers to listen actively and use lay terms that were 'developmentally appropriate' [1, 16]. One participant stated, "I don't really know and definitely can't describe my condition in medical terms [...] I would like, so to speak, some kind of summary of my medical record that a layman can understand, especially since I have become an adult" (p. 17) [13]. When this type of communication occurred, YAs suggested, "directness from the therapist [provider] was also very much appreciated" (p. 4) [1].

2.2. Including YAs in Care Decisions

This recommendation refers to the inclusion of YAs in care decisions and activities, with the goal of youth becoming empowered and prepared for adult healthcare prior to transition [14, 15]. YAs perceived this active participation as necessary in developing their skills of autonomy, which are required for adult healthcare, but also help during their transition [7]. As such, YAs concurred, "[…] that throughout the

transition process the development of the YA autonomy could be focused on more by service providers" (p. 132) [7]. Ideas for improving healthcare included provider and youth collaboratively setting expectations (e.g., sharing treatment goals), and creating a space where informed health decisions can take place [1, 14, 15]. According to one YA participant, prior to transfer to adult services, youth healthcare inclusion could "take the form of sharing information with patients, (e.g., test results, treatment rationale, and goals)" (p. 151) [14].

2.3. Shifting from Parent-Focused Care to Patient-Focused Care

The final recommendation related to patient-centered care emphasizes how YAs wanted to receive care that was focused around their holistic, individualized needs (e.g., include emotional and social aspects), and not their needs as perceived by their parents [1, 9, 17, 18]. Regarding the types of services received, YAs, "desired a treatment program that would take a holistic approach to their various diagnoses and difficulties" (p. 3) [1]. Overall, YAs' suggestions were in response to feeling that the healthcare they received in pediatrics was overly 'parent-centered' (p. 44) in its approach, with minimal conversations and expectations of responsibility directed towards the youth [13, 18].

Indeed, YAs desired a balanced integration of individual and family-oriented care on both sides of the pediatric and adult transition spectrum [13, 18]. For example, YA participants living with diabetes, "discussed the importance of pediatric providers shifting from a 'parent-centric' approach and encouraged speaking directly with emerging adult patients while maintaining parental involvement" (p. 44) [18].

3.0. Building Strong Support Networks

As reported in several studies, YAs wanted to build and establish strong relationships and support networks throughout the transition to adult healthcare [1, 2, 3, 4, 5, 7, 8, 9, 11, 12, 13, 17]. Specific recommendations in this area included: 1) nurturing relationships with care providers; 2) increasing family/caregiver involvement, and 3) improving access to peer support. These individuals and groups are in a position to provide both motivational and informational support, resulting in the development of trusting relationships [11, 12, 13].

3.1. Nurturing Relationships with Care Providers

YAs mainly rely on their primary care providers (e.g., nurses or physicians) for information and support throughout the transition process [12, 17]. Once youth made a connection with an adult healthcare provider, they wished to continue seeing that same provider, to establish a trusting relationship [1, 13, 17]. YAs wanted to see this adult healthcare provider more than once a year to enhance feelings of security and establish positive therapeutic relations [1, 4, 13, 17]. Participants stated, “The transfer was facilitated by meeting the same doctor who thereby became familiar with them as individuals, which created trust and a sense of security” (p. 5) [13]. One YA proposed that familiarity with the new provider could be enhanced if they, “Maybe follow you up more at the beginning [entry to adult healthcare]” (p. 100) [4].

3.2. Increasing Family/Caregiver Involvement

Family involvement in supporting youth from pediatric to adult healthcare increases advocacy for appropriate care and increases access to resources for YAs during transitions [7, 10, 12].

> YAs reported the valuable and crucial role of their parents/carers in supporting their transition to adult services; [One participant said], My nurses and occupational therapists just didn't want to start [the transition process], and mum was banging on the door saying, 'We need to move to adult services' (p.133) [7].

Families attending appointments with YAs during the transition process were viewed as a beneficial structural support and resource. One YA said, "So I think it was good for both of them [caregivers] to be there, so their questions could be answered as well" (p. 708) [9].

3.3.Improving Access to Peer Support

YAs expressed benefits in networking with peers with a similar diagnosis during the transition process, which could improve their experience [2, 5, 11]. YAs suggested that the creation of peer mentorship roles as a response to youth feeling 'nervous,' or to fill a knowledge gap around the transition process from someone who had first-hand experience [2, 11]. Patients expressed most interest, "in receiving news regarding their respective diseases, input from actual patients...and opportunities to network with other patients like themselves" (p. 996) [5]. Specifically, one participant suggested, "...Someone to connect with on your level that knows what you're going through. I've found it useful to talk to other patients..." (p. 720) [11]. Not only did youth express interest in peer mentoring pre-transfer, but one post-transfer patient, who had a positive experience, "wanted to share advice with individuals facing transition" (p. 280) [2].

4.0. Implementing Transition Education Preparedness Training

For YAs, there are both cognitive and physical skills to be learned in preparation for a successful transition experience [3, 9, 11, 13, 14, 16]. These competencies are required for youth to confidently perform several required tasks of independence (e.g., booking their own appointments in adult healthcare) [6, 14]. Specific recommendations include: 1) increasing education for youth (and their families); and 2) increasing training for care providers.

4.1.Increasing Education for Youth and Their Families

YAs recommended learning about the transition process before the actual transfer from pediatric to adult healthcare (e.g., insurance and medication management) [3, 14, 15]. This information could be acquired from print materials or in-person sessions (e.g., conferences or workshops) [11, 14, 17]. One YA suggested that a strategy for improving transition should include, "A pamphlet outlining what goes into a visit starting with travel, reservations, clinic appointment" (p. 719) [11]. YAs recommended that this educational strategy should involve details about adult clinic procedures and managing expectations [13, 14]. According to YAs, pre-transfer youth were encouraged to begin practicing self-management skills (e.g., meeting with their pediatrician alone and learning proactively when to seek support) while in pediatric healthcare [3, 9]. This process was intended to follow a gradual weaning from family involvement [5, 13, 14]. Patients' "recommended programming to orient emerging adults to both the logistics and the care practices of the new adult clinic settings, to help shape expectations and support adjustment" (p. 195) [16].

4.2. Increasing Training for Care Providers

Training, referring to enhanced transition-related skills and condition-specific competencies for care providers, was suggested by YAs as a way to prepare youth for the transition from pediatric to adult services [10, 16]. For example, one study exploring coping in young adult men as they prepare for transition reported: “Parents and young men also felt that clinicians should be knowledgeable of the latest research […]” (p. 76) [10]. In a “wish list” for improving the transition process, patients suggested their adult providers gain “expertise in emerging adult care” (p. 195) [16]. This training could prepare clinicians for discussions with emerging YAs such as, “Hey, you’re an adult, here are some adult-type situations you’re going to run into” (p. 194) [16].

Discussion

An increasing number of children and youth living with chronic conditions are growing up to become adult health service clients. As such, recent guidelines have been developed by the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians (AAP/AAFP/ACP) (White et al., 2023); the National Institute for Health and Care Excellence (National Institute for Health and Care Excellence, 2016); and Children’s Healthcare Canada to facilitate the transition from pediatric to adult healthcare (Canadian Association of Paediatric Health Centres, 2016). Although these recent guidelines have been developed with input from YAs (Canadian Association of Paediatric Health Centres, 2016; National Institute for Health and Care Excellence, 2016; White et al., 2023), research suggests that YAs continue to experience difficulty during this transition. Moreover, many research studies continue to focus on improving transitions to adult healthcare with data derived from those without

direct lived experience (e.g., health providers) (Morsa et al., 2018; Michaud et al., 2018; Nakhla et al., 2017). This scoping review synthesizes recommendations on how to improve the transition from pediatric to adult healthcare as voiced by YAs with chronic conditions who have completed the transition process themselves. Our review identified key recommendations related to improving continuity of care, facilitating patient-centred care, improving access to support, and implementing preparedness training for transitions in care. In this discussion, we explore implications in the area of service delivery.

Service Delivery Implications

During the transition from pediatric to adult healthcare, YAs face health barriers such as fragmented communication between pediatric and adult providers; experience poorly coordinated care; and lack the knowledge required to properly manage their health conditions (Allen et al., 2022; Butler, 2021; Cooley et al., 2011). Recommendations put forth by YAs in this review highlight the need for services that are continuous in nature; patient-centred; and are supported by family, peers, and clinicians. Practice reports and guidelines from the AAP/AAFP/ACP, Children's Healthcare Canada, and the Canadian Paediatric Society on the transition of youth to adult healthcare include recommendations for addressing these same barriers and improving clinical practice outcomes (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022; White et al., 2023). While these guidelines for improving transitions in healthcare have emerged over the past several years, YA experiences captured in this review suggest a gap in their adoption for clinical practice (McManus et al., 2020). Indeed, research has shown that once evidence is published, such as presented within practitioner guidelines, a delay of more than a decade often

exists before those recommendations become adopted into clinical practice (Beauchemin et al., 2019; Westfall et al., 2007). Commonly identified barriers to implementing guidelines into practice can be attributed to challenges with dissemination, education, and a lack of written protocols (Fischer et al., 2016). Potential strategies for operationalizing these transition guidelines may include adopting technology-based tools (e.g., EMRs) for integrating care across diverse settings, continuing to include YAs in the development of programs and policies, and implementing evidence-based transitions in care training for healthcare providers (Jin et al., 2019; Varty et al., 2020; White et al., 2023).

Many of the recommendations captured in this review highlight the need for continuity of care during the transition from pediatric to adult healthcare. Best practice guidelines for improving continuity of care during these transitions include the use of clinical communication tools, such as electronic medical records (EMR) (Amaria et al., 2011; Canadian Association of Paediatric Health Centres, 2016). EMR adoption is linked with increased adherence to clinical guidelines, improved healthcare efficacy, and enhanced patient-centred care (Buntin et al., 2011; Campanella et al., 2016; Kruse et al., 2018). As illustrated within this review, YAs often transferred from one care setting, such as hospital-based pediatric clinics, to sites such as primary care and community-based settings which may pose risks to the seamless transfer of clinically important information. These risks in information transfer are attributed to each site having its own EMR system infrastructure (e.g., single or multiple EMRs) and compatibilities (Payne et al., 2012). To fully utilize clinical decision support tools available in most EMRs, all clinical staff using these tools should: be involved with tool planning (e.g., deciding

customizations), partake in training, and evaluate tool usage (Carbone et al., 2020; Kruse et al., 2018). For example, the Plan-Do-Study-Act cycle, an iterative process improvement model developed by W. Edwards Deming, was implemented by a large children's hospital to assess provider adoption of EMR planning tools to improve transitions (Got Transition®, 2020a; Wiemann et al., 2015). This intervention led to an increase in transition planning and readiness (Davidson et al., 2022; Wiemann et al., 2015).

Beyond expressing the need for closing the communication gap between pediatrics and adult services, YAs reported the need for a designated point person to facilitate the transition process. For instance, a transition coordinator could help with improving the communication and collaboration between health providers and facilitate patient-centred care. Indeed, studies looking at sickle cell disease and pediatric liver transplant suggest that transition coordinators or navigators facilitate access to adult healthcare, improve medication adherence, and improve patient self-management skills through education (Allemang et al., 2017; Annunziato et al., 2008). YAs with disordered eating have reported positive experiences in receiving transition coordinator services, provided they begin interacting with the coordinator early enough in the transition process to begin developing a trusting relationship (Nadarajah et al., 2021). Transition guidelines from Canada and the UK, along with recommendations from families, reiterate that this role can promote successful transitions (Bindels-de Heus, 2013; Canadian Association of Paediatric Health Centres, 2016; National Institute for Health and Care Excellence, 2016).

Providing YAs and their families with support in personalizing and coordinating care is an important step in improving the transition from pediatric to adult healthcare; however, this review also underscores the importance of family and peer support. Indeed, the literature on transitions encourages the support of families for youth and YAs with medical complexity and developmental disabilities during transitions (Li et al., 2020; Toulany et al., 2022). Our review expands upon this recommendation by suggesting that YAs living with chronic conditions be provided with the opportunity for family involvement with their healthcare in adult services as well. Reviews with youth and YAs having chronic physical or mental conditions also reported that peer support positively impacts health outcomes for this population (Kohut et al., 2014; Richard et al., 2022). For example, YAs with cancer emphasize the importance of peer support; yet express a gap in availability (Holland et al., 2021). Practitioner guidelines encourage establishing peer interventions to provide support and to facilitate self-management for youth and their families using activities such as workshops (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022; White et al., 2023). Furthermore, YA recommendations from a study on irritable bowel disease suggest that it would be most beneficial if peer program facilitators had experience with chronic conditions themselves (Mackner et al., 2014).

Clearly, building support networks for YAs during this transition is essential; but this review highlights that YAs want to improve their self-management skills prior to transitioning to adult healthcare services as well. Ultimately, clinicians offering patient-centred care supports should intentionally incorporate structured approaches for supporting YAs to develop competencies in managing their own healthcare and

increasing transition preparedness (McManus et al., 2015). In fact, studies report that by offering developmentally appropriate health information, youth can become active participants in their care, thus increasing their ability to develop the self-management skills required for healthcare after transition (Bell & Condren, 2016; Curry et al., 2006). Moreover, parents have reported struggles in transferring healthcare responsibilities from themselves to their youth with chronic conditions; so, clinicians can play a vital role in developing their patient's self-management skills (Catarino et al., 2021; Gray et al., 2015). Clinicians are thus encouraged to support youth and YA patients by regularly tracking their health self-management skills using validated assessment tools to improve adherence to the shared treatment plan (Lozano & Houtrow, 2018; Mahan et al., 2017; Toulany et al., 2022).

The results of this scoping review suggest that healthcare providers must stay up to date with transition-related education in order to provide adequate transitional support. Studies interviewing pediatric residents and specialists found that healthcare providers experienced low knowledge and comfort levels with transitions from pediatric to adult healthcare due to a gap in the provision of structured curriculum (Mennito, 2012; Sathe et al., 2022). This finding is not surprising given one-third of undergraduate/graduate medical education programs fail to provide instruction about transition of care (Castillo & Kitsos, 2017). To overcome this educational gap, curricula in transitional care is advised for pre- and post-licensure programs and should include pediatric, adult, and general care providers (Sharma et al., 2014; White et al., 2023). Fittingly, health training programs in transitional care for healthcare providers in the USA are now offered as part of curriculum for internal medicine-pediatrics residents and as continuing medical education

programs for primary care and subspeciality clinicians (Society for Adolescent Health and Medicine, 2023; White et al., 2023). Additionally, healthcare providers are encouraged to explore and apply quality improvement approaches for testing measurable indicators, such as transition planning, in their clinical practices (i.e., aided by tools from Got Transition's® the Six Core Elements of Health Care Transition™ 3.0) (Canadian Association of Paediatric Health Centres, 2016; White et al., 2023; White et al., 2020).

YAs with type 1 diabetes report that this type of healthcare provider training could increase awareness surrounding the unique challenges experienced during the transition process (Hilliard et al., 2014). This training could include content focused on YA development, childhood-onset diseases, and healthcare transition processes (Canadian Association of Paediatric Health Centres, 2016; Cooley et al., 2011; Toulany et al., 2022; White et al., 2023). Further, current guidelines propose that training should reflect the tenets of family and patient-centred care (Alden et al., 2012; Canadian Association of Paediatric Health Centres, 2016). While new healthcare provider training programs based on transition guidelines exist (e.g., The Six Core Elements of Health Care Transition™), a gap remains in the literature for assessing the effectiveness of provider training within specific health systems, patient populations, and healthcare settings (Agency for Healthcare Research and Quality, 2020; Bauer et al., 2015; Got Transition®, 2020b).

Limitations

The majority of studies that met the inclusion criteria for this review represent health service experiences within a North American context. Also, this review features articles primarily exploring YAs experiences with pediatric tertiary care and adult

primary and subspecialty care, with an under-representation of other types of clinic settings. In the process of conducting this review, we discovered an absence of studies featuring the experiences of YAs with common conditions, such as cancer and developmental disabilities (e.g., autism, developmental delays, fetal alcohol syndrome), thus highlighting a gap in this research area. While the search strategy for this review was meant to broadly capture how chronic conditions with or without CCN are described in the literature, it is possible additional studies about specific conditions are missing from this review. For instance, although our study did not include the keyword 'childhood-onset,' some included studies featured this term. Additionally, all studies included within this review were written in English, therefore, a bias in study language was possible. Despite these limitations, this review has highlighted important recommendations for improving the transition from pediatric to adult healthcare and these gaps have important implications for service delivery and research.

Conclusion

The 18 qualitative and mixed methods studies examined in this scoping review focused on the care recommendations of YAs with chronic conditions who had transitioned from pediatric to adult healthcare services. This review contributes to the service delivery improvement literature for youth in transition by including the voice of YAs who have experienced the transfer to adult healthcare services. Our review suggests that despite guidelines on transitions in care featuring input from YAs, gaps remain in implementing structured transition policy, planning tools, and supports into clinical practice and health systems. Clinicians and decision-makers are encouraged to apply findings from this review to their transition service designs (e.g., interventions for

furthering and evaluating youth self-management skills). Further research is warranted for assessing how these strategies for improving the quality of care, as recommended by YAs with chronic conditions, can be applied and assessed across different settings to improve patient experience, outcomes, and costs of care. The time is past for health delivery decisions to be made without engaging the youth and YAs they serve.

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MC provided data screening and analysis; substantial drafting; revising; and approving the work. SD contributed to the conception and design of the review; interpretation of data; revision of the draft; and final approval of the version to be published. AL contributed to the conception and design of the review; interpretation of data; revision of the draft; and final approval of the version to be published. LM contributed to the interpretation of data; revision of the draft; and final approval of the version to be published. AG designed and ran the search strategies, provided data screening, contributed significantly to drafting the methods, and revising and approving the work.

Competing Interests

The authors declare no conflict of interest**.**

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Chapter 4: Manuscript Three

Title: Improving the Transition from Pediatric to Adult Healthcare: Recommendations from Young Adults with Lived Experience

(In Preparation) Cassidy, M., Doucet, S., Luke, A., & MacNeill, L. (2024). Improving the transition from pediatric to adult healthcare: Recommendations from young adults with lived experience. Journal target: *Canadian Journal of Family and Youth.*

Note: Primary Author Contribution: MC made substantial contributions to the design of this work, conducted interviews and transcription, performed data collection and analysis, interpreted data for the work, drafted this work, provided critical revisions, and approved the final manuscript.

Abstract

Background: The process of transitioning from pediatric to adult healthcare represents a pivotal juncture in the life trajectory of young adults with complex care needs and their families. As service demands increase for this population, healthcare providers must determine the best ways to meet their needs. Following the transition to adult healthcare, YAs are vulnerable to poor outcomes (e.g., increased stress and repeated emergency room visits that strain the system). Studies that explore how to address gaps in care often do not reflect the perspectives of YAs themselves. As such, seeking their input about health services is a crucial step towards improving service delivery. **Objective:** This study aimed to explore the experiences and recommendations of YAs with complex care needs to improve the transition process from pediatric to adult healthcare across settings and sectors. **Methods:** A qualitative descriptive design was used. Semi-structured interviews were conducted with 23 young adults (aged 19–29) with complex care needs from a small province in Canada. Maximum variation sampling was used to capture diverse perspectives (e.g., individuals with an array of CCN). Data were managed using NVivo software and analyzed using inductive thematic analysis. **Results:** The following themes were identified in the data, highlighting the importance of: 1) continuity of care, 2) improved access to supports, 3) transition readiness, and 4) a patient-centred care team. **Conclusion:** Results from this study can inform practice, policy, and research by guiding the development of service delivery improvement strategies for YAs and their families involved in the transition from pediatric to adult healthcare.

Keywords: pediatric to adult transition, quality improvement, young adults, families, healthcare, education

Introduction

Improving the experience of youth and their families as they transition from pediatric to adult healthcare is a top priority for patients, their caregivers, and the care team (Castillo & Kitsos, 2017; Greenlee et al., 2017; White et al., 2023). As more youth with complex care needs (CCN) transition to adult healthcare, the health system faces novel challenges in meeting the needs of this population (Canadian Association of Paediatric Health Centres, 2016). Despite new transition guidelines and tools being available, young adults (YAs) with CCN continue to report negative experiences and outcomes, such as disengagement with services and declines in health (Butler, 2021; Toulany et al., 2022; White et al., 2017). This suggests that a need exists to hear firsthand from YAs with CCN about their experiences with the transition from pediatric to adult healthcare. The purpose of this study was to explore the experiences and recommendations from the perspective of YAs with CCN who have transitioned from pediatric to adult healthcare to improve this transition process across settings and sectors.

Background

Understanding Complex Care Needs and Young Adulthood

Complex care needs are defined as multi-dimensional health and social care needs, with or without a medical diagnosis (Brenner et al., 2018). These needs are individual and contextualized and often require the provision of services and supports from multiple sectors, such as healthcare and education, particularly during transitions in care (Brenner et al., 2018). Transition to adult healthcare is defined as the planned process of moving youth and YAs with chronic health conditions from pediatric care into adult healthcare

(Schmidt et al., 2020; White et al., 2023). Transitional care addresses psychosocial, medical, educational, vocational, and overall wellness needs, with the aim to improve continuity of care (Rosen et al., 2003). The transition process may span the course of several years commencing ideally when youth begin transition readiness activities through to integration of YAs into adult healthcare services (Got Transition®, 2014). Prior to completing this process,YAs experience a one-time event, referred to as 'transfer,' when the responsibility for healthcare shifts officially from a paediatric to an adult care provider or team (Toulany et al., 2022). This transfer typically occurs between the ages of 18–22 (Got Transition®, 2014; McManus et al., 2020). Young adulthood, the time between 18 and 30 years of age, is a crucial developmental stage. During this period, accessing and receiving health interventions, such as medical appointments and transition services (Allen et al., 2022), can have lasting implications throughout the adult life course, such as reduced health risks (Sandler & Garvey, 2019; Shanahan et al., 2021; Singh & Tuomainen, 2015; Walker-Harding et al., 2017).

The Current State of Transitions in Care Guidelines and Programming Research

Fortunately, recent guidelines for enhancing the transition from pediatrics to adult healthcare are unfolding throughout North America. For instance, Children's Healthcare Canada (CHC) created the evidence-based *A guideline for transition from paediatric to adult healthcare for youth with special healthcare needs: A national approach* (Canadian Association of Paediatric Health Centres, 2016). Representing one of the first countries to develop transitions in care guidelines, this Canadian report was developed in consultation with a multi-disciplinary team, including a Guideline Development Group consisting of YAs, family members, healthcare providers,

researchers, and decision makers (Canadian Association of Paediatric Health Centres, 2016). The Canadian Paediatric Society (2022) has also produced clear clinical recommendations in a position statement titled: *A call for action: Recommendations to improve transition to adult care for youth with complex health care needs* (Toulany et al., 2022). Additionally, hospitals such as BC's Children's (ON TRAC model) and Toronto's SickKids (Transplant and Regenerative Medicine Centre) have developed their own transition frameworks and resources to support patients, families, and providers (BC Children's Hospital, 2022; SickKids, 2021, 2023). Together, these guiding frameworks encourage healthcare providers and the systems in which they work to adopt continuous processes for transferring the medical histories of YAs from pediatric to adult healthcare as part of a structured and person-centred transition plan while also assisting with transition preparedness (Canadian Association of Paediatric Health Centres, 2016; Lestishock et al., 2020; Pape & Ernst, 2022; Toulany et al., 2022).

While many frameworks and initiatives have been developed over the past decade to improve the quality of services for youth transitioning from pediatric to adult healthcare, youth and their families continue to report difficulties during this transition (Calleja et al., 2020; Malik-Soni et al., 2022; Murray et al., 2022; Schraeder et al., 2020). For example, youth and YAs with CCN and their families have reported a lack of preparedness for the transition from pediatric to adult healthcare, along with a lack of programs aimed at bridging this transition (Canadian Association of Paediatric Health Centres, 2016; Davidson et al., 2022; Vaks et al., 2016; Varty et al., 2020). Indeed, many youths and YAs lack a plan for continued assistance beyond pediatrics, as well as the skills to self-manage their varied healthcare needs (Lebrun-Harris et al., 2018; White

et al., 2023). These individuals are left to navigate an unfamiliar landscape of "depersonalized and overburdened" adult service models (Afzali & Wahbeh, 2017; Njuguna et al. 2019, p.840; Pinzón-Iregui et al., 2017).

Fragmentation in health services and reduced access to supports during the transition from pediatric to adult healthcare can lead to adverse outcomes for youth and YAs with CCN, while also placing a burden on their families (Montano & Young, 2012; Nakhla et al., 2009; Roy et al., 2021). For example, studies looking at a variety of chronic conditions demonstrated that YAs can experience decreased medication adherence and increased ER visits during the post-transfer period from pediatric to adult healthcare, which negatively impact their quality of life and health status (Butler, 2021; Campagna et al., 2020; Shepard et al., 2018). To address these issues and improve patient outcomes, there is an urgent need for healthcare providers and researchers to adopt innovative service delivery approaches. To date, systematic reviews exploring pediatric to adult transition experiences have focused on areas such as: an evaluation of research featuring youth and YAs with special healthcare needs (Betz, 2013); a meta- synthesis of youth and YAs with chronic diseases when transferring to adult wards within a hospital setting (Fegran, 2014); a qualitative meta-synthesis of the experiences of youth and YAs with chronic conditions related to the transition process (Varty et al., 2020); an examination of transition intervention outcomes for youth with special healthcare needs (Schmidt et al., 2020); and transition barriers for youth and YAs with a focus on all chronic health conditions (Gray et al., 2018; Hart et al., 2019). Such reviews reaffirm the existence of service gaps (Betz et al., 2013; Fegran, 2014; Gray et al., 2018; Varty et al., 2020), which could be due, in part, to inconsistent implementation of clinical guidelines (e.g., Got

Transition) during transitions in care service delivery (Lebrun-Harris et al., 2018; McManus et al., 2020; Varty et al., 2020).

Until recently, research on transitions in care often overlooked the voices of YAs as participants (Betz et al., 2013; Morsa et al., 2018). Despite an increase in research featuring the voices of YAs, the literature suggests that YAs and youth still lack appropriate care during the transition process (Butler, 2021; Canadian Association of Paediatric Health Centres, 2016). Some reviews on transition programs have included studies capturing the voices of youth and YAs having conditions such as juvenile arthritis (Burke et al., 2018), developmental disabilities (Williamson et al., 2017), cerebral palsy (Williamson et al., 2017), or cancer (Kohut et al., 2014), with focus on areas such as: exploring healthcare access (Williamson et al., 2017); assessing peer supports (Kohut et al., 2014; Richard et al., 2022); and satisfaction with transition program availability (Burke et al., 2018). However, several research studies on how to improve transition programs involve obtaining the perspectives of healthcare providers (Gray et al., 2021; Morsa et al., 2018; Pape & Ernst, 2022; Schraeder et al., 2020), which may overlook key quality improvement features if they fail to incorporate the perspectives of YAs. A pivotal systematic review on evaluating pediatric to adult healthcare transition interventions suggests a gap exists in obtaining patient experiences of care in areas such as integration into adult healthcare (Gabriel et al., 2017), which leads to difficulties when refining those interventions. Traditionally, individuals working within the healthcare sector (e.g., healthcare providers) have informed the direction of transition services and research, rather than patients with lived experience (Lugasi et al., 2011; Morsa et al., 2018). Focusing on patient voices, such as YAs with

CCN, can increase the understanding of patient service requirements (Cassidy et al., 2022; Gonzalez, 2019). Indeed, targeted research centred around the experiences and recommendations of patients represents a necessary step towards enhancing outcomes for patients and families, their clinicians, and ultimately the health system.

The Present Study

The current study aims to explore the experiences and recommendations of YAs with CCN to improve the transition process from pediatric to adult healthcare. Suggestions for service delivery improvement from across sectors (e.g., health, education, and social services), as reported by this YA population, can expand what is known about how to facilitate the transition to adult healthcare. Further, issues with the implementation of transition guidelines could be related to region-specific factors, such as lack of infrastructure and resources in certain regions (e.g., having access to a tertiary care hospital). As such, the research question is "What are the experiences of YAs aged 19–30 with CCN who transferred from pediatric to adult healthcare and what are their recommendations on how to improve this transition in care?" The study's findings can benefit clinical practice and research while guiding transition policy and informing decision makers involved with service delivery across settings and sectors.

Methods

Study Design

This study employed a qualitative descriptive research design, which offers a pragmatic and comprehensive approach to produce insight into YAs' experiences and recommendations during transitions from pediatric to adult healthcare (Bradshaw et al., 2017; Colorafi & Evans, 2016). Health research including lived experiences can produce

practical recommendations for the target population and is an intended outcome for this study (Beames et al., 2021). This study received REB approval from the University of New Brunswick (UNB), as well as the Horizon Health and Vitalité regional health networks (Appendices D–F).

Context/Setting

This study was conducted in New Brunswick, a small semi-rural Canadian province. This semi-rural setting provides elements of urban development (e.g., cities) and rural landscapes (e.g., towns/villages) (Dijkstra et al., 2020). Primary and specialty healthcare providers from the province's regional health authorities in various settings (e.g., community health clinics, private mental health practices, post-secondary wellness clinics, and urgent care) and sectors deliver healthcare for individuals beginning in their pediatric years through to adult healthcare. A pediatric hospital does not exist in this province; therefore, children and youth are often referred to children's hospitals in other provinces when requiring specialized healthcare.

Sampling and Recruitment

Maximum variation sampling was used to capture diverse participant perspectives (Creswell & Clark, 2011). Participant characteristics were varied in terms of gender and type(s) of CCN. Complex care needs (CCN) are defined as multi-dimensional health and social care needs, with or without a medical diagnosis (Brenner et al., 2018). The inclusion criteria for the age of YAs ranged from 19 to 30 years to allow sufficient time for YAs to fully complete their transition into adult services. To be included, YAs also had to self-report having CCN. Participants were required to be provincial residents of New Brunswick and to have sought services within that province. Recruitment took place

in 18 separate settings, including: (a) health and social service clinics in the community; (b) institutes of higher learning; and (c) community groups serving the study population. Interested participants reached out to the research team. All participants gave audio recorded oral consent prior to participating (see Appendix G).

Data Collection

Semi-structured interviews were scheduled at a time selected by the participant and lasted approximately 30 minutes each. A semi-structured interview guide was developed by the research team (see Appendix H). The interview guide was first piloted with a YA representative from the study population and the questions were then revised based on feedback. The interview guide, consisting of thirteen open-ended questions, followed a semi-structured format, meaning that participants could elaborate on and describe any factors that facilitated or hindered their transition experience (Colorafi & Evans, 2016). Interviews were conducted by the first author (MC), a PhD candidate, and were audio recorded and transcribed verbatim. Data collection continued until new data did not significantly add to existing themes (Guest et al., 2006; Robinson, 2014). All audio recordings were stored securely, and transcripts were stored separately from any identifying participant information.

Data Analysis

Data were stored, organized, and analyzed using NVivo software. Data were analyzed using inductive thematic analysis, which is frequently used in qualitative health research (Colorafi & Evans, 2016). Braun and Clarke's (2006) six phases of data analysis were followed: (a) data familiarization; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) providing a

report. Braun and Clarke's (2006) analysis process involved transcribing the interviews verbatim. Initial codes were developed inductively by the primary author with support from committee members (SD, AL, LM). These data driven codes were reflexively modified as new data and insights about the data were identified. Themes were developed and refined, ensuring alignment with the coded data. Clear and comprehensive descriptions for the themes were established, supported by participant quotes drawn from the coded data. Final themes were then approved through group consensus. Descriptive narratives were then carefully chosen and aligned with the research question.

Results

Twenty-three YAs with CCN were interviewed. Participants ranged in age from 19–29 years, and 74% identified as female. See Table 4.1 for a complete overview of the participants' demographic information. The sample reflected a diverse range of condition types (e.g., autoimmune, cancer, endocrine, gastrointestinal, mental health, neurological, and respiratory) as demonstrated in Table 4.2.

Table 4.1
Study Participant Characteristics: 23 YAs with CCN

Variable	Data
	Median (range)
Age	24 (19-29)
Years since transition from pediatric care	5 (1–11)
Age when completed care with pediatric services	18 (18–24)
	n (%)
Gender[a]	
Male	26%
Female	74%
Highest level of education	
High school	10 (43%)
College/Trades certificate	2 (8%)
University bachelors	11 (48%)
Employment at time of participation	
Working Full-time	13 (56%)
Working Part-time	1 (4%)

No employment	9 (39%)
Relationship status	
Single	8 (35%)
Dating	9 (39%)
Married/engaged	6 (26%)
Living situation	
Lives alone	4 (17%)
Lives with roommate(s)	8 (35%)
Lives with partner	5 (22%)
Lives with spouse	5 (22%)
Lives with family (full time)	1 (4%)

[a] non-binary data was not collected.

Table 4.2

Participant Diagnoses

	Frequency (*n*)	Percent (%)
Autoimmune	**2**	**4.17**
Chronic Pain	2	4.17
Cancer	**3**	**6.2**
Acute Lymphoblastic Leukemia	1	2
Brain Tumor (Benign)	1	2
Lymphoma and Leukemia	1	2
Dermatological	**1**	**2**
Cystic Acne	1	2
Endocrine	**5**	**10.4**
Congenital Hyperinsulinemia Hypoglycemia	1	2.08
Diabetes (Type 1)	3	6.24
Hormone Imbalance Disorder	1	2.08
Gastrointestinal	**4**	**8.3**
Colitis	2	4.15
Irritable Bowel Syndrome	1	2.07
Undiagnosed Digestive Disorder	1	2.07
Genetic	**1**	**2**
Cystic Fibrosis	1	2
Mental Health	**20**	**42**
Anxiety	10	20.8
Bipolar Disorder	1	2.08
Borderline Personality Disorder	1	2.08
Depression	6	12.5
Disordered Eating	1	2.08
Obsessive Compulsive Disorder	1	2.08
Musculoskeletal	**2**	**4.17**
Brittle Bone Disorder	1	2.08
Pelvic Floor Disorder	1	2.08
Neurological	**7**	**14.5**

Attention Deficit Disorder	1	2.08
Attention Deficit Hyperactivity Disorder	2	4.17
Chronic migraines	1	2.07
Epilepsy	2	4.15
Tourette Syndrome	1	2.07
Respiratory	**3**	**6.26**
Asthma	1	2.08
Chronic Lung Condition	1	2.08
Lung Disease	1	2.08
Total	48*	100

Note: *Many clients reported more than one diagnosis

Based on the perspectives of YAs, key recommendations were identified for improving the transition experience to adult services and included four overarching themes: 1) continuity of care, 2) improved access to supports, 3) transition readiness, and 4) a patient-centred care (PCC) team.

Theme 1: Continuity of Care

YAs reported that improving continuity of care could lead to better outcomes and greater satisfaction with the transition from pediatric to adult healthcare. According to YAs, core features for a seamless transition to adult healthcare included continuity of information and service provision among healthcare providers. Care received in this coherent way reassures patients that they would not "fall through the cracks" during the transition in service delivery. Continuity of care included the following three subthemes: (a) passing the baton, (b) personalized transition plan, and (c) transition coordinator.

1.1. Passing the Baton

Passing the baton refers to YA preferences on how information is shared, the regularity of planned communications with providers, and what information needs to be shared with adult healthcare providers (e.g., health history, self-efficacy competencies). Communication challenges were attributed to differences in governance between the

pediatric and adult clinical structures, coupled with variations in healthcare systems (e.g., interprovincial, or interinstitutional). Overall, YAs reported a gap in communication between their existing pediatric and new adult healthcare providers throughout the transition process:

> There's a disconnect between the adult clinics and the pediatric clinics, they don't seem to talk. (YA08)

As a solution to this problem, YAs recommended early and increased amounts of two-way information transfer between pediatric and adult providers and their staff. They suggest this communication should increase throughout the transition process:

> My [adult] neurologist had spoken to my [pediatric] neurologist, so they did like a smooth … transition in that sense. (YA03).

YAs were also frustrated when the ability to seamlessly share medical information related to experiences within the pediatric system did not carry forward to their adult healthcare providers. This disruption in information continuity was attributed to a decrease in frequency and duration of adult healthcare provider visits. Furthermore, YAs expressed that when these timebound adult healthcare provider visits were secured, they experienced emotional distress spending valuable time detailing their medical histories from the beginning:

> It really was like starting from scratch and having to go through, you know, 20 odd years of different things that have happened to you, … you can't get through that in a 15-minute [adult healthcare] appointment. (YA08)

1.2. Personalized Transition Plan

YAs expressed wanting a personalized transition plan which includes elements such as clear timelines and milestones to help streamline the transition process. YAs recommended that this plan be developed early in the transition process and include input from the pediatric care team, the adult healthcare provider, the youth, and their parents or caregivers to help prevent possible gaps in care:

> It was very gradual. So, she [pediatric team RN] would start [the process]. Every time I would go see him [pediatric team doctor], he would tell me, … in a couple of months, we're going to start doing this, then he would give me time to adapt to be prepared for what we were going to do, so, we would always have a plan. (YA03)

YAs in this study also reported inconsistent approaches to transition planning, thus they advised that a consistent plan be used that clearly identifies providers, along with their roles and the YAs' goals for each transition step:

> What does that [awareness of transition steps] mean in terms of attainable, … measurable goals. (YA21)

1.3.Transition Coordinator

YAs expressed the need for a point person, such as a transition coordinator, to facilitate their transition to adult healthcare. They suggested this be someone who could share relevant provider contact information, resources, services, and logistical support, such as navigating funding and inter-provincial medical documentation as well as help to fill out related forms. Overall, the position was proposed to manage all facets of the transition process, from transition planning through to adult healthcare integration. As

such, the coordinator role could assist with addressing questions related to the transition process itself, or regarding options and details for available adult healthcare providers, programs, or services. It was suggested that the coordinator could be affiliated with a non-profit association, primary healthcare program, or healthcare clinic, and support could be provided either in person or virtually:

> I think that [a virtual format, … a website] could be helpful, … I think that for many people that could be a useful, … thing to maybe have, to be able to look through this stuff [e.g., adult service options and clinic procedures], and then have somebody to talk to about it. (YA23)
>
> Well, there was one day where, … I came to the clinic [pediatric] and they had, … one of the coordinators from the adult program kind of come and meet me or anyone that was transitioning at that point.… So that was some sort of, like, initial communication that was really good…. In a blue skies *[sic]* world there would be someone that, … it is their sole job to manage transitions. (YA09)

Theme 2: Improved Access to Supports

Young Adults (YAs) recommended having improved access to reliable supports during the transition to adult healthcare. These supports were ideally situated in close regional proximity to the YAs and included: (a) healthcare providers, (b) peer supports, and (c) school-based supports.

2.1. Healthcare Providers

YAs reported that access to primary healthcare providers and specialists, could best support their transition care needs by arranging scheduled time for face-to-face healthcare visits to proactively manage their symptoms and improve their wellbeing.

These healthcare providers included family physicians, pediatric or adult specialists (including providers with mental health expertise), nurses, and physiotherapists. Inadequate access to these healthcare providers left YAs feeling uninformed and lacking timely guidance for best managing their conditions. In situations where primary care provider support was absent during the transition process, YAs felt alone to manage their condition and unsure of where to seek care:

> There was no one [health provider] who … taught me or showed me how to do anything, … it was like survival of the fittest, … you had no choice but to figure it out, really. (YA08)

> When you don't really know, … when someone's [health provider] gonna *[sic]* see you again, you actually kind of end up there [ER]. So, it became kind of a cycle for the first couple of years I'd say between 18 and 22 of going to the emergency room because you don't really know what your other options are. (YA15)

YAs wanted their medical support to include frequent clinical follow-ups to ensure symptom management over time (e.g., during scenarios where YAs may be prone to flare-ups from their condition, such as childbirth) rather than being left on their own to manage their healthcare:

> Recognizing that I know most physicians are very, very, very busy so, … being mindful of that but, … even just taking an hour, a couple hours, … maybe once every six months or once a year, whatever it is, and … coming to the table and, …saying, … here's what I'm observing, here's how … can we fix it. What, … are the issues that we can address moving forward. (YA08)

Many YAs reported their transition to adult healthcare was hampered by insufficient access to mental health care providers, delayed support from providers, and inadequate access to appropriate resources. They suggested that specially trained psychologists, psychiatrists, and counselors should be more accessible throughout the transition process:

> Most of my conditions were psychological …, but looking back now, … having access to the proper doctors [e.g., psychological expertise] or maybe having a better avenue to having one, maybe there is some medication that would *[sic]* of helped me accomplish certain things a little bit better. (YA07)

Given the lengthy wait times in accessing and securing appointments with mental health providers, YAs expressed that awareness of mental health provider wait times was beneficial and that other timely options for mental health support services (e.g., classes featuring information on aspects such as the transition process) were necessary to avoid disengagement with seeking mental health services:

> I personally would love to see … a [provincial] government website of the list of counselors available and what they specialize in …. Here's what wait times are like… everything [e.g., available resources and classes from mental health organizations] collated in one area. (YA15)

YAs also reported that continued coverage for their medical expense costs on entry to adult services was crucial in avoiding negative outcomes, such as delayed access to allied health services. YAs attributed their challenges in paying for provider appointments to many simultaneously occurring life changes, such as a lack of access to employment insurance plans (e.g., aging out of their family's health plan) and competing costs (e.g., post-secondary schooling). In addition, high out-of-pocket costs for mental health supports, loss of parental plan health insurance, and lack of overall clinician availability

(compounded by large patient volumes) were barriers to accessing healthcare providers, particularly mental health providers:

> Who do you have to help you once you've transitioned to being this, … adult? When the funds stop? When you're on your own? When mom and dad aren't paying for you anymore? … If I would have started seeing somebody soon enough, I think I could have avoided that maybe depression stage. (YA07)
>
> I was able to get a lot of [mental health] services while I was in pediatric care, but as soon as I moved into adult care, it kind of just disappeared in the blink of an eye. 'You don't have coverage, well, that sucks.' (YA08)
>
> With pediatric care, I was going to [mental health] therapy once every two weeks…, but now, with my [adult] therapist we have to look almost two months ahead. (YA15)

2.2. Peer Supports

YAs advocated for improved access to peer support during the transition from pediatric to adult healthcare services and strongly recommended connecting with their peers via organized virtual (e.g., WebEx or social media) or face-to-face group opportunities:

> Kind of like a little online resource [a Facebook group], and a lot of families and individuals, … share stories and strategies that they've used dealing with their condition as they grow up. (YA14)
>
> I think, if people are scattered all over the place, … it would probably be more practical to be virtual [student support groups], but I think as well, … if in the big cities, maybe something in the summer, some meet up opportunity? (YA19)

The participants recommended that these peer groups ideally be composed of YAs living with similar health conditions (with or without a diagnosis), concerns, or interests. YAs suggested these groups could facilitate knowledge sharing on topics such as integration into the adult healthcare system. Groups, such as non-profit health organizations, health clinics, or educational institutions (e.g., secondary or post-secondary) were suggested to lead the organization of these support groups.

2.3. School-Based Supports

YAs recommended that access to transition-related health services and information be provided from within both secondary school and post-secondary level institutions. In addition, YAs suggested that teachers, school-based transition professionals, or an external expert in transition-related health services, could provide student learning opportunities (e.g., via an assembly or education module) on how to achieve a successful transition (e.g., access to Q & A sessions):

> Something maybe through the schools, … maybe through the high schools if someone [health professional or individual with transition expertise], … came in and educated everyone ... on the resources, or if there's a specific program, or if, or even if you have questions … who to contact. That type of thing. (YA06)
>
> They [school psychologist] can help you transition… and then there's a team that you get assigned to that helps you throughout, or there's a group. (YA02)
>
> Maybe if student wellness can inform frosh coming into [post-secondary school] about what sorts of services they can attain at student wellness, without them [students] having to look for that information. (YA19)

YAs suggested that during secondary school, supports should focus on setting YAs up for successful post-secondary health-related outcomes. Specifically, additions to the secondary school curriculum were encouraged to educate all youth about successfully transitioning to the adult healthcare system:

> I think for me, I would have absorbed it best … if they had had someone come in for maybe a week [into a final high school year class], and over the course of a week … be it a guest speaker or a teacher at the school who is educated in this area, just take a week of maybe one-hour classes and go over all the different processes and all the different requirements that would be needed and all maybe some scenarios that you would encounter … as somebody who is recently transitioned into adult healthcare. (YA23)

Theme 3: Transition Readiness

Transition readiness pertains to a YA's capacity to exhibit the behaviours necessary for effectively acquiring services within the adult healthcare system. YAs indicated that their journey from pediatric to adult healthcare would be improved if transition preparations and education had begun earlier in the process. They suggested that early transition education would help prepare YAs for a gradual orientation to adult healthcare. In addition, YAs felt that acquiring these skills would empower them to take over the care responsibilities themselves, while best setting them up to manage their long-term healthcare needs. Transition readiness subthemes included:
(a) transition orientation, and (b) developing core life skills.

3.1.Transition Orientation

YAs desired a more structured orientation to the transition process, one that would provide information, education, and resources on the transition to adult healthcare, along with expectations for adult services (e.g., their processes and procedures). The intention behind an orientation would be to enhance the YAs comfort level for, and awareness of, the tasks they will be required to perform (e.g., medical appointment booking) prior to the transfer to adult healthcare. These activities or events could be designed to increase transition readiness and could take place during a healthcare provider meeting, a set orientation session, or through print materials:

> There's pamphlets in the, in the [providers] office, and then there can be questions, so I see this pamphlet or brochure and …, it says this, well why is this [transition] happening or just a sit-down meeting with parents and the doctor, just more information. (YA05)

YAs also emphasized the need for early orientation surrounding the medical insurance coverage process within the adult healthcare system:

> An information session with, … medical coverage companies, whether that be Blue Cross or, you know, other ones that are available and just kind of having sessions for individuals who are in, about to transition them and their families to recognize, you know, here's what you need to do, here's what's going to happen, here are the steps to take, here's what not to do. (YA08)

> What services are available, how are they gonna *[sic]* be funded, you know what I mean?… If they could only be funded 50%, well you need to know that. You need to know that you might need to get a second job. (YA07)

3.2. Developing Core Life Skills

YAs reported a need for life skills development prior to the transition to adult healthcare. YAs wanted information on services and resources to help improve their autonomy and develop self-management skills, such as self-advocacy. Self-management refers to a process through which YAs enhance their competencies necessary for handling their conditions (e.g., scheduling healthcare appointments). As part of self-management, YAs expressed the importance of self-advocacy, referring to their ability to articulate their needs to secure access to the providers and services essential for successfully managing their health. They emphasized the need to develop their own self-advocacy skills prior to entering the adult system given that their families had previously held that role, thus leaving a gap:

> 'Cause *[sic]*… I was very blind-sided, and I didn't realize the extent to which, like I said earlier, you kind of had to be your own advocate, so having those conversations a lot earlier would have been probably very helpful and potentially even …, a step-by-step guide, or, like, a checklist. (YA08)

Part of this self-management included understanding their current disease or condition along with the details and actions (e.g., health-seeking behaviours) required for long-term prevention and health maintenance:

> I think there should be more conversation of that independence, … and what does taking care of your health look like. (YA21)

Theme 4: Patient-Centred Care Team

YAs recommended that an interdisciplinary team of professionals collaborate in partnership with the YA to manage their unique care needs. For example, it was

suggested this team include care providers representing primary and specialty healthcare, along with allied health professionals, and mental health counselors. They suggested that family members also be included as a part of the team. YAs wanted their healthcare team to demonstrate competency surrounding their unique developmental needs and care preferences (e.g., level of family engagement). Considerations for an appropriate healthcare team included the following two subthemes: a) training for transition-ready care providers and b) family involvement.

4.1. Transition-Ready Care Providers

YAs expressed that it would be helpful to have healthcare providers who are: (a) experienced with interpersonal communication skills (e.g., active listening), (b) up to date on current resources, (c) knowledgeable about available health treatments (e.g., the latest therapeutic options along with the potential long-term side effect profiles of past and current treatment regimens), and (d) who provide patient-centred care. Specifically, YAs wanted their personal treatment goals and preferences to be listened to, valued, and prioritized by their healthcare provider:

> I mean, to me, you've got to be like, 'What would you like [for transition support guidance]? (YA07)

Given YAs often felt their health concerns were diminished by their adult healthcare providers, training on active listening and respectful patient interactions was suggested:

> I did visit my GP after I was kind of brushed off [upon seeking mental health support by a post-secondary wellness provider], … after a year and then it [condition] got worse. And … I didn't know about, mental health centres …., and he [GP] brushed me off as well. (YA11)

YAs strongly recommended that their adult healthcare providers and family doctors improve their knowledge on mental health and available resources, individualized patient care preferences, and the latest in therapeutic treatment options:

> Family doctors aren't trained extensively in mental healthcare and so it's often left to, 'Well, you know, have you talked to anybody else, well, what are they on?' (YA15)

4.2.Family Involvement

An issue raised by YAs was that pediatric care often included their family (e.g., caregivers/parents), yet while in adult services, they found themselves conducting appointments on their own. Despite this shift in caregiver involvement, YAs often reported their family as a preferred primary source of help during the transition process and wanted their adult healthcare providers to allow continued information sharing and caregiver involvement in their healthcare:

> I had … the support of my parents and my family with me so I just find it's very important and nice when the doctors are ok with that. (YA03)
>
> Just one meeting, … with even a family member, just so that there is an extra set of ears to know, OK this is what's going to happen and what to expect, because sometimes, … when you're in these [transition] meetings, you can take so much. So, to have someone else come sit in and listen and take in that information, I think would be helpful. (YA05)

Families were also involved in their YAs' transition from pediatric to adult healthcare by advocating and leveraging their health connections to acquire necessary services:

> I kind of had to advocate for myself.… I get brushed off a lot [by care providers]… When you're a child your mom is there to fight for you, but when you're all on your own, I find it's a little harder to get through and to get what you need. (YA06)
>
> Definitely more of my support came from … family than any … institution. And I had … what I needed, but I am definitely fortunate to have had those family connections. I don't really know, … I don't say that … there aren't any [supports] if you don't have any family connections, but I wouldn't know of, I didn't have to look … very hard for, for other resources. (YA19)

Discussion

This study explored the experiences of YAs with CCN who have already transitioned from pediatric to adult healthcare and their recommendations for improving the transition process across settings and sectors. By and large, despite families' concerted efforts to support their YAs in this study as they transitioned to adult services, participants reported significant service disruptions and lack of preparedness upon leaving pediatric care. Overall, YAs who recently transferred to adult services prioritized four areas for service improvements during the transition from pediatric to adult healthcare: improved continuity of care, increased access to supports, developing transition readiness skills, and having a patient-centred team.

Continuity of Care

Existing gaps in care often lead to negative health outcomes for YAs with CCN as they leave pediatric services for integration into the adult healthcare system. These gaps in healthcare are often caused by fragmentation in the transfer of their medical records

between healthcare providers, disruption in providing YAs access to their health histories, non-existent transition policies, and lack of transition planning (Coyne et al., 2019; Toulany et al., 2022; Zhou et al., 2016). Children's Healthcare Canada (CHC) guidelines suggest that pediatric and adult clinicians should adopt an integrated communication approach (e.g., medical summary transfer) that is reinforced by relevant clinical policies, procedures, and tools (e.g., patient portals) for improving the transition experiences of YAs (Canadian Association of Paediatric Health Centres, 2016).

One key area identified by participants in the current study was the disruptive communication gaps that occurred when transferring their medical history from pediatric to adult healthcare providers. This information gap left YAs feeling diminished in their ability to participate in informed discussions with their new providers regarding the next steps in their care. For example, one recent study found that despite YAs with long-term conditions being advised their health information would carry forward to the adult healthcare provider, medical files had been reported missing during the transition process (Coyne et al., 2019). Neglecting to share medical summaries can lead to lapses in care, medical errors, and impact patient trust (Steinway et al., 2017). This crucial gap in clinical information transfer from pediatric to adult healthcare suggests that structured transition policies and procedures are required to ensure that patient information is not lost during transfer between health systems (Canadian Association of Paediatric Health Centres, 2016; Got Transition, 2020a; Toulany et al., 2022). Indeed, transition programs that incorporate structured transition policies, including the transfer of medical information to adult services, have demonstrated improved continuity of care for the YAs (Essaddam et al., 2018; Moons et al., 2021; Saulsberry et al., 2019).

Structured transition programs, with mandates and tools for transferring patient documentation from pediatric to adult healthcare services, are producing positive outcomes and gaining recognition from clinicians. One such transition program for youth and YAs (ages 12–25) having sickle cell disease from St Jude Children's Research Hospital involved a nurse transition manager forwarding the patient's medical summary to their adult provider (Saulsberry et al., 2019). The YA also received a transition policy during their first adult care appointment (Saulsberry et al., 2019). The structured transition approach, which included a transition policy, resulted in improved rates of admission to adult care compared to individuals who did not participate in the program (Saulsberry et al., 2019). Another transition program for YAs with type 1 diabetes demonstrated clinical benefits when a structured health summary (e.g., medical history, psychosocial background), referred to as a 'passport,' transferred from the pediatric to adult provider (Essaddam et al., 2018). Seventy-five percent of those YA program participants experienced improvements in their diabetes management (Essaddam et al., 2018). Surrey Place—a Canadian centre specializing in intellectual and developmental disabilities—has also developed a useful medical summary template known as the SHARE Transition Plan Health Care Toolkit for youth, YAs (ages 12–21) and their families to aid with this ongoing communication transfer (Surrey Place, 2019). Further, the National Association of Pediatric Nurse Practitioners has produced youth/YA and family centred recommendations suggesting that all health records (e.g., medical summary) and plans of care should be integrated into electronic health records, and that related policies should use provider-inclusive language to reflect all members of the YA's integrated team (Betz et al., 2017). The Society of Pediatric Nursing (SPN) has formulated recommendations aimed at improving continuity

in care throughout the transition process, placing emphasis centred around the needs of youth/YAs, and their families (Betz et al., 2017). This approach, referred to as the *SPN position statement: Transition of pediatric patients into adult care* (Betz et al., 2017), underscores the pivotal role of care providers, particularly pediatric nurses, in facilitating a successful transition process. SPN emphasizes the importance of ensuring the seamless transfer of health records for YAs to adult providers and agencies before the transfer event (Betz et al., 2017). Ideally, SPN suggests that a direct handoff of the YA's records between pediatric and adult providers would occur to facilitate a smooth transition (Betz et al., 2017). Additional studies on pediatric transitions (e.g., with patients who experience type 1 diabetes, mental health, or juvenile rheumatic conditions) have reported that a transition summary document between the pediatric and the adult healthcare provider may promote continuity of care, establish a quality standard for practice, and result in improved patient outcomes and satisfaction (Broad et al., 2017; Foster et al., 2017; Iverson et al., 2019; Kuipers et al., 2021; Nakhla et al., 2017).

A study on YAs with type 1 diabetes suggested that incorporating joint visits with the pediatrician, adult healthcare provider, and the transferring YA could facilitate the appropriate sharing of medical summary communications (Iverson et al., 2019). The Telehealth Toolkit is a useful guide to customize an agenda for a joint visit between a transferring YA along with pediatric and adult healthcare providers as part of the Got Transition® programming (White & Greenberg, 2022). While a limited number of clinical practices have formal transition policies that consider information transfer, Got Transitions® Six Core Elements of Healthcare Transition™ 3.0. offers a valuable policy template (Chira et al., 2014; Got Transition, 2020b). The Six Core Elements™ (transition

policy; transition tracking and monitoring; transition readiness; transition planning; transfer of care; and transfer completion) are designed for guiding clinicians as they assist youth and YAs in transition from pediatric to adult healthcare (Cleverley et al., 2020; White et al., 2020).

Beyond facilitating the transfer of information, the CHC guidelines, *A guideline for transition from paediatric to adult healthcare for youth with special healthcare needs: A national approach,* advocate for helping these youth and YAs to build their capacity for understanding their conditions and treatments (Canadian Association of Paediatric Health Centres, 2016). This will help them interact with health services on an ongoing basis as they integrate into adult services (Canadian Association of Paediatric Health Centres, 2016). The findings from the current study support this CHC recommendation which encourages pediatric healthcare providers to provide youth with access to their own health records at the time of referral to adult services. YAs felt having access to their medical histories could prevent details pertinent for healthcare decision-making from being missed by new providers and would empower them to participate in discussions regarding their healthcare. Offering online portals, where patients can securely access their own medical records, has been suggested as an emerging solution for supporting patient empowerment while encouraging self-management (Gorfinkel & Lexchin, 2018). YAs owning details about their medical data can also facilitate continuity of care while mitigating medical file loss due to the fragmented electronic documentation systems of various providers (i.e., as set by clinic, health authority, or provincial boundaries).

In Canada, patient access to health system records through select hospitals and clinics is starting to roll out (e.g., Ontario SickKids Hospital's MyChart and

Saskatchewan's MySaskHealthRecord) (Basky, 2019; Government of Saskatchewan, 2022; SickKids, 2022). Additionally, a pan-Canadian survey conducted by the Canadian Medical Association (CMA) and the market research firm Ipsos revealed that 79% of YAs in Canada expressed interest in gaining access to a 24-hour patient portal connected with their primary care provider and team (Canadian Medical Association, 2019). Thus, decision makers should prioritize the development and access to such portals to meet the needs of YAs transferring from pediatric to adult healthcare. Ontario SickKids Hospital's MyChart and BC Children's Hospital's Just TRAC It! are examples of such continuous records (BC Children's Hospital, 2023; Han et al., 2021; SickKids, 2022). For instance, Just TRAC It! allows youth to share their pediatric medical history from their smartphone or tablet (BC Children's Hospital, 2023; Han et al., 2021). As an important consideration, in Quebec, the release of patient medical results is delayed 30 days to allow the ordering clinicians to first discuss results with their patients (Basky, 2019).

In addition to maintaining continuity in health record documentation and transfer, current guidelines highlight the importance of transition planning to facilitate a smooth transfer to adult services (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022). Participants in the current study stated that having a documented transition plan outlining next steps for healthcare and where to find necessary resources helped them avoid disjointed service delivery. YAs said this planning should ideally begin early (e.g., age 15 or younger) with special emphasis on one to two years before transfer (e.g., age 17) to provide enough time for lengthy application processes (e.g., health coverage) to occur, such as those required by certain government procedures. A

clinical report from the American Academy of Pediatrics (AAP) et al. (2011) suggests this planning process should ideally begin around age 12 with youth and their family and is facilitated when health systems have a standard transition policy and patient tracking database (AAP et al., 2011; Canadian Association of Paediatric Health Centres, 2016; Mubanga et al., 2017). For the YAs in the current study, having a clear plan that indicated each step of the transition process reduced feelings of stress related to these overall life changes. Similarly, studies looking at youth and YAs with type 1 diabetes and mental health conditions have suggested that personalized and structured transition plans are key factors for enhancing the transition experience (Broad et al., 2017; Cadario et al., 2009).

YAs in the current study also highlighted the need for guided support for bridging the services required for transition success. One solution would be the introduction of transition coordinators. For instance, designated transition coordinators have been recommended to improve medication adherence and address gaps in self-management, while providing care coordination and emotional support to youth and YAs with CCN and their families (Annunziato et al., 2013; Hillis et al., 2016; Ravens et al., 2020; Steinway et al., 2017). Among transition programs, the role of transition coordinator has been held by individuals with various professional backgrounds, such as nursing, medicine, and allied health sciences (Betz et al., 2016; Ravens et al., 2020). One such intervention, including a transition coordinator for YAs with sickle cell disease at a large medical centre, was found to improve the successful transfer to and retention in adult healthcare (Manwani et al., 2022). Another clinical trial for youth and YAs (ages 17–18) having type 1 diabetes featuring a transition coordinator, accessible through technology (e.g., texting, email), led to improvements in clinic attendance in

adult care (Butalia et al., 2021). Not surprisingly, evidence-based guidelines on transition from pediatric to adult care advocate for having a coordinator as a key member of the YA's interdisciplinary team (Pape & Ernst, 2022; Toulany et al., 2022).

Access to Supports

YAs in the current study suggest that improved access to healthcare providers, mental health supports, providers with mental health training, curriculum on transitions in care from the educational sector, and peer supports are needed to achieve a successful integration into adult healthcare services. These YA recommendations also pinpointed the critical need for greater access to, and financial assistance for, mental health resources and services. When these services were unavailable, YAs were left feeling unprepared to self-manage their condition(s). Even in instances when services were available, YAs still reported gaps in their healthcare due to high patient volumes, and as a result, long wait times in adult services. A systematic review on transitions to adult healthcare reaffirmed that barriers to access exist for patients with a variety of childhood-onset chronic conditions when trying to obtain a referral for qualified adult practitioners (Gray et al., 2018). Proposed solutions identified in the literature for improving service access for youth and YAs with chronic conditions and/or CCN include the creation of transition clinics equipped with a multidisciplinary team and facilitator-led transition programs (e.g., having peer and/or educational support) (Marani et al., 2020; Nadarajah et al., 2021; Steinway et al., 2017). These models have been found to improve access to medical care (including follow-ups) and reduce acute medical complications (Marani et al., 2020). Another type of transition model for mental health services in Australia, referred to as headspace, featured a designated staff member

(i.e., access worker) who regularly contacted YAs (18–25 years) to assist them with accessing services with care providers and mental health specialists during their wait time for provider appointments (Muir et al., 2012). The YAs in that study reported that the initiative resulted in improved access and active involvement with healthcare services (Muir et al., 2012). As such, researchers and policymakers, with guidance from YAs, should explore how these models could be feasibly implemented and assessed within the context of local settings.

The YAs in the present study recommended the need to expand access to mental health supports and services for improving the transition to adult healthcare. Indeed, in 2018, YAs (20–29 years) accounted for the highest usage of mental health resources from emergency departments within Canada, underscoring that access to community-based mental health care is critical following transition to adult healthcare (Canadian Institute for Health Information, 2019; Moroz et al., 2020). Moreover, a recent study reported an increase in hospitalizations for YAs if they had experienced inconsistent mental health services during the transition from pediatric care (Toulany et al., 2019). It is thus essential to provide better access along with more affordable mental health services for this population to avoid these adverse outcomes. Furthermore, findings from this current study suggest that a YAs' transition plan should clearly assign them to a healthcare provider with expertise in mental health (e.g., psychologist or counselor) if those services are needed, along with appropriate resources.

YAs from this study also suggested that embedding transition supports within their familiar school setting, such as through formalized curriculum, would be beneficial for improving their transition to adult healthcare. This type of training would introduce

them to real-world scenarios they could anticipate and provide resources for overcoming common barriers and achieving successful transitions (e.g., steps for booking medical appointments). Notably, limited studies exist surrounding the transition to adult healthcare from the secondary and post-secondary learning sectors. Indeed, school-based transition services (i.e., individualized education plans) tend to focus on preparing learners for adult roles, without specifically addressing healthcare roles and responsibilities (Bargeron et al., 2015). As advised by the YAs within this study, this role could be held by a public health nurse, or a trained facilitator housed within the schools. Similarly, a US national association of school nurses position statement advocates that school-based nurses should be considered to provide expertise in the areas of transition planning (Baszler et al., 2014; Molner et al., 2019).

Providing YAs with opportunities to participate in peer support groups, as recommended by participants in this study, may also offer a promising strategy for enhancing transition outcomes. Indeed, a systematic review assessing peer support interventions found that peer supports improved the behavioural and emotional health of youth and YAs (up to age 18) with chronic conditions (Kohut et al., 2014). Moreover, a qualitative study featuring the healthcare experiences of post-transfer YAs with type 1 diabetes reported that peer support is a "wish-list" item for improving transitions (Garvey et al., 2014). Another study on developing a peer education program for participants with CCN also reported that peer transition groups could help YAs exchange valuable information amongst peers on vocational and medical issues (Bomba et al., 2017). Furthermore, peer support interventions are deemed as appropriate solutions for facilitating condition self-management and may help to reduce possible

support burdens on families (e.g., emotional) (Thompson et al., 2022). As such, researchers should focus attention on ways to improve access to peer support interventions for YAs during the transition to adult healthcare services.

Transition Readiness

In general, the YA recommendations in this study echoed the CHC guidelines, underscoring the need for increased education and learning resources about transitions in care to equip them with the necessary skills required for optimizing their health as adults (Canadian Association of Paediatric Health Centres, 2016). YAs in the current study preferred settings such as health clinics and secondary and post-secondary institutions for enhancing their transitions in care readiness, with further support from online sources. Specific suggestions for acquiring this education included offering an orientation event or providing accessible information through a website or brochure. Several studies have found that interventions incorporating patient education programs, such as transition workshops and tours, significantly enhance the preparedness of youth and YAs with CCN into the adult healthcare system (Bomba et al., 2017; Crowley et al., 2011; Schmidt et al., 2020). These interventions lead to positive outcomes, including enhanced medication adherence, improved quality of life, and increased proficiency in self-care measures (Bomba et al., 2017; Crowley et al., 2011; Schmidt et al., 2020). YAs in the current study also suggested that this education could occur during a structured class or event in secondary school, such as with an expert in transitions from pediatric to adult healthcare. As indicated by the YAs in this study, a standardized repository of transition resources, such as governed by a government body with expertise in transitions (e.g., offered by provincial governments or CanChild and CHC's *Health Hub in Transition*) could also be

offered specifically for YAs with CCN as the primary audience (Health Hub in Transition, 2022).

To further enhance their preparedness, YAs recommended that developing core life skills, particularly around self-management and self-advocacy, prior to final transfer would also have improved their transition to adult healthcare. These findings are not surprising given a US National poll reported only 5% of pre-transition youth (ages 13–18) would ask questions independently about issues during healthcare visits (C. S. Mott Children's Hospital, 2015). As such, coaching patients to enhance their self-management and advocacy skills is imperative to ensure a smooth transition to adult services (Gobeil-Lavoie et al., 2019; Okumura et al., 2015; Toulany et al., 2022). Indeed, families can support the early development of these skills by partnering with health providers and educators to design interventions intended to enhance chronic disease self-management (Catarino et al., 2021). Furthermore, validated research tools for measuring transition readiness, such as the Transition Readiness Assessment Questionnaire (TRAQ), could evaluate crucial life skills, such as the self-management and self-advocacy skills of youth from within the school sector (Johnson et al., 2021). Researchers and healthcare providers are encouraged to promote the adoption of these tools to improve transition readiness outcomes.

YAs also highlighted the importance of proactively acquiring details about their health insurance options, such as financial assistance for accessing care providers and prescriptions, to best prepare them for integration into adult healthcare. The CHC guidelines reiterate the importance for YAs to have their physical health, mental health, and financial needs addressed (Canadian Association of Paediatric Health, 2016).

Participants from the current study expanded upon this recommendation by indicating that health insurers should proactively communicate to YAs with CCN surrounding any pending termination of their health insurance policy (i.e., attributed to aging out of their family plan).

Participants also strongly advocated for governments to find ways, such as co-pays, to support YAs in covering healthcare provider costs, such as private psychology, so they could redirect those funds to cover other life expenses (e.g., post-secondary tuition). Of note, the CanChild Centre for Childhood Disability Research and the Hamilton Family Network have developed a tool for youth and YAs up to age 21, as well as their families, called Keeping It Together to bring awareness to patients and their families surrounding issues such as insurance planning for the transition to adult healthcare (Freeman et al., 2015).

Patient-Centred Care

YAs in the current study stressed the importance of receiving care from an interdisciplinary team—with the inclusion of their families—that is developmentally appropriate and customized to their needs. They believed this patient-centre care (PCC) approach would improve the transition experience from pediatric to adult healthcare. The Institute of Medicine (2001) defines PCC as care that is provided in a respectful manner and that values patient preferences. Regulatory bodies and CHC guidelines have encouraged that these PCC principles, which centre directly on the issues expressed by patients, should be included in health professional training, both pre- and post-licensure (Canadian Association of Paediatric Health Centres, 2016). In fact, transitions in care literature suggests that all allied health team members and their front-line staff should

participate in training focused on providing developmentally appropriate care that is patient-centred to YAs (Cooley et al., 2011; Nathawad & Hanks, 2017; Toulany et al., 2022; White et al., 2023). Indeed, YAs in the current study reported that their healthcare providers could have facilitated their transition to adult healthcare had they demonstrated active listening and respected their individualized needs.

Finally, the YAs in this study shared that they wanted the individualized choices they make surrounding their healthcare to be respected, especially regarding who the YA may choose to involve at their healthcare appointments. YAs from this study frequently expressed wanting family present during and after the transfer to adult services. This finding aligns with guidelines, such as CHC to individualize transition planning and serves as an important prompt for adult care providers to remind YAs that their preference for a support person(s) can be maintained beyond pediatric care (Canadian Association of Paediatric Health Centres, 2016; National Institute for Health and Care Excellence, 2016; Toulany et al., 2022). Studies have reaffirmed that when healthcare providers had approval from YAs with CCN to involve families in their healthcare during transition, communication and treatment outcomes were improved (Allen et al., 2018; Colver et al., 2019). Accordingly, adult health and social service providers, upon consent, could consider involving the YAs family at the outset of care, and capture this information within the YA's transition plan (National Institute for Health and Care Excellence, 2016).

Overall, YAs in this study would encourage their healthcare providers to develop transitions in care competencies that are aligned with PCC (e.g., providing developmentally appropriate care). A governing body such as the Medical Council of

Canada could develop curriculum aligning pediatric to adult healthcare transitions with required competencies (e.g., skilled communication) for pre-licensure physicians (Medical Council of Canada, 2022). For other health providers, the University of British Columbia offers the ongoing accredited e-learning Transitioning to Adult Care for Youth with Chronic Health Conditions and Disabilities (University of British Columbia, 2022).

Limitations

This study captures a breadth of experiences and recommendations from YAs on how to improve the transition from pediatric to adult healthcare, which is a phenomenon experienced by YAs worldwide. It is important to note that participants in this study were YAs with CCN from a small province in Atlantic Canada with no designated children's hospital to centralize care coordination for this population. As such, these findings may not be transferable to other geographic settings where larger pediatric hospitals and clinics exist. Despite our best efforts to recruit participants representing diverse CCN, some representation was missing (e.g., the needs of YAs with autism spectrum disorder [ASD]). This could be attributed to the simultaneous recruitment for a study on ASD occurring in the same geographical area. It should also be noted that 74% of study participants were female, thus limiting generalization of the study findings. While recall of experiences could be a limitation, the average participant age was 24, with a mean of 5 years since their final transfer to adult services. Thus, the likelihood of participant recall bias was mitigated due to the shortened time gap from when the YAs finalized their transition to adult services and the time of their study interview. Lastly, data was not collected on the types of healthcare services utilized by YAs which may limit details describing the frequency and scope of services utilized. To address the

study limitations, future research could be conducted in other geographical settings, include more male participants, and represent further diversity in CCN.

Conclusion

Interviews with YAs who had recently transitioned from pediatric to adult healthcare provided recommendations in four areas that policymakers, care providers, educators, and researchers can focus on for prioritizing improvements for YAs and their families. Although new Canadian transitions in care guidelines exist, some regions have yet to see improved outcomes for YAs. Research, such as the current study, is needed to further understand transitional care within specific populations and contexts and how the implementation of these guidelines can be improved (Canadian Association of Paediatric Health Centres, 2016). Overall results from this study underscore the necessity for structured transition plans, improved access to supports, tailored education for transition readiness, and the establishment of patient-centred teams along with family support for YAs to experience successful transitions. Priorities include policymakers facilitating access to electronic health portals, ongoing financial assistance for mental health services, and collaborative efforts between educators and healthcare professionals to implement school curricula targeting health self-management. Additionally, researchers could collaborate with YAs and their families to develop PCC service interventions for pediatric to adult healthcare transition. Moving forward, policymakers and care providers should design quality improvement interventions informed by a deep understanding of the needs of youth, YAs, and their families (Mazur et al., 2017; Varty et. al, 2020). Indeed, study findings serve as a reminder that YAs with CCN experience many simultaneous life changes upon entry to adulthood which are exacerbated by losing the

familiarity of long-term pediatric services and the central caregiving role of families. To ensure that the healthcare of YAs does not fall through the cracks within the system, it is vital that care providers, researchers, and policymakers design and deliver quality health services based on YA recommendations.

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Chapter 5: Discussion and Concluding Remarks

As a guide for the reader, this concluding chapter reviews why the results from this dissertation's manuscripts are timely and can inform interventions to help improve the transition experiences and patient outcomes for YAs with chronic conditions and/or complex care needs (CCN) in NB and beyond. These manuscripts reaffirm that YAs continue to face challenges in receiving necessary healthcare services and supports when transitioning from pediatric care to adult healthcare. Furthermore, the findings from this dissertation offer important insights on how to improve service delivery.

Canadian clinical practice guidelines and transition models have existed since 2016, with the goal to guide best practice for service delivery and research (Canadian Association of Paediatric Health Centres, 2016). However, the YAs from manuscript three suggest that barriers remain when transitioning from pediatric to adult healthcare. Thus, it is important to continue to address these barriers to improve service delivery and produce desired patient outcomes. Quality improvement methodology suggests that capturing input from patients with lived experience is a necessary strategy to refine service delivery and improve outcomes (Dreier et al., 2021; Skelton-Wilson et al., 2021; Wong et al., 2020).

The purpose of this research was to explore the lived experiences and recommendations of YAs with chronic conditions and/or CCN for improving transitions from pediatric to adult healthcare. My research approach to exploring YAs' experiences with, and recommendations for, transitions in care included undertaking a scoping review and conducting a qualitative research study. This concluding chapter presents summaries of the three preceding chapters and compares findings across manuscripts. This is

followed by sections detailing proposed implications for research, policy, and practice.

Manuscript One: Improving the Pediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs: A Scoping Review Protocol

Improving the transition experience from pediatric to adult healthcare for YAs with complex care needs (CCN) is challenging due to service provision gaps (Betz et al., 2013; Johnson et al., 2021; Nelson, 2016; Rich, 2017; Shanahan et al., 2021). A suggested approach to addressing these service barriers is to develop a better understanding of patient experiences (Luxford & Sutton, 2014). This protocol (hereinafter referred to as manuscript one) presented methods for mapping the recommendations of YAs with CCN transitioning from pediatric to adult healthcare. This scoping review protocol was developed under the guidance of a JBI Centre of Excellence team composed of a librarian (AG) along with an experienced supervisory committee (SD, AL, and LM). Methodological rigour was ensured by peer review of the protocol (Pollock et al., 2021). Manuscript one reaffirmed that the voices of YAs with CCN were considered necessary for developing strategies to enhance service delivery (Okumura et al., 2015). While some research and support interventions addressing barriers to transitions in care have been conducted, much of the literature has not incorporated the voices of YAs into their recommendations for improving transitions in care service delivery (Morsa et al., 2018; Okumura et al., 2022). Moreover, by way of registering this protocol with JBI, it was evident this topic reflected an important area for research and that synthesizing YAs' recommendations would address this knowledge gap (University of Tasmania, 2022). Furthermore, the peer-reviewed *Healthy*

Populations Journal published this manuscript for its research alignment with the United Nations Sustainable Development goal of reducing health inequalities (United Nations, 2020).

Manuscript Two: Improving the Transition from Pediatric to Adult Healthcare: A Scoping Review on the Recommendations of Young Adults with Lived Experience

This paper is a scoping review that aimed to identify recommendations within the literature on how to improve the transition from pediatric to adult healthcare from the perspective of YAs who have gone through the process. The review adhered to JBI methodology for scoping reviews. We searched MEDLINE (Ovid), CINAHL (EBSCO), PsycINFO (EBSCO), and EMBASE (Elsevier) databases, and conducted a grey literature search for relevant material. This review featured the recommendations of YAs with chronic conditions and/or CCN who have transitioned from pediatric to adult healthcare, in any setting (e.g., hospital, clinic, or community) and across all sectors (e.g., health, education, and social services). Eighteen studies met the inclusion criteria for this review. These studies included YAs with 14 different chronic, childhood-onset conditions, receiving primary health services in North America (67%) and Europe (33%). YAs' recommendations for improving the transition from pediatric to adult healthcare included: (a) improving continuity of care (n=12), (b) facilitating patient-centred care (n=9), (c) building strong support networks (n=11), and (d) implementing transition education preparedness training (n=7). Review findings can benefit service delivery by identifying important barriers to health, education, and social services for youth transitioning to adult healthcare that need to be addressed. This paper contributed to the development of my primary study by reaffirming the gaps that YAs experience during transitions in care.

This review also highlighted that gaps remain in identifying solutions for addressing how to improve transition planning and the transfer of care. The findings suggest the need to explore more detailed strategies for improving the transition planning process, as voiced by those who have experienced the transfer to adult healthcare services to improve practice guideline recommendations for YAs with chronic conditions and/or CCN.

Chapter 4, Manuscript Three: "Improving the Transition from Pediatric to Adult Care: Recommendations from Young Adults with Lived Experience"

This paper presents a qualitative descriptive study exploring the experiences and recommendations of young adults with lived experience who have undergone the transition from pediatric to adult healthcare services. Study findings contribute to a greater understanding of this transition process, offering clear ways for improving the transition from pediatric to adult healthcare services in a semi-rural Atlantic province. As service demands increase for YAs with chronic conditions and/or CCN, healthcare providers must determine the best way to meet their high-resource needs. The process of transition to adult healthcare is a critical time for the overall life course and health outcomes for these youth with CCN (e.g., T1 diabetes, autism, and anxiety). Following the transition to adult healthcare, youth are vulnerable to deteriorating outcomes (e.g., increased stress and costly ER visits). Of note, studies exploring how to address these gaps are mostly from perspectives other than the YAs themselves. Seeking direct input from youth on their experiences with health services is a crucial step towards improving service delivery. This study aimed to better understand the experiences of YAs with CCN who have transitioned from pediatric to adult healthcare services. A qualitative descriptive design was used to explore their experiences. Semi-structured interviews were

conducted with 23 YAs (aged 19–30) from NB, Canada. Maximum variation sampling was used to capture diverse perspectives (e.g., representing individuals with several types of complex needs). Participant interview questions were designed to identify specific gaps in transition services and provide strategies and recommendations to address these gaps. The following themes were identified in the data: (a) continuity of care, (b) improved access to supports, (c) transition readiness, and (d) a patient-centred care team. Results from this study will inform policy and lead to the development of necessary service delivery improvement strategies for enhancing the experiences of future youth transitioning from pediatric services.

Comparison Across Manuscripts Two and Three

Although there were similarities across findings in manuscripts two and three, manuscript three provided additional, detailed information on the recommendations of YAs transitioning from pediatric to adult healthcare in a specific context (i.e., within the province of NB). For example, YAs in manuscript two wanted support to enhance their preparedness for the transition process, providing suggestions for improving transition readiness within healthcare settings. YAs in manuscript three built on this recommendation and suggested that transition in care supports should also become embedded into secondary and post-secondary school settings. Of note, in the United States, the 2023 American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians (AAP/AAFP/ACP) position statement recommended that healthcare transition supports be added in school-based health centres (White et al., 2023). This recommendation should also be considered for application to the Canadian context. YAs from manuscript three also provide detailed suggestions on

innovative ways beyond the use of school health centres for delivering the skills required for transition. For example, YAs in manuscript three suggested establishing and embedding formalized curriculum on transition topics (e.g., how to prepare for adult healthcare services) and presenting information at awareness events (e.g., school assemblies).

While manuscripts two and three both suggested that YAs should receive support from several health and allied health providers, the findings from manuscript three highlighted the importance of mental health providers in particular. Participants in manuscript three, who were recruited from the province of New Brunswick, advocated for access to a variety of mental health providers and services (e.g., classes), along with corresponding financial assistance due to their experiences with losing their private insurance funding to sustain those necessary services. The NB Health Council (2022) reiterates that timely access to mental health services remains a challenge throughout the province of NB for youth emerging into young adulthood. Furthermore, participants from manuscript three wanted their allied health providers to improve their knowledge and skills in the treatment of mental health conditions for YAs with CCN. YAs felt this type of training would facilitate the transition readiness process. This finding is not surprising given almost half of the participants from manuscript three reported having mental health conditions, often coexisting with a physical condition. The Canadian Mental Health Association reaffirms that patients with chronic physical conditions report mental health conditions (e.g., depression, anxiety) at twice the rate of the general population (Canadian Mental Health Association, 2022).

Finally, compared with manuscript two, the YAs in manuscript three recommended additional ways to improve communication and collaboration during the transition from pediatric to adult healthcare. For example, the YAs from manuscript three highlighted the benefits of having a personalized transition plan that is designed with a healthcare team, which is a recommendation that did not emerge from manuscript two. The YAs from manuscript three also suggested creating secured portals with electronic records that patients can access along with their personalized transition plans. The YAs in manuscript three wanted EMRs to be shared between pediatric and adult healthcare providers from the same region, and between healthcare providers in different settings and geographical areas. It is possible that since manuscript two reported on health service programs from the USA, their healthcare providers may have had better EMR interoperability between their pediatric and adult provider systems, hence, providing plausible insight into why this finding did not appear in manuscript two. Notably, Canada ranks second to last for EMR adoption amongst the commonwealth countries (Guerriere & Kim, 2022). By contrast, the USA has greater adoption of EMRs into clinical practices, in part attributed to federal policies incentivizing the meaningful use of EMRs to improve patient outcomes (Guerriere & Kim, 2022).

Implications for Research, Policy, and Practice

Based on the findings from this dissertation, several practical implications emerged for researchers, policymakers, and healthcare providers with regards to improving transitions from pediatric to adult healthcare for YAs with chronic conditions and/or CCN. Overall, YA voices captured within this dissertation expressed that various healthcare, education, and social resources are needed to support YAs so they may

experience a seamless integration into adult healthcare services. The following recommendations for a successful transition should be considered and integrated into: (a) future research initiatives; (b) education and resources for YAs and their families; and (c) policy and practice improvements.

Future Research Initiatives

Throughout this research process, it became evident that although Canadian transitions in care guidelines are available to improve care continuity, access to supports, and acquisition of skills for YAs and their healthcare providers, a gap still exists in the systematic implementation of those recommendations (Canadian Association of Paediatric Health Centres, 2016; McManus et al., 2020). Findings from both manuscripts 2 and 3 indicated that during transitions, YAs reported: (a) issues with securing access to required resources from healthcare professionals; (b) discontinuities in how their information was transferred from pediatric to adult healthcare providers; (c) interactions with healthcare providers that lacked the necessary education to best support the healthcare needs of YAs; (d) a lack of support navigating the transition process (e.g., peer or family supports); and (e) a gap in proactively acquiring the skills required for self-managing their condition. These challenges, as experienced by the YAs in this dissertation, reaffirm that transition guidelines have not been successfully implemented in full within this population. As such, future researchers are encouraged to assess the barriers preventing the effective adoption of clinical practice guidelines (Cassidy et al., 2021). Research teams focused on enhancing the uptake of clinical guidelines should include diverse health stakeholders, such as representatives from pediatric and adult

healthcare, decision makers, YAs, and their families (Canadian Institute of Health Research [CIHR], 2019).

Researchers are encouraged to understand the specific and unique barriers to the process of adopting guidelines within their local clinical settings prior to developing a tailored strategy for improving guideline implementation (Fischer et al., 2016; Harris et al., 2013; NICE, 2023). Commonly identified barriers to guideline implementation into clinical practice include: a lack of content knowledge, negative attitudes toward guidelines, and a lack of managerial support for their uptake (Kastner et al., 2015; Liang et al., 2017; Peters et al., 2022). Once these barriers are better understood, researchers can assess and select what types of methods should be applied for tracking guideline adherence over time (Fischer et al., 2016; NICE, 2023; Storm-Versloot et al., 2012). By following a structured process for identifying localized barriers, researchers can then be poised to develop targeted solutions to overcome the challenges of adopting these guidelines within specific settings and contexts (Fischer et al., 2016). Moreover, employing frameworks, such as RE-AIM (reach, effectiveness, adoption, implementation, maintenance), to assess the success of the implementation of a transition program, would be useful for understanding the effectiveness of an intervention or program that is implemented into a clinical practice or in community (King et al., 2020; Moullin et al., 2020; RE-AIM, 2023). Indeed, outcomes from the RE-AIM framework would be valuable for demonstrating program impact at both patient and service delivery levels (Harden et al., 2018; Sweet et al., 2014). Lastly, results from adopting an implementation framework would help to address the research gap on how these

recommendations, such as those geared toward improving transitions, can be applied to clinical practice (Sweet et al., 2014).

We also recommend that researchers adopt new ways for assessing the effectiveness of clinical guideline implementation into practice as indicated by best practice resources, such as the Registered Nurses Association of Ontario's (RNAO) *Toolkit: Implementation of Best Practice Guidelines* (Registered Nurses Association of Ontario, 2012). This toolkit is designed to support healthcare professionals charged with leading best practice guideline implementation and research (Registered Nurses Association of Ontario, 2012). As an initial step for applying the toolkit, RNAO suggests that organizations identify one or more individuals to be accountable for the planning, implementation, and evaluation process of adopting best practice guidelines into clinical practice (Registered Nurses Association of Ontario, 2012). The toolkit stresses the importance of healthcare providers improving their knowledge of guidelines to improve adherence to their usage (Registered Nurses Association of Ontario, 2012). To address this lack of awareness, the toolkit provides an example by Stacey et al. (2006) demonstrating that researchers can create an educational training intervention (e.g., online tutorial) for healthcare providers that is combined with a knowledge test to effectively determine if the healthcare provider has acquired guideline knowledge (Stacey et al., 2006). This is one of several suggestions for researchers that can be found within the toolkit and those wanting to seek more guideline implementation ideas are encouraged to consult RNAO's report (Registered Nurses Association of Ontario, 2012).

Beyond clinical practice settings, we suggest that research focused on improving and measuring health outcomes, such as transition preparedness for YAs with chronic

conditions and/or CCN, is needed. Measuring the outcomes of transition programs and services is necessary to better understand transition readiness, post-transfer outcomes to adult services, and the long-term impacts of improvement in care interventions (Castillo & Kitsos, 2017; Sharma et al., 2014). Further, measuring transition readiness can also have implications for improving population health outcomes. For example, the health outcomes of all youth and YAs could be improved by exposure to transition preparedness activities and assessment tools from within the school sector. As such, researchers seeking to better understand this gap in preparedness and self-management in YAs with chronic conditions and/or CCN are encouraged to incorporate valid instruments for assessing transition readiness (e.g., TRAQ questionnaire) and self-assessment skills (e.g., Adolescent Autonomy Checklist) (Calhoun et al., 2019; Johnson et al., 2021). The TRAQ questionnaire is now available in French, which provides added value and efficiency for researchers intending to reach Canada's bilingual population (Health Hub in Transition, 2021; Tsang et al., 2017). TRAQ also offers additional benefits to researchers designing interventions for populations having more than one type of health condition, since it is designed as a disease-neutral self-administered questionnaire (Chapados et al., 2021). The frequent assessment of youth self-management skills throughout the transition process would give researchers specific outcomes to target; thereby narrowing gaps, such as transition readiness prior to adulthood.

Regardless of setting or sector, research efforts on improving the patient service delivery experience should by and large include the patient's "voice," and should focus on patient-reported outcome measures (Goodrich & Fitzsimons, 2018). Researchers are

also encouraged to engage YAs with a variety of chronic conditions and/or CCN as collaborators when developing research projects, where they can be involved in the co-design of health interventions (Hackett et al., 2018; Panek-Hudson et al., 2021; Thabrew et al., 2018). Co-design consists of YAs with lived experiences collaborating with researchers and the designers of health interventions to develop improved strategies based on the deep understanding of what those with lived experience know and prefer, to ensure that improvements will be useful and relevant to others like them (Bird et al., 2021; Hackett et al., 2018; Thabrew et al., 2018).

Education and Resources for YAs and Their Families

The findings from this dissertation highlighted specific activities that YAs with chronic conditions and/or CCN and their families can partake in to improve their transition experiences. YAs reported that in order to experience successful transitions in care, they recommend exposure to educational activities prior to transitioning that are designed for improving their health-related competencies. YAs also expressed that participating in peer supports, along with support from their families, would bolster their informational needs. Based on these findings, the following changes are recommended for YAs: (a) healthcare education, and (b) peer support for both YAs and their families.

Healthcare Education for YAs. Recommendations arising from YAs in manuscript three included that educational institutions should consider the following actions for improving healthcare outcomes: (a) develop a curriculum for improving pediatric to adult transitions in care; and (b) incorporate programming for learners on general wellness, health maintenance, and health literacy.

One such novel recommendation from YAs is to develop and include a curriculum for preparing learners to acquire the transitions in care skills necessary to improve their lifelong active involvement with healthcare services and health outcomes. These flexible teaching sessions (e.g., to occur in class or by assembly) can include practical scenarios designed to prepare YAs on: (a) how to apply health service seeking behaviors (e.g., finding a new care provider), (b) what to expect in adult healthcare, (c) what steps to take if they encounter health service barriers, and (d) what resources are available. These initiatives could include an assessment of YAs' self-management skills, transition preparedness, and core life skills. This assessment could be facilitated by professionals trained in administering validated self-management questionnaires (Chan et al., 2019). This could take place in school settings during structured events, such as designated workshops. Of note, a classroom-based curriculum, titled My Health Care, has been designed for youth and YAs having intellectual or developmental disabilities (Hess et al., 2016). The aims of this curriculum are to improve health literacy, communication, and self-advocacy skills (Hess et al., 2016). Apart from My Health Care, to the best of this author's knowledge, the recommendation within this dissertation to establish curriculum within the education system, to prepare all youth or YAs for the transition from pediatric to adult healthcare services, represents a novel finding. For example, educational programming on transitions has traditionally occurred within the structure of the healthcare system, such as transition clinics and individual healthcare provider practices (Got Transition, 2022; Hobart & Phan, 2019; Steinway et al., 2017).

While studies on educational interventions to improve transition-related knowledge and health engagement for YAs with a variety of conditions, such as sickle

cell disease, have been undertaken, they were set predominantly in healthcare environments and their designs did not report on effectiveness (e.g., long term retention rates with adult services) (Chugani et al., 2020; Lyons et al., 2014; Manwani et al., 2022). Within these health settings, educational programming for populations having diverse chronic conditions has typically been conducted in group settings (Chancel et al., 2020; Ernst et al., 2022); presented as short workshops (i.e., module-based programming that looked at psychosocial skills and specific conditions) (Newman et al., 2022; Schmidt et al., 2018); or facilitated by a transition coordinator (Manwani et al., 2022; Minchau, 2022). Moreover, these educational interventions have each been centred around one predominant type of health condition (e.g., ASD, spina bifida, sickle cell disease) (Chancel et al., 2020; Lindsay et al., 2016; Manwani et al., 2022; Newman et al., 2022).

Recently, a pilot educational intervention, designed by a mental health organization, was implemented to improve the healthcare transition readiness for YAs preparing to attend college (Chugani et al., 2020). This intervention consisted of six educational group sessions run by a facilitator for YAs and their families and consisted of topics such as navigating health services and ways to self-manage their conditions (Chugani et al., 2020). This pilot intervention took place 6 months prior to the YA beginning post-secondary schooling (Chugani et al., 2020). While the YAs reported that they would recommend the program based on aspects such as program feasibility and satisfaction, the effectiveness of this pilot program has yet to be reported (Chugani et al., 2020).

Despite a lack of transitions in care interventions for improving YA readiness within the educational sector, recent studies strongly encourage healthcare providers to

collaborate with members from the education system to improve the transition outcomes of youth (Benham-Clarke et al., 2021; Ladhani et al., 2019). For example, Ladhani et al. (2019) conducted a rapid review of YAs with mental health challenges as they transitioned to adulthood. Findings from their review suggest that collaboration between the educational and health systems are necessary to improve the outcomes of YAs (Ladhani et al., 2019). Another qualitative study including YAs with ADHD reported that the transition to post-secondary institutions can have serious impacts on healthcare outcomes (e.g., discontinuities in planning between the health and education sectors, and reduced medication adherence) (Benham-Clarke et al., 2021). Further, they concluded that educational settings must better coordinate with healthcare services to support YAs (Benham-Clarke et al., 2021). Moving forward, the following recommendations are clear for YAs and families: (a) future transition supports would benefit from greater collaboration between the health and education sectors to design transitions in care preparedness curricula and activities within secondary and post-secondary school settings; (b) these educational interventions should be informed by YAs with chronic conditions and/or CCN, and (c) these programs should be evaluated to ensure that they are effective in improving the transition preparedness skills and competencies of YAs.

Implementation of this curriculum would require adopting a population health approach, where the health of all youth and YA learners, beyond those with chronic conditions and or/CCN, can be improved by partaking in educational activities intended to increase their health-related competencies (Myers, 2020; White et al., 2023). This newly established curriculum would require dual accountability between the health and education sectors. Roles for healthcare providers in the development of this curriculum

could include subject matter expertise around transitions in care and best practices in healthcare (Canadian Medical Association, 2018; Canadian Nurses Association, 2017). In creating this programming within the educational sector in New Brunswick, new roles would need to be developed to carry out this initiative. Educational learning specialists, with support from officials at the Department of Education and Early Childhood Development, along with directors from NB school Districts, could help to develop this necessary curriculum in alignment with their strategies for learners. In fact, the NB Department of Education and Early Childhood Development's vision, *Portrait of a Learner*, aligns with the findings from our manuscript three by encouraging the development of learners' personal agency and the competencies necessary for achieving lifelong wellness (NB Department of Education and Early Childhood Development, 2019).

YAs, families, and healthcare providers all play important roles in improving transition outcomes by actively engaging in activities that are purposefully tailored for improving transition experiences. Where feasible, YAs and their families are encouraged to find educational opportunities for youth and YAs to develop and practice health self-advocacy and self-management skills (Margolis, 2017; Toulany et al., 2022). For example, parents can encourage YAs to prepare questions in advance and to ask questions during health service appointments (Children's Hospital of Orange County, 2023). Along with healthcare provider support, parents can also provide opportunities for their YAs to take the lead with necessary health self-management tasks, such as booking their own appointments (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022). To further help prepare youth, YAs, and their families for

the transition process, Got Transition® has created the free downloadable educational resource *A family toolkit: Pediatric to adult healthcare transition* (Got Transition® & National Healthcare Transition Family Advisory Committee, n.d.). This informational toolkit suggests questions to ask healthcare providers, provides information on decision-making supports, and offers ways for handling the changing health management roles of parents and YAs (Got Transition® & National Healthcare Transition Family Advisory Committee, n.d.).

Peer Support for YAs and Their Families. Peer support groups were another resource strongly recommended to assist YAs and their families as they integrate into adult healthcare (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022). Peer support for youth with chronic conditions has demonstrated a positive impact on health outcomes (Kohut et al., 2014; Patterson et al., 2021; Wakefield et al., 2022). Several YA recommendations were made for ways to offer these groups, with options such as face-to-face or virtual delivery (e.g., social media, such as Facebook). YAs suggested that these groups should be composed of participants with similar health challenges (with or without a diagnosis), interests, or ages. Some options for group facilitation included health professionals, health organizations, transition clinics, or educational institutions (e.g., post-secondary) (Cassano et al., 2008; Harrison et al. 2023; White et al., 2023). Working groups composed of YAs with lived experience, caregivers, and representatives from community social services, interdisciplinary healthcare, and educational sectors could determine the best strategies for setting up regionalized peer support groups. Peer group leaders are encouraged to consider recent literature on best practices when establishing and evaluating the effectiveness of these groups (Fisher et

al., 2017; Kulandaivelu & Kohut, 2021). Naturally, peer mentor training will be required to make the implementation of peer supports feasible (Patient-Centred Outcomes Research Institute, 2023). One recent North American model for peer training for organ transplant patients was developed from the iPeer2Peer online peer mentorship program, which is led by YA mentors who have positively managed their conditions (Anthony et al., 2020; Stinson et al., 2016). Establishing online and face-to-face peer support interventions for parents, with support from health professionals, is also an important option for consideration to aid families, since it can lead to more effective transitional healthcare for youth and YAs (Rafferty & Beck, 2020).

Policy and Practice Improvements for Clinical Healthcare Providers

Support from healthcare providers was identified by YAs throughout this dissertation as a key factor in their successful transition from pediatric to adult healthcare. To operationalize these recommendations into clinical practice, decision makers will need to adopt policy changes in the following areas: (a) provision of adult service providers; (b) transition planning support and resources; (c) providing patient-centred care; and (d) implementing health provider training.

Provision of Adult Service Providers. Healthcare providers, such as pediatricians, nurses, and allied health providers, should consider offering reasonable assistance to YAs and their families in securing an adult service provider equivalent to their former pediatric provider. This search for a new adult healthcare provider could also be facilitated by a non-clinician, such as a local support group or a government entity since they may have insider knowledge to aid with the process of identifying adult healthcare providers willing to treat vulnerable patients (e.g., YAs with CCN)

(Community Living British Columbia; 2018; Dennis et al., 2014; Peart et al., 2018). When feasible, pediatric clinicians are encouraged to introduce YAs to their new adult health service providers and care team members. This meeting can occur in-office, virtually, or during a structured tour or workshop as recommended by the YAs within this dissertation.

Recommendations to improve access to adult healthcare providers included the need for improved access to mental health services and providers throughout the transition process. Notably, 48% of the YAs with CCN in manuscript three identified as having at least one mental health condition. Many of these participants reported that a lack of access to mental health services led to a deterioration of their health conditions, which impacted their well-being. To address this need for improved access to mental health services, governments should prioritize the development of policies and action plans to increase the provision of mental health services for YAs with chronic conditions and/or CCN during and after the transition to adult healthcare (Malla et al., 2018; McGorry et al., 2022; Wiens et al., 2020). Indeed, current research suggests that decision makers should establish integrated primary care models with an emphasis on health promotion and treatment to facilitate the transition of YAs to specialized mental health services (Babajide et al., 2020; Jurewicz, 2015). Increasing access to mental health supports for youth and YAs in Canada is urged as a top priority for the Canadian government, academia, and service providers so that YAs may avoid negative health and social outcomes (Malla et al. 2018).

In order to improve access to mental health providers and services, YAs would also benefit from the development of policies intended to improve the funding supports

and resources associated with acquiring these necessary services (e.g., private psychology). As such, governments are advised to explore other funding support models for YAs (e.g., co-pays or other forms of financial assistance) and to develop associated policies. These designated policies, such as transitions in care funding policies for YAs with chronic conditions and/or CCN, must be made explicit within each region's strategy for mental health (Nasmith et al., 2010; The Mental Health Commission of Canada, 2015). One strategy to improve access to mental health is to broaden the number of providers that can offer mental health supports to YAs. To achieve this goal, health associations should also advocate increasing healthcare provider remuneration from public insurance plans under Medicare for the treatment of YAs' mental health needs (Moroz et al., 2020).

In addition, neutral third-party organizations not directly involved with the provision of mental health services are encouraged to communicate the mental health options, resources, and support policies available to YAs (e.g., via a website) as a means of providing content that will be perceived as credible to YAs. The ongoing communication of this information such as via a website, could be led and curated by provincial government agencies, large professional healthcare organizations, or healthcare associations according to their capacity and reputation as a trusted source of information (Winefield et al., 2004). To manage this initiative, designated support may be required from a software programmer (e.g., 2 days per week) and project lead for site maintenance (e.g., 1 day per week) (Winefield et al., 2004). When considering areas of content for this website, the YAs within manuscript three expressed an interest in acquiring the following details on health services and related policies, particularly

around mental health: (a) provider availability and wait times; (b) associated costs and funding options; and (c) interim supports (should a backlog occur in accessing providers).

Changes to healthcare provider remuneration models and transitional healthcare billing may also help ensure that patients receive an optimal amount of time with their clinicians throughout the transition process. As such, decision makers should seek ways of remunerating pediatric and adult healthcare providers for their involvement with documented and structured transitions in care related clinical practices (White et al., 2023). For instance, in NB, physicians and Nurse Practitioners could receive remunerations for this dual transition-related patient session using the Medicare billing code "team meeting" (e.g., ISD code 8805 called "communication with an allied health professional regarding a patient") (Government of New Brunswick, 2021). However, the current NB physician billing rate of $20 per 15 minutes could also be reconsidered at a higher rate of compensation to account for aspects such as the flexible time and the nature of integrated care services provided during the transition period (Toulany et al., 2022). Furthermore, considerations should be made to explore new blended models of remuneration that focus on patient satisfaction along with other health-focused quality outcomes (Lee, 2019; Rudmik et al., 2014; White et al., 2023).

Transition Planning Support and Resources. Healthcare providers are encouraged to follow a structured and individualized transition plan for youth/YAs and their families (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022). This plan should ideally start in early adolescence and continue through until integration into adult services has occurred (Got Transition®, 2020a). As part of this plan,

clinicians, and their allied care teams, are encouraged to: (a) periodically assess the patient's self-management skills; (b) develop transition milestones that are tailored to the unique developmental needs of the YA; and (c) provide the YA and their families with timely information to address expectations for the upcoming transfer to adult healthcare. Indeed, structured transition planning that includes the development of health self-management skills can facilitate treatment plan adherence (Lozano & Houtrow, 2018). Accordingly, the use of a validated self-management assessment tool (e.g., TRAQ) should be used throughout the YA's transition (Johnson et al., 2021; Lozano & Houtrow, 2018; Sawicki et al., 2015). Another recent study assessed the health literacy levels of patients ('BRIEF' self-assessment scale) and determined it was also a valuable component in assessing transition readiness (Haun et al., 2012; Rague et al., 2021).

A structured transition plan, along with related assessments, should be transferred from the healthcare provider responsible for the youth's pediatric care to the subsequent adult services providers(s), as consented to by the YA. To address this necessary transfer of personal health information, a policy is required surrounding the transfer of electronic medical records. Policymakers are thus advised to develop policies that mandate the transfer of patient medical records during transition from pediatric providers to adult service providers (Canadian Association of Paediatric Health Centres, 2016; Got Transition, 2020a). Provincial regulatory authorities should encourage their professionals wherever possible to transfer the personal health information of patients according to corresponding legislation (Canadian Medical Association, 2017). This exchange of medical history should not be limited to provincial jurisdictions due to the transient nature of YAs (e.g., pursuing post-secondary studies). For this continuity of care to be

established, NB should develop policies that make obligatory the use of portable electronic medical records. This policy should state that this transitions in care medical summary (e.g., transition planning tool) will be incorporated into the clinicians' EMR systems and can be made accessible to all members of the YA's care team once the infrastructure exists (Wiemann et al., 2015). Lastly, policymakers are advised to follow the path of YAs transitioning from pediatric to adult services and to make attempts wherever possible to ensure that healthcare provider EMR systems meet communication interoperability requirements for sharing the medical records for all patient populations (Reisman, 2017).

Alternatively, a system could be developed that would allow the patient to access and transport their own medical details (e.g., an online and secure patient portal) (Cooley et al., 2011). For example, this portable record option currently exists where patients with diabetes can upload and selectively share their own medical history (e.g., glucose readings) with providers (Doyle-Delgado & Chamberlain, 2020). Patient-accessible medical records may empower YAs in ways such as giving them the autonomy to select which healthcare provider could also gain access to their medical history by way of informed consent (Canadian Medical Protective Agency, 2021, 2022; Ross & Lin, 2003). Further, when patients gain access to their healthcare information (e.g., medical records), they can be informed about their health status and improve their ability to self-manage their healthcare (Tapuria et al., 2021). As expressed by YAs in manuscript three study, this type of personalized record summary would include information like their prescriptions and surgeries. Moreover, this recommendation would align with the 1993

Supreme Court of Canada ruling that medical records should belong to the patient (du Quebec, 2018).

Not only do YAs want their healthcare records to remain continuous, but they also desire continuity in their health insurance to avoid gaps in care. Specifically, YAs expressed the need to receive mandatory notification of their health policy expiration and procedures. As recommended by participants in our manuscript three, health insurance regulatory bodies are encouraged to proactively communicate with YAs and their families about upcoming healthcare insurance policy renewals or termination deadlines within a reasonable time frame prior to the YA losing insurance coverage (e.g., age 18). Thus, insurance regulators must hold insurers accountable should they not communicate these details to policyholders such as families and YAs in a timely way. Should policyholders experience unresolved issues with their insurance provider, such as in circumstances where insurers do not provide notification to the policy owner(s) prior to the expiration of a policy, the OmbudService for Life & Health Insurance is the impartial dispute resolution service to contact in Canada (OmbudService for Life & Health Insurance, 2023). However, policymakers are encouraged to put in place accountability measures should insurers not follow their stated procedures. Insurance-related details could be tracked proactively within the YA's personalized plan for the transition from pediatric to adult healthcare (Cooley et al., 2011).

Providing Patient-Centred Care. Healthcare providers are also encouraged to incorporate patient-centred care (PCC) into their practice. PCC is defined as care that is provided in a respectful manner and that values patient preferences (Institute of Medicine, 2001; Taylor & Staniszewska, 2023). Conducting transition services using a

PCC approach truly positions youth and YAs at the centre of their care team. For instance, YAs from manuscripts two and three reported they felt their needs were best met when they were empowered to become a central member of the transition healthcare planning team. YAs further felt their needs were addressed when collaborating with healthcare providers to develop an individualized transition plan. This patient-centric experience was bolstered when healthcare providers sought YAs' permission regarding their preferred level of family involvement during the transition process. YAs in this dissertation stated that if care had been provided using a PCC approach, this would have improved their ability to self- manage their healthcare while also maintaining their active involvement with health services. In addition, an initial visit with the incoming healthcare provider is encouraged to permit sufficient time for relaying pediatric medical history while also establishing a patient-physician relationship that is patient-centric by design (College of Physicians and Surgeons of Alberta, 2021). Structuring clinical appointments in this manner was recommended by the YAs in manuscript three to allow for time to establish new and trusting relationships, while providing reassurance that important aspects of their pediatric medical history will not get lost upon transfer.

Overall, clinicians and health service organizations are encouraged to familiarize themselves with best practices for applying these PCC approaches (Alberta Health Services, 2014; Bokhour et al., 2018; Poitras et al., 2018). Reviews focusing on the effectiveness of providing PCC report that interventions for improving PCC are associated with positive health outcomes (Poitras et al., 2018; Santana et al., 2018). Furthermore, the Agency for Healthcare Quality and Research (2022) reported that capturing patient experiences, such as by survey, can indicate if care is provided in a

patient-centred way. For a greater understanding of how PCC is being delivered, healthcare providers are encouraged to incorporate anonymous surveys such as Got Transition's Health Care Transition Feedback Survey for Young Adults into their clinical practices (Got Transition, 2020b). Survey results can help providers to improve the quality of their YAs' experiences as they integrate into adult healthcare (Got Transition, 2020b). To ensure that the healthcare provided to YAs reflects the principles of PCC in clinical practice, policymakers could work with healthcare providers to develop other options to gather feedback from patients that would indicate how clinics are performing with regards to the delivery of PCC (Santana et al., 2018). YAs and their families can also participate in the development of these PCC policies through involvement with patient and advisory councils (Chan et al. 2021; Shaller, 2007). Further, the performance results of PCC metrics could be captured in a public report and potentially be linked to healthcare provider remuneration structures (Shaller, 2007).

Implementing Health Provider Training. By and large, all healthcare providers caring for YAs with chronic conditions and/or CCN are responsible in part for improving the transition in care experience for their patients and, therefore, are encouraged to participate in learning opportunities to enhance their knowledge of best practices for transitions in care and related health treatment areas, such as mental health (Castillo & Kitsos, 2017; Toulany et al., 2022). In NB, formalized training on transitions in care from pediatric to adult services is not currently embedded into pre-licensure health provider programs, such as: Dalhousie Medicine, University of New Brunswick Nursing, University of New Brunswick's LPN program, or the NB Community College's Respiratory Therapy program (Designated program representatives, personal

communications, Feb. 25-28, 2022). As such, it is recommended that transitions in care curriculum should be embedded in pre-licensure health programs in regions that do not already offer this training. These learning initiatives should incorporate patient-centred principles, such as conducting care in individualized and developmentally appropriate ways (Society for Adolescent Health and Medicine, 2023; White et al., 2023). Indeed, the provision of developmentally appropriate care is urged by all major guidelines relating to the transition from pediatric to adult healthcare transition and should be a key take away from training sessions (Canadian Association of Paediatric Health Centres, 2016; Cooley et al. 2011; Toulany et al., 2022). Training session content should ideally include patient profiles, such as real clinical cases featuring childhood-onset conditions, which are increasingly represented in adult healthcare services (e.g., ADHD and autism) (Wijnen-Meijer, 2021). Participants within manuscript three felt having clinicians with increased knowledge of the transition process would have better prepared them for the health and mental health service changes that lay ahead. Beyond training in transition readiness to enhance provider competencies, the New Brunswick Medical Society (NBMS) (2021) has also recently reiterated the need for professionals with specialized mental health training. This training suggestion reaffirms the recommendations of study participants from manuscript three who encouraged primary health providers to attend sessions to enhance their mental health competencies for supporting groups such as youth and YAs (i.e., evidence-based diagnosis and mental health treatments) (Centre for Addiction and Mental Health, 2016).

To achieve improvement in the mental health proficiencies of providers, policy changes are required for broadening providers competencies and remunerations for

mental health services. NB healthcare associations, with support from educational and subject matter experts on YA mental health and transitions from pediatric to adult healthcare should be involved with establishing these policies. Of interest, the current remuneration structure from Medicare for mental health services by non-psychiatrists in Canada has been reported as a barrier to improving both mental health and chronic condition care (Moroz et al., 2020; Urquhart, 2021). As such, concerted efforts should be made to improve access to healthcare providers in NB with expertise in treating specialized mental health conditions (e.g., PTSD and ADHD).

Overall, policy changes are needed to develop curriculum to improve the competencies of healthcare providers so they may best support the needs of YAs during the transition from pediatric to adult healthcare. To achieve this desired result, decision makers involved with pre-licensure allied health policy and programs, including curriculum designers, along with academic and clinical practice experts that work with YA populations with chronic conditions and/or CCN (Swan et al., 2019), are encouraged to create and incorporate a policy and corresponding curriculum that includes best practices for transitions in care (Kuo et al., 2018). For the groups governing post-licensure clinicians (e.g., NB Medical Association, Nurses Association of NB), it is also recommended that policymakers support the dissemination of best practice standards for the transition from pediatrics to adult healthcare (Canadian Association of Paediatric Health Centres, 2016). Furthermore, policymakers will be well supported in pursuing activities to develop transitions in care education for healthcare providers due to the growing body of evidence reaffirming this course of action. For example, recommendations for adopting transitions in care training for healthcare providers was

reported in a recent Canadian rapid review and has also been endorsed by all major pediatric to adult healthcare transition clinical practice guidelines (Canadian Association of Paediatric Health Centres, 2016; Toulany et al., 2022; Voorheis et al., 2020; White et al., 2023). See Appendix I for a summary of dissertation recommendations.

Concluding Thoughts

Despite efforts to improve the experiences and health outcomes of YAs in the transition from pediatric to adult healthcare, continued research and improvements in practice and policy are urgently needed. Although guidelines and programs have recently been developed with input from YAs, YAs and their families continue to report poor transition experiences. Indeed, there is clearly a gap between guideline development and implementation within certain regions, such as NB. YA voices are needed to bridge these gaps in the existing transition process for compelling reasons. First, existing research on adults with chronic conditions and/or CCN and lived experience representing a broad span of ages has led to health service improvements, thus highlighting the targeted need for YA voices (Pomey & Lebel, 2016; Song et al., 2019). Second, the YAs in this study described several innovative and feasible ways for providers to address their unmet healthcare needs (e.g., exposure to transitions in care curriculum in schools). Third, while YAs clearly identified the need for accessible services and supports from care providers and their institutions, they also emphasized the importance of the early development of critical skills (e.g., health self-advocacy, self-management, and wellness behaviours).

Policymakers, healthcare providers, educators, and families all have roles to play when supporting the self-management of YAs so they may acquire lifelong tools for

overcoming health service challenges and avoiding disengagement from healthcare. As parting thoughts, if we continue to overlook the reasons why service provision guidelines are not being implemented, we will not improve the experiences of YAs with chronic conditions and/or CCN. We must reverse the trends of unsuccessful transition outcomes. This dissertation offers tangible solutions for overcoming the emerging challenges faced by YAs when transitioning from pediatric to adult healthcare and for societies seeking to improve the health of their populations.

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Appendix A

Search Strategies

Databases

Medline (Ovid MEDLINE (R) and Epub Ahead of Print, In-Process and Other Non-Indexed Citations, Daily and Versions(R) 1946 to September 21, 2020): Originally searched Dec. 30/19, re-run on June 2, 2020, re-run on September 23, 2020

#	Query	Results Dec.	Results Sept.
1	exp Chronic Disease/	260202	264078
2	Disabled Children/	6093	6329
3	Health Services for Persons with Disabilities/	95	109
4	(chronic adj1 (illness or condition* or disease*)).ab,ti.	88268	94483
5	"multimorbid*".ab,ti.	4144	4800
6	(complex* adj3 (care or need* or illness or disease or medical* or condition or health)).ab,ti.	44134	47451
7	"medically fragile".ab,ti.	223	234
8	"Special health* needs ".ab,ti.	294	317
9	1 OR 2 OR 3 OR 4 OR 5 Or 6 OR 7 OR 8	375707	388505
10	exp "Continuity of Patient Care"/	236617	246613
11	"transition*".ab,ti.	391324	415396
12	"continuity of care".ab,ti.	6404	6856
13	“continuum of care”.ab,ti.	2382	2545
14	10 OR 11 OR 12 OR 13	625837	659764
15	Young Adult/	796953	858967
16	Adolescent/	1981483	2036132
17	"young adult* ".ab,ti.	90642	

			96111
18	"Adolescen*".ab,ti.	266008	281526
19	"youth*".ab,ti.	70622	75624
20	"juvenile*".ab,ti.	79027	82083
21	15 OR 16 OR 17 OR 18 OR 19 OR 20	2529322	2624021
22	9 AND 14 AND 21	3295	3458
23	limit 22 to english language	3019	3177
June 2, 2020			
24	Limit 22 to yr="2020"	51	
September 23, 2020			
25	limit 22 to dt=20200602-20200923		32

PsycINFO (EBSCO): Originally searched Dec. 30/19, re-run on June 2, 2020, re-run on September 23, 2020

#	**Query**	**Results Dec.**	**Results Sept.**
1	DE "Adolescent Health"	1,569	1,911
2	DE "Emerging Adulthood"	2,401	2,992
3	TI "young adult" OR AB "young adult"	12,352	12,972
4	TI adolescen* OR AB adolescen*	227,863	236,226
5	TI youth* OR AB youth*	94,806	99,551
6	S1 OR S2 OR S3 OR S4 OR S5	295,836	307,822
7	TI (complex* N3 (care OR need* OR illness OR disease OR medical* OR condition OR health)) OR AB (complex* N3 (care OR need* OR illness OR disease OR medical* OR condition OR health))	15,157	15,974
8	DE "Chronic Illness" OR DE "Chronic Alcoholic Intoxication" OR DE "Chronic Fatigue Syndrome" OR DE	28,720	29,985

	"Chronic Mental Illness" OR DE "Chronic Pain" OR DE "Chronically Ill Children"		
9	TI (chronic N1 (illness or condition* or disease*)) OR AB (chronic N1 (illness or condition* or disease*))	. 33,799	. 35,356
10	TI "Special health* needs" OR AB "Special health* needs"	. 119	. 124
11	S7 OR S8 OR S9 OR S10	. 73,568	. 70,638
12	DE "Continuum of Care"	1,772	1,852
13	TI transition* OR AB transition*	. 70,269	. 73,520
14	TI "continuity of care" OR AB "continuity of care"	1,983	2,087
15	TI "continuum of care" OR AB "continuum of care"	. 927	. 965
16	S12 OR S13 OR S14 OR S14	73,568	76,406
17	S6 AND S11 AND S16	. 411	. 433
18	English limit + academic journals	. 272	-
June 2, 2020			
19	17 AND RD 20191231-	. 12	-
September 23, 2020			
20	S17 AND RD 20200602-	-	. 12
21	English limit + academic journals		9

CINAHL Full-text (EBSCO): Originally searched Dec. 30/19, re-run on June 2, 2020, re- run on September 23, 2020

#	**Query**	. **Results Dec.**	. **Results Sept.**
1	(MH "Adolescence+")	. 476,097	. 525,343
2	(MH "Young Adult")	223,296	245,941
3	TI "young adult" OR AB "young adult"		

		8,166	9,245
4	TI adolescen* OR AB adolescen*	119,779	133,963
5	TI youth* OR AB youth*	43,822	49,771
6	S1 OR S2 OR S3 OR S4 OR S5	613,965	679,213
7	TI (complex* N3 (care OR need* OR illness OR disease OR medical* OR condition OR health)) OR AB (complex* N3 (care OR need* OR illness OR disease OR medical* OR condition OR health))	21,574	24,587
8	(MH "Chronic Disease+")	57,679	64,492
9	(MH "Child, Disabled")	10,439	12,013
10	(MH "Health Services for Persons with Disabilities")	210	250
11	TI (chronic N1 (illness or condition* or disease*)) OR AB (chronic N1 (illness or condition* or disease*))	71,806	81,762
12	TI "Special health* needs" OR AB "Special health* needs"	257	293
13	S7 OR S8 OR S9 OR S10 OR S11 OR S12	141,441	160,309
14	(MH "Transitional Care")	1,385	1,713
15	(MH "Continuity of Patient Care+")	17,358	19,319
16	(MH "Transitional Programs")	2,764	3,165
17	TI transition* OR AB transition*	47,783	54,710
18	TI "continuity of care" OR AB "continuity of care"	4,171	4,708
19	S14 OR S15 OR S16 OR S17 OR S18	66,009	75,036
20	S6 AND S13 AND S19	1,120	1279
21	English + academic journals	1027	
June 2, 2020			
22	EM 20191231-	152,374	
23	S6 AND S13 AND S19		

		1,409	
24	S22 AND S23	. 53	.
September 23, 2020			
23	EM 20200602-	-	. 93,473
24	S20 AND EM 20200602-	.	22

EMBASE (Elsevier): Originally searched Dec. 30/19, re-run on June 2, 2020, re-run on September 23, 2020

#	Query	Results Dec.	Results Sept.
1	'adolescent'/exp	1,621,51 5	1,675,580
2	(complex* NEAR/3 (care OR need* OR illness OR disease OR medical* OR condition OR health)):ab,ti	60,998	65,606
3	'young adult'/exp	323,838	360,017
4	'young adult':ab,ti	37,229	39,304
5	adolescen*:ab,ti	351,291	- 360,017
6	youth*:ab,ti	86,900	- 93,078
7	'chronic disease'/exp	195,154	201,142
8	'handicapped child'/exp	8,244	8,508
9	(chronic NEAR/1 (illness OR condition* OR disease*)):ab,ti	124,453	132,694
10	multimorbid*:ab,ti	5,472	7,396
11	'medically fragile':ab,ti	301	327
12	'special health* needs':ab,ti	344	373
13	'transitional care'/exp	2,501	- 3,041
14	'transition*':ab,ti	407,415	438,156
15	'continuity of care':ab,ti	8,466	8,987
16	'continuum of care':ab,ti	3,320	3,548
17	#1 OR #3 OR #4 OR #5 OR #6	1,961,61 1	2,047,376
18	#2 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12	336,187	353,306

19	#13 OR #14 OR #15 OR #16	418,411	449,933
20	#17 AND #18 AND #19	1,745	- 1906
21	#17 AND #18 AND #19 AND ([article]/lim OR [article in press]/lim OR [data papers]/lim OR [editorial]/lim OR [erratum]/lim OR [letter]/lim OR [note]/lim OR [review]/lim OR [short survey]/lim) AND [english]/lim	1,062	1171 -
June 2, 2020			
22	#17 AND #18 AND #19 AND [31-12-2019]/sd	112	
September 23, 2020			
23	#17 AND #18 AND #19 AND [2-6-2020]/sd		- 78

Grey Literature, Hand Searching, and Reference Lists

Grey Literature

Source/Date Searched	**Search Method**	**Relevant Results**
Direct website searches - Research Centres/Organizations April 24, 2020	*Sick Kids* >hand searched website http://www.sickkids.ca/PaediatricMedicine/What-we-do/Complex- Care-Program/Research-and-Publications/index.html , 0 relevant *The National Center for Complex Health & Social Needs* > homepage search box = transition 7 results, 0 relevant Hand searched these two sections > 0 relevant: https://www.nationalcomplex.care/category/research- policy/resources/publications-reports/ https://www.nationalcomplex.care/category/research- policy/resources/conference-materials/ *Pediatric Complex Care Association* > homepage search box = transition 3 results, 0 relevant https://pediatriccomplexcare.org/clinical-research/ > 0 relevant	0
Direct website searches - Google Search April 24, 2020	Search strategy: complex care young adults transition recommendations > first 10 pages of results,	1

	100 results; 1 relevant result, excluded = duplicate of previously screened article	
Direct website searches - Google Scholar April 24, 2020	Search strategy: young adult AND complex care AND transition* recommend* > sort by relevance, do not include patents, first 10 pages 100 results	. 2
Conference proceedings - Harvard Complex Care conference April 24, 2020	Examined conference PowerPoint hand-out materials along with individual session reference lists.	. 2 .
Conference proceedings - EMBASE (Elsevier) April 24, 2020	Used previous EMBASE search strategy, limited to Conference abstracts ([conference abstract]/lim OR [conference paper]/lim OR [conference review]/lim) AND [english]/lim 613 2 relevant results found requiring author follow-up for more details; excluded	0 .
Dissertations - Proquest Dissertations & Theses Global April 22, 2020 .	Search strategy: ab((chronic NEAR/1 (illness OR condition* OR disease*))) OR ab((complex* NEAR/3 (care OR need* OR illness OR disease OR medical* OR condition OR health)) :) OR ab('medically fragile' OR 'special health* needs')) AND ab(youth* OR adolescen* OR 'young adult') AND ab('continuum of care' OR 'continuity of care' OR 'transition*') English limit = 183 results	4

Hand Searching

Source/Date Searched	**Search Method**	. **Relevant Results**
Journal of Adolescent Health April 24, 2020	Hand searched journal website transition AND complex care 240 results, limited to research articles, conference abstracts, conference info	0
International Journal of Adolescent Medicine and Health April 24, 2020	Hand searched journal website transition AND complex care 41 results	. 0

Journal of Adolescent Research April 24, 2020	Hand searched journal website transition AND complex care > 138 results (research articles)	0

Reference Lists

Source/Date Searched	**Search Method**	**Relevant Results**
Snowball method and citation searching April 21, 2020	Examined the reference lists of included studies from database searching using Scopus and Google Scholar; also examined articles which cited them	7
Snowball method and citation searching April 24, 2020	Examined reference lists of included studies from grey literature searching using Scopus and Google Scholar; also examined articles which cited them	4

Appendix B

Data Extraction Table

Author(s)	
Year of Publication	
Country of Origin	
Type of Literature	
Research Design	
Study Aim or Purpose	
Population(s)	
Sample Size	
Transition Description	
Transition Recommendation(s)	

Appendix C

Full Citations of Included Studies

1	Ådnanes, M., & Steihaug, S. (2016). "You never know what happens next" – Young adult service users' experience with mental health care and treatment through one year. *International Journal of Integrated Care, 16*, 1–11. https://doi.org/10.5334/ijic.2435
2	Bryant, R., Young, A., Cesario, S., & Binder, B. (2011). Transition of chronically ill youth to adult health care: Experience of youth with hemoglobinopathy. *Journal of Pediatric Health Care, 25(5),* 275–283. https://doi.org/10.1016/j.pedhc.2010.02.006
3	Chandra, S., Luetkemeyer, S., Romero, R., & Gupta, N. A. (2015). Growing up: Not an easy transition - Perspectives of patients and parents regarding transfer from a pediatric liver transplant center to adult care. *International Journal of Hepatology,* 2015. https://doi.org/10.1155/2015/765957
4	Grivetta, S. A., Gilot, C. B., Coggiola, M., Mignone, F., Silvestro, E., Orofino, G., Altini, P., Di Chio, C., & Gabiano, C. (2012). HIV positive youth's healthcare transition from pediatric to adult service: Nursing implications. *Children's Nurses: Italian Journal of Pediatric Nursing Science, 4(3).*
5	Huang, J. S., Gottschalk, M., Pian, M., Dillon, L., Barajas, D., & Bartholomew, L. K. (2011). Transition to adult care: Systematic assessment of adolescents with chronic illnesses and their medical teams. *The Journal of Pediatrics, 159(6),* 994-998. https://doi.org/10.1016/j.jpeds.2011.05.038
6	Kakkar, F., Van der Linden, D., Valois, S., Maurice, F., Onnorouille, M., Lapointe, N., Souyedns, H., Lamarre, V. (2016). Health outcomes and the transition experience of HIV- infected adolescents after transfer to adult care in Québec, Canada. *BMC Pediatrics, 16,* 1–7. https://doi.org/10.1186/s12887-016-0644-4
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Appendix D

REB Horizon Health Network

Horizon Health Network Research Ethics Board

c/o Ethics Services Saint John Regional Hospital, 2nd Floor 400 University Avenue / PO Box 2100 Saint John, New Brunswick, Canada E2L 4L2 Tel: (506) 648-6094 Fax: (506) 648-7734

January 31, 2020 Dr. Shelley Doucet
University of New Brunswick
Dept. Nursing and Health Sciences,
University of New Brunswick,
100 Tucker Park Rd, Saint John, NB E2L 4L5
506-654-4319
sdoucet@unb.ca

LETTER OF INSTITUTIONAL

REVIEW AND FINAL APPROVAL

RE: ROMEO File #: 100617 Event

12319

Dear Dr. Shelley Doucet,

This will acknowledge receipt of your response to the REB for study 2019-2823, Improving transitions from pediatric to adult healthcare for youth/young adults with complex care needs (CCN) and their families in New Brunswick, for review and approval. The following documents have been reviewed and approved via the delegated review function of the REB and will be reported at the February 18, 2020 REB meeting; this approval is valid for one year less a day: January 30, 2021.

Documents

Reviewed and

Approved:

Documents also

received and on file:

Document Name	Version Date
Study Protocol – Protocol Transition to Adult Care.pdf	2020/01/17

Document Name	Version Date
Other - Doucet Shelley - Curriculum Vitae - Dec 2019.pdf	2019/12/12
Study Protocol - Protocol_Transition to Adult Care.pdf	2019/12/12

If further action is required, the REB will send additional correspondence post-meeting; otherwise, this report will be filed accordingly.

The Research Ethics Board for Horizon Health Network is organized and operates according to the principles of the ICH Harmonized Tripartite Guidelines: Good Clinical Practice, Tri-Council Policy Statement and Division 5 of the Food and Drug Regulations. The Horizon Health Network REB carries out its functions in a manner consistent with Good Clinical Practices; and has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site. This approval and the views of this Research Ethics Board have been documented in writing.

If you have any questions about the review and approval process, please contact our office, via (506) 648-6094 or ResearchEthics@HorizonNB.ca. If you encounter any issues when working in the Research Portal, please contact our system administrator in the Office of Research Services, via ROMEO@HorizonNB.ca.

We wish you continued success with your research project.

With kind regards,

Dr. Marc Smith

Chair, Horizon Health Network Research Ethics Board
*This statement is in lieu of Health Canada's Research Ethics Board Attestation form.

Appendix E

REB UNB

Dr. Shelley Doucet & Dr. Alison Luke Faculty of Nursing & Health Sciences Centre for Research in Integrated Care (CRIC) UNBSJ

Dear Shelley & Alison,

As Chair of the Research Ethics Board at the University of New Brunswick (Saint John), I have reviewed your revised application for your proposed research titled **"Improving transitions from pediatric to adult healthcare for youth/young adults with complex care needs (CCN) and their families in New Brunswick"- (REB File #008-2020)** for its compliance with Tri- Council Policy (TCP) and with UNB Policy (UPRIH). On the basis of the review, I am pleased to inform you that this research appears to be in compliance with TCP and UPRIH. Accordingly, please consider this E-mail to represent official notification of REB approval of your project for a period of three years (March 27, 2020 – March 27, 2023). Thank you for accepting the recommended modifications to the application and consent form which were suggested. I have saved the modified materials and added them to your file.

If you require an official hard copy letter to satisfy a funding body, please inform our REB office (reb@unb.ca) as soon as possible. If the funds for this research project are held until REB approval, you will have to inform the Office of Research Services at UNB of this approval in order to release your funds.

Please note that, in the future, if you find that you must make any changes to your protocol, those changes must be considered and approved by the REB before they are implemented. To initiate changes, please submit the REB Case Modification Request form, available online through the Research Ethics page of the Office of the VP (Research).

Annual Reports for this project are due on the 15th of January each year, provided that this date is at least six months after the date of project approval. Final reports are due 90 days after project completion. Both of these reports can be found on our website at http://www.unb.ca/research/ors/forms/index.php#ethics.

If you have not already done so, please send an e-mail copy of your project summary (your answer to question # 1 of the ethics application form) to reb@unb.ca as soon as possible, including your REB File# in the subject line. Thank you for your co-operation in this matter.

Best wishes for the successful completion of your research project. Dr. Beth Keyes,

Chair
UNBSJ Research Ethics Board

Appendix F

REB Vitalité Health Network

Bureau de l'éthique
Ethics Office

275, rue Main Street
Bureau • Suite 600
Bathurst, NB E2A 1A9
506-394-3368
www.vitalitenb.ca

February 9, 2021

Dr. Shelley Doucet
Centre for Research in Integrated Care (CRIC)
University of New Brunswick Saint John
100 Tucker Park Rd
Saint John, NB E2K 5E2

SUBJECT: Improving transitions from pediatric to adult healthcare for youth/young adults with complex care needs (CCN) and their families in New Brunswick.

Principal Investigators: Dr. Shelley Doucet and Dr. Alison Luke
Site: Provincial (NB)

Amendment – Final approval
- Protocol, Version 2 – February 2021
- Recruitment Poster for Youth, French and English –February 2021
- Youth Informed Consent, French and English, Version 2 – February 2021

Dear Dr. Doucet,

Based on a delegated review performed by the Chair and two members of the Research Ethics Board, the Board grants you final approval to the documents listed above for the study entitled *Improving transitions from pediatric to adult healthcare for youth/young adults with complex care needs (CCN) and their families in New Brunswick*.

We wish to remind you that the Research Ethics Board is organized and operates based on good clinical practice guidelines and also adheres to the food and drug regulations, title 5, section C, concerning REB membership requirements.

Sincerely,

Pierrette Fortin
Chair of the Research Ethics Board

RÉSEAU DE SANTÉ vitalité HEALTH NETWORK

Appendix G

Consent Form

Improving transitions from pediatric to adult healthcare for youth/young adults with complex care needs (CCN) and their families in New Brunswick

RESEARCH TEAM

Shelley Doucet, Associate Professor, University of New Brunswick, sdoucet@unb.ca; 506-648-5605

Lillian MacNeill, Research Associate, University of New Brunswick, lillian.macneill@unb.ca; 506-653-2863

Jennifer Splane, Master of Nursing Student, University of New Brunswick, j.splane@unb.ca; 506-647-7959

Alison Luke, Research Associate, University of New Brunswick, aluke1@unb.ca; 506-648-5704

Monique Cassidy, Doctoral Student, University of New Brunswick, monique.cassidy@unb.ca; 506-721-5100

Sarah Gander, Pediatrician, Horizon Health Network, sarah.gander@horizonnb.ca; 506-214-1186

INTRODUCTION

You are being invited to participate in a research study because you are either: A youth or young adult with complex care needs, a caregiver of a youth or young adult with complex care needs, or a health or social care provider involved in the care/support of youth with complex care needs.

In order to decide whether you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This process is called informed consent.

- Your participation is entirely voluntary.
- You may withdraw from the study at any time.
- If the study is changed in any way which could affect your willingness to stay in the study, you will be notified about the changes and may be asked to sign a new informed consent form.
- By consenting to participate, you have not waived any rights to legal recourse in the event of research-related harm.

This form gives detailed information about the research study. Once you understand the study, you will be asked to sign this form or provide verbal consent if you wish to participate. Please take your time to make your decision. Feel free to discuss it with others.

PURPOSE OF THE STUDY

The purpose of this study is to learn more about the transition experience from pediatric to adult care and to collect information that could help inform a transition strategy in New Brunswick. Through these conversations, we hope to explore your experiences, as well as the interventions, policies, and programs that are already in place to support the transition from pediatric to adult care, as well as the barriers and gaps in services, and recommendations to improve care and services through a transition strategy. The proposed project has the potential to improve of the quality of life of children and youth with complex care needs and their families and benefit New Brunswick indirectly with cost savings linked to more successful transitions in care.

PROCEDURE

If you agree to participate in this research project, you will be asked to take part in a primary interview with a trained research assistant with the possibility of a follow-up interview. The primary interview will consist of approximately 10 open-ended questions. During the interview, you may be asked about experiences you have had with transitions from pediatric to adult care. In addition, you will be asked some questions about yourself, which will be used to describe the participants in the study. This interview will take about one hour. If you are interested in providing feedback on the study's preliminary findings, you will be contacted by phone for a follow-up interview; however, you will be under no obligation to give any feedback on the analysis.

Interviews will occur with the research assistant in person or virtually (i.e., over the phone or through the Zoom video-conference platform) at a time that is convenient for you. If the interview is conducted over the phone, the researcher will ensure they are located in a private location and will encourage you to choose an interview time when you can be in a private location. The research team will maintain security on video platforms by taking steps to provide confidentiality, such as creating a unique password to access the interview, allowing only your email to log in, and locking the virtual meeting room after you and researcher have entered.

The sessions will be recorded using a digital recorder and transcribed. Audio tapes will only be heard by the research team and a transcriptionist, and they will be destroyed once transcription is completed. As a thank-you for your time you will have the option to be entered into a draw for one of two $50 Amazon gift cards.

Participation is voluntary. This means that you do not have to participate if you do not want to. If you do participate, it is okay to refuse to answer any questions you do not want to answer. You can agree to participate now, and then change your mind at any time while you are participating, and have your information removed from the study. There will be no consequences. If you choose to withdraw from the study, you are encouraged to contact the Study Research Assistant.

POTENTIAL RISKS/DISCOMFORTS

This study is of minimal risk to you. We will be focusing primarily on your experiences and suggestions. You may skip any question you do not wish to answer, and you may end your participation in the interview at any time by advising the researcher of this decision.

POTENTIAL BENEFITS

There may be no direct benefit to you for participating in this research study. However, learning about your experiences will inform ways to the improve transitions in care from pediatric to adult health care in New Brunswick.

PRIVACY AND CONFIDENTIALITY

If you decide to participate in this research, the study interviewer will only collect the information they need for this study and only researchers associated with this study will have access to study records. To keep your identity confidential, the interview transcripts will be coded with a study identification number instead of using names. Any identifying information will be removed from the data that is collected and will be stored separately. Audio-recordings will be transcribed by a professional transcriptionist or member of the research team and, once transcribed and confirmed for accuracy, will be destroyed within seven years of being recorded. Paper copies of study materials and data collected will be shredded once they have been transcribed electronically, within seven years of being collected.

All electronic copies of study materials and data collected from you will be kept for a minimum of seven years on a secure, password-protected network housed at the

University of New Brunswick in Saint John. Your name will not be included in any presentations or publications resulting from this study; however, anonymous quotations from your interview may be used.

QUESTIONS OR CONCERNS

If you have any questions or concerns about your participation in this study, please contact the lead investigators Dr. Shelley Doucet [sdoucet@unb.ca; (506) 654-3419] or Dr. Alison Luke [aluke1@unb.ca; (506) 65101365].

Additionally, you may contact Beth Keyes, Chair of the UNB Saint John Research Ethics Board by phone [(506) 648-5908] or by email [REB@unb.ca]; the Horizon Health Research Ethics Board by phone [(506) 648-6094] or by email [reboffice@HorizonNB.ca]; the Research Ethics Board at Vitalité Health Network by phone [506)-394-3368] or by email [ethique.ethics@vitalitenb.ca]; or the Nova Scotia Health Authority Research Ethics Board by phone [(902)-473-8426] or by email [ken.jenkins@nshealth.ca].

PARTICIPANT'S RESPONSIBILITIES

If you choose to participate in this study, you will be expected to:

- Complete the study interviews in person or virtually (i.e., over the phone or through the Zoom video-conference platform), at a time convenient for you.

QUESTIONS

If you have questions after you read this form, ask the research assistant to explain. You should not sign this form or provide verbal consent until you are sure that you understand the study.

PARTICIPANTS STATEMENT

I have read the above information and understand the purpose of the research as well as the potential benefits and risks of participation in the study. I have had the opportunity to ask questions, and all my questions have been answered. I hereby give my informed consent to be a participant in this study.

Name of participant _____

Signature of participant _____ Date

_____

OR

Obtained verbal consent of participant Date

_____

FOR PARTICIPANTS UNDER THE AGE OF 19 YEARS

I understand the purpose of the research as well as the potential benefits and risks of participation in the study. I have had the opportunity to ask questions, and all my questions have been answered. I hereby give my informed consent to be a participant in this study.

Name of participant _____

Signature of participant _____ Date

_____

Signature of parent/guardian _____ Date

OR

Obtained verbal assent of participant Date

_____

Obtained verbal consent of parent/guardian. Date

_____

STATEMENT BY PERSON PROVIDING INFORMATION ON STUDY

I have explained to the above participant the nature, requirements and the purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised. I believe that the participant understands the implications and the voluntary nature of the study.

Researcher Signature: Date:

Appendix H

Semi-Structured Interview Guide: *Youth /Young Adult Questions*

Date: _____ Code: _____ Location:_____

Introduction

Hello, my name is (insert). I am a member of the research team, working with Dr. Shelley Doucet and Dr. Alison Luke at the University of New Brunswick. We are exploring the experiences of youth/young adults/young adults during their transition from pediatric to adult healthcare.

I would like to thank you for agreeing to participate in this interview. Before we start, I would like to review the consent form with you. If you have any questions, please do not hesitate to ask.
(Go through the form and answer questions)

As a reminder, your participation in this interview is voluntary. If you do choose to participate, you are free to withdraw at any time without any consequences. If you choose to participate in this interview, this information will be maintained in confidence.

If you have no further questions, then we can begin. I am now turning on the recording device.
(Start device)

1) Please describe your health and how you feel your condition affects you.

2) Have you transitioned from pediatric to adult healthcare? *Or are you in the process of transitioning?*

3) How do you foresee your health affecting the things that you would like to accomplish in the future or how has your health influenced the outcome of your goals for the future?

4) From your experience, what would you say are (or were) your health needs for a successful transition to adulthood?

5) Do you have (or have you had) any health, social, or school/work needs that are not (or were not) being looked after that have contributed to barriers in the transition to adult healthcare? *If yes: What are they?*

6) What resources/services/policies are you aware of that would be (or have been) helpful in your transition, or learning about the transition from pediatric care to adult healthcare? *Prompt: Have these services helped you feel more confident or ready to transition from pediatric to adult healthcare? What do you think would help better prepare for this transition?*

7) Have you experienced difficulties accessing services, interventions, or programs related to your transition in care (or plan for transition in care)? *Prompting questions: What are examples of gaps or barriers you have experienced?*

8) Are you aware of any transition resources/services/policies that exist outside of the province that support NB youth/young adults? *If yes: what are they?*

9) Do you (or did you) feel educated and supported in your transition from pediatric care to adult healthcare? *Prompting questions: What is your support system?*

10) Do you (or did you) feel prepared to gradually take care of your healthcare needs independently? *Prompting question: Do you feel confident to manage your health as an adult? Are you aware of the differences in pediatric and adult healthcare?*

11) Is there anything you would like to see more of in the current resources/services/policies that are available for the transition between pediatric and adult based care?

12) If I told you there was going to be a transition strategy for individuals transitioning from pediatric to adult healthcare, what do you think this would ideally look like?

13) Is there anything else you would like to add before we end our discussion?

That concludes our interview. I would like to thank you again for your time and participation in this study to gain insights on exploring the experiences of youth/young adults during their transition from pediatric to adult healthcare.

Appendix I

Summary of Dissertation Recommendations

Stakeholder	Recommendations
Researchers	• Assess transition interventions that are recommended by transition in care guidelines for their impact on measurable health outcomes (e.g., healthcare utilization, patient experience, and population health). • Enhance quality improvement research efforts to include the "voice of the client" (e.g., patients), including patient-reported outcome measures. • Capture the perspectives of under-represented populations in transitions improvement research, such as those who have neurodevelopmental and intellectual disabilities. • Incorporate validated instruments when assessing YA transition readiness and other transition outcomes (e.g., TRAQ).
Healthcare education in school institutions for youth and YAs (i.e., high school, middle schools, and post-secondary institutions)	• Develop cross-sector collaborations (e.g., education and health) to provide youth and YAs with the competencies and skills required for successful transitions (e.g., packaged as a formal learning curriculum). • Offer training to enhance YAs' self-management, self-advocacy, and core life skills (e.g., demonstrating health-seeking behaviours and assessing the reliability of health information sources). • Leverage strategic communication channels (i.e., online or via structured educational sessions) to spread awareness of available transition supports and resources (e.g., a regional transition coordinator and/or designated institutional health advocate). • Assess the baseline self-management skills of YAs with structured plans to monitor progressive growth (e.g., Adolescent Autonomy Checklist). This assessment could be conducted by a local health professional (e.g., public health nurse), researcher, or an educator with training on transitions.
YAs and families	• Practice ways to nurture YA health self-management responsibilities (e.g., families can encourage YAs to engage in conversations with health providers before transfer to adult care). • Families can support YAs to seek opportunities to expand their YAs knowledge for overall lifelong health and wellness behaviours. • Request to receive a copy of transition planning documentation complete with pertinent healthy history details. • Participate in the co-design of health interventions for improving transitions in care models and services. • Engage in activities related to supporting pediatric to adult transitions in care guideline development.

Clinical healthcare providers and policy-makers	• Begin early transition planning (e.g., age 12) with the YA and their caregivers. • Offer assistance in finding the YA an adult care provider and, where possible, discuss those options in a meeting well in advance of the final transfer. • When possible, introduce the YA to their new provider (face-to-face or virtually). • Support the implementation of shared electronic medical records to aid in transferring health information between the pediatric and adult systems. • Seek remuneration models to ensure providers are reimbursed for their transition-related planning and visits. • Facilitate change management by offering opportunities for YAs to meet and learn more about the adult care team (e.g., a workshop or tour) pre- transfer, expanding upon awareness of their future care provider along with corresponding clinic procedures and expectations. • Prepare the youth with self-management skills and begin directing communications more towards the youth (vs. their caregivers). • Assess individual patient self-management capacity and care goals. • Proactively engage the YA to determine what ways would be appropriate to involve family members or other preferred designated support individuals (e.g., applying patient-centred care). • Conduct interactions with YAs in a way that embodies the principles of patient-centred care. • Establish peer support groups for YAs and their families. • Proactively communicate available health services and resources throughout the transition process (along with wait times and costs) for YAs and their families (e.g., via a website). • Incorporate training on transition planning and best practices into pre- and post-licensure health professional programs. • Participate in training on transition planning and best practices, as well as the complex childhood conditions experienced by clients in their care. • Create accredited training and learning sessions on treating and supporting the mental health needs of YAs. • Expand service offerings along with the training and hiring of professionals specialized in mental health. • Consider ways to increase financial coverage for YAs to access vital services (e.g., mental health). • Legislate health insurance providers to communicate proactively with families and their YAs if there will be disruptions in health coverage to prevent unanticipated gaps. • Ensure transition policies are implemented across sectors to minimize service gaps.

Appendix J

Copyright Approval Manuscript One

Healthy Populations Journal

COPYRIGHT NOTICE

The journal aims to reduce barriers to publishing and sharing research and inequalities to accessing information. This journal provides immediate open access to its content on the principle that making research freely available to the public supports a greater global exchange of knowledge. The open- access nature of the journal means that there will be no charge for authors or readers to use the journal. The journal has a Creative Commons Attribution Non-Commercial (CCBYNC) attribution which allows the author (and others) to share and distribute their full-text article in other public domains, such as Google Scholar or Research Gate.

Healthy Populations Journal. (2022). *Copyright notice*. Retrieved July 1, 2022, from https://ojs.library.dal.ca/hpj/about/submissions#:~:text=Copyright%20Notice,-The%20journal%20aims&text=The%20journal%20has%20a%20Creative,Google%20Scholar%20or%20Research%20Gate.

Appendix K

Copyright Approval Manuscript Two

BMJ Open Copyright Notice

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BMJ Open. (2023). *Copyright.* Retrieved January 3, 2023, from https://bmjopen.bmj.com/pages/authors

Appendix L

Field Notes

Type of Contact: _____ Interview Date & Time: _____

Participant Code: _____

Describe the participant context, emotions, questions, and critical reflections (Phillippi & Lauderdale, 2018).

Reflective Notes: *Thoughts, feelings, views*

Additional Notes:

Reference:

Phillippi, J. & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research, 28*(3), 381-388.

CURRICULUM VITAE

JUNE 2023

Section I - PERSONAL DATA

A. Personal Details

NAME: Monique Cassidy

B. Education

DEGREES: **PhD Candidate, Interdisciplinary Studies** (2018 – Expected May 2024), University of New Brunswick, Saint John, N.B. (4.2/4.3 GPA). *Dissertation: Improving the transition from pediatric to adult healthcare: Recommendations from young adults with lived experience.* (Supervisors: Dr. Shelley Doucet & Dr. Alison Luke)

Master of Education (Health Professions) (2014 - 2016), University of New Brunswick in partnership with Dalhousie Medicine, Saint John, N.B. (4.1 GPA)

Bachelor of Public Relations (2000 - 2003), Mount Saint Vincent University, Halifax, N.S. (Co-Operative Education Program)

Bachelor of Science in Kinesiology (1996 - 2000), University of New Brunswick, Fredericton, N.B. (Deans List)

AWARDS: Graduate Student Research Award. University of New Brunswick. (2021-2022)

NB Health Research Foundation 2020 Health Research Week Poster Presentation Award: PhD Student. (Nov. 2020)

Graduate Student Research Award. Centre for Research in Integrated Care, UNB. (2018-2019)

"Award of Excellence." NB Kinesiology Association. (2015)

Awarded prestigious Irving Oil Student of the Year Award and Accounting Division Role Irving Oil Head Office for academic and group leadership. (1996)

C. Non-academic Employment History

GNB DEPARTMENT OF EDUCATION
Process Improvement Facilitator (2021- Current)

- Coached division-wide directors and their teams to enhance their individualized learning needs for achieving professional business development initiatives (e.g., via one-on-one and group learning sessions).
- Designed and facilitated senior leadership workshops and divisional conference events on operational project/change management methodologies (i.e., Continuous Improvement).
- Developed the department's new MS Teams collaborative site along with its corresponding live and video training sessions for all staff.
- Successfully designed the first department-wide tool to manage information complete with KPIs representing all the programming and services for divisions and branches.
- Led cross-functional community of best practice bi-weekly learning sessions.
- Portfolio lead responsible for 20 modernizing curriculum projects for NB education system stakeholders.
- Responsible for successfully implementing Lean Six Sigma Black Belt DMAIC projects, along with statistical analysis and ongoing formal management.
- Responsible for change leadership plan development and communications using PROSCI Change Management methodology.
- Project lead teaching directors and business leads on developing a department-wide IT dashboard installation for key performance measures.
- Lead, Performance and Continuous Improvement Marketing Team.
- Developed focus group surveys and corresponding implementation strategies.
- Developed GROW model coaching methodology learning program.
- Conducted employee onboarding and mentorship.
- Developed and facilitated Key Performance Indicator learning sessions for departmental divisions and branches based on rigorous performance result methodology.
- Responsible for coaching and development of GNB Lean Six Sigma Yellow Belts.
- Developed large scale business case proposal.

Centre for Research in Integrated Care, University of New Brunswick (Multi-roles, 2018 – 2021)

(1) Communications Reporting Officer (for NB research projects NaviCare & Primary and Integrated Healthcare Innovations Network)

- Developed and implemented strategic promotional plan (NaviCare).
- Strengthened branding via communications campaigns, social media (Twitter, Facebook and live presentations) and new innovative tools. Grew strategic relations with 300+ stakeholders.
- Contributed to preparing annual reports & media articles published for both community and alumnae.
- Led experiential learning design and staff onboarding for employees, including skills assessment
- Gathered feedback from clients for quality improvement.
- Promoted provincial events, i.e., widely attended "Patients Den" and "UNB Talks."
- Led & implemented Saint John community and provincial outreach strategy (with NaviCare team) which resulted in doubling of program usage.
- Conducted focus groups with strategic stakeholders (NaviCare) to refine outreach methods.
- Speaker at "Together We Care" event for Saint John community and partners.
- Facilitated live conference "Tweeting" at multi-stakeholder NB workshop.

(2) Research Coordinator (Maritimes) Pan-Canadian Project: Randomized Control Trial, Child Bright "*Ready-Or-Not: Brain Based Disabilities.*" Innovative $25 million-dollar CIHR supported project developing and evaluating e-health intervention (app) to improve transition in care journey for patients and families.

- Project coordinator.
- Site coordination.
- Multi-site ethics approval.
- Budget coordination and logistics.
- Stakeholder meeting management and presentation design.

(3) QUEST-SJ, Communications Lead. A regional qualitative health research collaborative. Group includes learners from all health disciplines (i.e., NBCC, DalMed, Horizon Health, & Saint John community NGOs) and representing all UNB Faculties.

- Marketing plan design & execution.
- Member survey design.
- Recruitment development (grew membership by 27%)
- Created innovative member directory.
- Facilitated live e-learning sessions.

(4) Project Coordinator (NB) and Research Assistant. PriCare "*Case Management in Primary Care for Frequent Users of Healthcare Services with Chronic Diseases and Complex Care Needs: Implementation and Realist Evaluations*" project. National $2 million-dollar CIHR implementation science research project addressing triple aim improvement indicators of patient outcomes and health care efficiencies.

- Conducted focus groups and individual interviews with clinicians and case managers.
- Designed and led successful presentations for all stakeholder groups (PIs, decision-makers, Case Managers, clinicians, and patient partners).
- Transcribed and collected all NB data.
- Led regional meetings for clinicians and patient partners.
- Responsible for successful site recruitment.
- Managed all ethics monitoring and submissions to health and university REBs.
- Managed contracts (e.g., Data security, HR terms of reference).
- Assigned weekly work deliverables to project team members.
- Designed content and visuals for national training curriculum.
- General HR responsibilities (e.g., hiring process, onboarding, and performance management).
- Conducted data analysis and written deliverables for publication.
- Selected by team to present national team's work at widely attended North American Primary Care Research Group conference (San Francisco, Nov. 2020).

(5) Research Assistant, Transitions in Care Project.

- Conducted and transcribed interviews.
- Promoted study activities.

HORIZON HEALTH NETWORK
Consultant, NB Social Pediatrics (2019-2020)

- Completed 50 interview surveys with mothers to determine prenatal exposures related to autism. Achieved 100% success rate in recruitment approach.
- Conducted both literature and medical chart reviews.
- Wrote manuscript for publishing.

SANOFI
Executive HealthCare Representative, New Brunswick & Atlantic Canada (2003 – 2017)

- Managed growth of multi-million-dollar sales portfolio for 300+ allied health clients.
- Delivered 140 live and web strategic educational events.
- Partnered with government on patient savings campaigns/initiatives (e.g., GNB diabetes strategy) to educate 150 primary care clients on chronic disease guidelines and services.
- Created and promoted new patient delivery clinics within diverse primary healthcare settings.
- Partnered with Horizon Health (12,000 end users) to implement strategic events and innovative deliverables throughout NB (e.g., developing a hypoglycemia learning tool).
- Hired and managed allied health diabetic educators for the provision of patient care in NB primary care clinics.

SCENTSY
Certified Entrepreneurial Consultant, New Brunswick (2014 – 2016)

- Organized successful direct sales expos and events throughout NB.
- Oversaw strategic marketing, budgeting, and inventory efficiency management.

Section II - RESEARCH

A. Papers in Refereed Journals

Cassidy, M., Doucet, S., Luke, A., Goudreau, A., & MacNeill, L. (2022). *Improving the transition from paediatric to adult healthcare: A scoping review on the recommendations of young adults with lived experience.* (Accepted). Journal: BMJ Open. Manuscript ID is bmjopen-2021-051314. Personal Contribution: Lead author.

Hudon, C., Danish, A., Lambert, M., Howse, D., Cassidy, M., Dumont-Samson, O., Porter, J., Rubenstein, D., Sabourin, V., Doucet, S., Ramsden, V. R., Bisson, M., Schwartz, C., & Chouinard, M. C. (2022). *Reconciling validity and challenges of patient comfort and understanding: Guidelines to patient-oriented questionnaires.* Journal: Health Expectations, *25*(5), 2147-2154. Manuscript ID is hex.13373. Personal Contribution: Co-author.

Cassidy, M., Doucet, S., Luke, A., & Goudreau, A. (2021). *Transitions from Pediatric to Adult Care as Experienced by Young Adults with Complex Care Needs: A Scoping Review Protocol.* Department of Interdisciplinary Studies, UNB. (Accepted) Journal: Healthy Populations Journal. Manuscript ID is 10643-19533. Personal Contribution: Lead author.

Hudon, C., Danish, A., Lambert, M., Howse, D., Cassidy, M., Dumont-Samson, O., Porter, J., Rubenstein, D., Sabourin, V., Doucet, S., Ramsden, V., Bisson, M., & Chouinard, M-C. (2021) *Conciliating validity and challenges of patient comfort and understanding: Guidelines to patient-oriented questionnaire*s. (Accepted) Journal: Health Expectations. Manuscript ID is HEX-2021-4061 Personal Contribution: Co-author.

Danish, A., Chouinard, M-C., Aubrey-Bassler, K., Burge, F. Doucet, S., Ramsden, V., Delahunty-Pike. A., Cassidy, M., Lambert, M., Penney, C.; Longjohn, C., Porter, J., Roy, J., Rubenstein, D. & Sabourin, V. (2020). *Protocol for a mixed-method analysis of implementation of case management in primary care for frequent users of health care services with chronic diseases and complex care needs.* (Accepted) Journal: BMJ Open. Manuscript ID is bmjopen-2020-038241. Personal Contribution: Analysis and interpretation of data; substantial revision to the manuscript.

B. Papers/Posters/Presentations

Luke, A., Doucet., S., MacNeill, L., Cassidy, M., & Splane, J. (May 29-31, 2023). *Recommendations for improving transitions from pediatric to adult healthcare for youth with complex care needs (CCN) and their families in Atlantic Canada*. Canadian Association for Health Services and Policy Research (CAHSPR), Montreal, Quebec.

Cassidy M, Doucet S, Luke A, & MacNeill, L. (2022). *Improving the Transition from Pediatric to Adult Care: Recommendations from Young Adults with Lived Experience* Unpublished manuscript, Department of Interdisciplinary Studies, UNB. (In preparation, March 2023). Journal: Canadian Journal of Family and Youth. Personal Contribution: Lead author.

Luke A, MacNeill L, Cassidy M, and Splane, J. *Improving the Paediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs* (In preparation, March 2023). Government of New Brunswick.

Cassidy M, Doucet S, Luke A. *Improving the Paediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs.* Poster & Presentation (Accepted) at "AHEAD" conference. [Peer reviewed; Personal contribution: primary author - research, writing content and design; Atlantic Health Exploration and Discovery (August 9-10, 2021) – Saint John NB (virtual), Audience: Atlantic health providers and researchers]

Hudon C, Danish A, Lambert M, Howse D and Cassidy M. *Reconciliating validity and challenges of patient comfort and understanding: Guidelines to patient- oriented questionnaires.* Poster & Oral Presentation (Accepted) at "Canadian Association for Health Services and Policy Research (CAHSPR)." [Peer reviewed; Personal contribution: co-author – research and revisions; 21st Scientific Conference (May 19-21, 2021) – National (virtual), Audience: Canadian researchers and service delivery providers.

Doucet S, Luke A, MacNeill L, Splane J and Cassidy M. *Improving transitions from pediatric to adult healthcare for youth/young adults with complex care needs (CCN): Preliminary findings*. Poster & Oral Presentation (Accepted) at "Canadian Association for Health Services and Policy Research (CAHSPR)." [Peer reviewed; Personal contribution: co-author – research and revisions; 21st Scientific Conference (May 19-21, 2021) – National (virtual), Audience: Canadian researchers and service delivery providers.

Cassidy M, Doucet S, Luke A (2021, May 6-7). *Improving the Paediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs.* Poster & Oral Presentation (Accepted) at Department of Interdisciplinary Studies, UNB, 27th Annual UNB Graduate Studies Conference (Fredericton, NB). [Peer reviewed; Personal contribution: primary author; Audience: Researchers and graduate students].

Cassidy M (2021, Apr. 13). *Best Practices for Interviewing Children and Young People.* [Invited speaker: Primary Presenter; QUEST-SJ Qualitative Health Research Group –Provincial (virtual), Audience: 140 Researchers, Clinicians, Academics, Community Group Networks].

Cassidy M (2021, Feb. 17). *Best Practices for Interviewing Children and Young People.* [Dean invited: Primary Presenter; University of New Brunswick –NB (virtual), Audience: UNB IDST Graduate Studies.

Cassidy M, Doucet S, Luke A, Goudreau A. (2020, Dec). *Improving the Paediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs.* Poster (Accepted) at "Transitions In Care First Annual Pop Up" conference. [Peer reviewed; Personal contribution: primary author - research, writing content and design; Transitions In Care Conference (Jan, 26, 2021) – National (virtual), Audience: Canadian Researchers, Youth, Families and Clinicians]. https://www.childrenshealthcarecanada.ca/transitions-poster-hall/2021/1/13/improving-the-pediatric-to-adult-care-transition-experience-recommendations-from-young-adults-with-complex-care-needs

Luke A, Doucet S, MacNeill L, Cassidy M, Splane J. (2020, Dec). *Improving transitions from pediatric to adult healthcare for youth with complex care needs (CCN): Preliminary Findings.* Poster (Accepted) at "Transitions In Care First Annual Pop Up" conference. [Peer reviewed; Personal contribution: co-author - research, and review; Transitions In Care Conference (Jan, 26, 2021) – National (virtual), Audience: Canadian Researchers, Youth, Families and Clinicians]. https://www.childrenshealthcarecanada.ca/transitions-poster-hall/2021/1/13/improving-transitions-from-pediatric-to-adult-healthcare-for-youthyoung-adults-with-complex-care-needs-ccn-preliminary-findings

Cassidy M, Doucet S, Luke A, Goudreau A. (2020, Nov). *Improving the Paediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs.* Poster presentation, video and NBHRF committee selected lead live presenter (Accepted) at "NBHRF" conference. [Peer reviewed; Personal contribution: primary author - research, writing content and design; NBHRF Annual Conference (Nov, 2020) – New Brunswick (virtual), Audience: NB Researchers].

Danish A, Chouinard M-C, Warren M, Sabourin V, Aubrey-Bassler K, Burge F, Doucet S, Ramsden V, Cassidy M, Condran B, Lambert M, Penney C, Porter J, Rubenstein D, Stoddard R, Hudon C. (2020, Oct). *A conceptual model for the implementation analysis of a case management intervention.* Poster Presentation (submitted) at "IFIC (North American Conference on Integrated Care). ID 45. [Peer reviewed; Personal contribution: co-author. IFIC "Innovation. Inspiration. Co- designing for health and well-being with individuals and communities in association with the 6th world congress on integrated care" Oct 5-7, 2020 – (Toronto, ON). ID H4U8d3. [Note: Conference cancelled due to pandemic.] Audience: International care providers and stakeholders with interests of integrated healthcare.

Danish A, Lambert M, Cassidy M, Warren M, Chouinard M-C, Howse D, Bisson M, Doucet S, Aubrey-Bassler, K, Hudon C. (2020, Nov). *A strategic analysis of patient engagement in a multi-site case management intervention in primary care.* Poster presentation and Lead presenter (accepted) at NAPCRG conference (San Francisco, CA). ID 1588**.** [Peer reviewed; Personal contribution: co- author - research; "NAPCRG 2020: 48th Annual meeting (Nov 20, 2020) Audience: North American Primary Care Research Group (NAPCRG) is a multidisciplinary organization for primary care researchers.

Cassidy M. (2020, August, 12). *PriCare: Case Management in Telehealth.* Lead Presenter to NB Provincial Research Team. Personal contribution: design of curriculum, presentation and facilitation; PriCare research group. Audience: NB Team Stakeholders: Primary care providers and management, patient partners, researcher team members and PIs.

Cassidy M, Doucet S, Luke A, Goudreau A. (2020, July). *Improving the Paediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs.* Poster presentation and live conference presenter (Accepted) at "Building Bridges – When Everyone Matters" conference. [Peer reviewed; Lead presenter invited by committee to special poster panel invitation. Personal contribution: primary author - research, writing content and design; Children's Healthcare Canada (Nov 16, 2020) – Saskatchewan (virtual), Audience: National 'leaders and influencers in children's health'].

Cassidy M, Doucet S, Luke A, Goudreau A. (2020, June). *Improving the Paediatric to Adult Care Transition Experience: Recommendations from Young Adults with Complex Care Needs.* Poster presentation (accepted) at "AHEAD" conference. [Peer reviewed; Personal contribution: primary author - research, writing content and design; Atlantic Health Exploration and Discovery (June 1, 2020) – Saint John NB (virtual), Audience: Atlantic health providers and researchers].

Danish A, Chouinard M-C, Warren M, Sabourin V, Aubrey-Bassler K, Burge F, Doucet S, Ramsden V, Cassidy M, Condran B, Lambert M, Penney C, Porter J, Rubenstein D, Stoddard R, Hudon C. (2020, May). *Patient engagement in the pre-implementation of a case management intervention for chronic illnesses and complex care needs.* Poster presentation (accepted) at "CAHSPR" conference (Saskatoon, SK). ID: 99. [Peer reviewed; Personal contribution: co-author - critical revision of article; Audience: Researchers and decision makers]. Note: Conference cancelled due to pandemic.

Danish A, Chouinard M-C, Warren M, Sabourin V, Aubrey-Bassler K, Burge F, Doucet S, Ramsden V, Cassidy M, Condran B, Lambert M, Penney C, Porter J, Rubenstein D, Stoddard R, Hudon C. (2020). *A conceptual model for the implementation analysis of a case management intervention.* ID 45. Submitted to NACIC, 1st Annual North American Integrated Care conference (2020, Oct 6) (Toronto, ON). [Peer reviewed; Personal contribution: co-author, analysis and interpretation of data; Audience: 100-500 Global primary care researchers].

Danish A, Chouinard M-C, Warren M, Sabourin V, Aubrey-Bassler K, Burge F, Doucet S, Ramsden V, Cassidy M, Condran B, Lambert M, Penney C, Porter J, Rubenstein D, Stoddard R, Hudon C. (2020, Nov.). *Patient engagement in case management.* Submitted to NAPCRG (San Francisco, CA). [Peer reviewed; Personal contribution: co-author, substantial review; 48th NAPCRG Annual Meeting (Nov 2020) – San Francisco Hilton, Audience: Global primary care researchers].

Cassidy M, Doucet S, Luke A, Doherty D, London-Anthony, K. (2020, May). *The Implementation of Case Management in Primary Care for Frequent Users of Health Care.* Poster presentation (accepted) at Horizon Health Network (Moncton, NB) Patient and Family Centred Care Experience Conference. [Peer reviewed; Personal contribution: primary author - research, writing content and design; "Vision 2020: Partnering to Enhance the Care Experience Conference" (May 2020) – Saint John NB (virtual); Audience: Atlantic health providers and researchers]. Note: Conference rescheduled to May 5, 2021, due to pandemic.

Hudon C, Chouinard MC, Aubrey-Bassler K, Burge F, Doucet S, Ramsden V, Bisson M, Cassidy M, Condran B, Danish A, Delahunty-Pike A, Dumont- Samson O, Howse D, Lambert M, Penney C, Porter J, Rubenstein D, Sabourin V, Thériault C, Warren M. (2020, Apr). *Case management in primary care for frequent users of healthcare services with chronic diseases and complex care needs: a qualitative analysis of the barriers and facilitators to implementation at baseline.* Poster presentation (submitted) at NAPCRG conference (San Francisco, CA). ID 1590**.** [Peer reviewed; Personal contribution: co-author - research; "NAPCRG 2020: 48th Annual meeting (Nov 20, 2020) Audience: North American Primary Care Research Group (NAPCRG) is a multidisciplinary organization for primary care researchers].

Doucet S, Splane J, Cassidy M, Barry K, Gander S. (2020, May). *Improving transitions to adult healthcare for youth/young adults with complex care needs (CCN) and their families.* Poster presentation (accepted) at NAPCRG conference (San Francisco, CA). ID 1866**.** [Peer reviewed; Personal contribution: co-author - research; "NAPCRG 2020: 48th Annual meeting (Nov 20, 2020) Audience: North American Primary Care Research Group is a multidisciplinary organization for primary care researchers].

Cassidy M, Doucet S, Luke A, & Goudreau, A. (2020, March). *What are Young Adults' Recommendations with Complex Care Needs on How to Improve the Transition Experience from Paediatric to Adult Care?* Poster presentation (accepted) at 27th Annual UNB 2020 Graduate Conference (Fredericton, NB). [Peer reviewed; Personal contribution: primary author - research, writing content and design; Audience: Researchers and graduate students]. Note: Conference cancelled due to pandemic.

Cassidy M, Doucet S, Luke A, & Goudreau, A. (2019, Nov. 16). *Transitions from Pediatric to Adult Care as Experienced by Young Adults with Complex Care Needs.* Poster & Presentation. World Child Day Conference (Saint John, NB). [Unreviewed; Personal contribution: primary author - research, writing content and design; Audience: 200+ Health care providers, decision makers, community partners and researchers].

Cassidy M (2019, Nov. 20). *Transitions from Pediatric to Adult Care as Experienced by Young Adults with Complex Care Needs.* Role: Speaker Presentation & Poster – Pediatric Grand Rounds (Saint John Regional Hospital, NB). [Unreviewed; Personal contribution: primary author - research, writing content and design; Audience: Department of pediatrics].

Hudon C, Chouinard MC, Aubrey-Bassler K, Burge F, Doucet S, Ramsden V, Bisson M, Cassidy M, Condran B, Danish A, Delahunty-Pike A, Dumont- Samson O, Howse D, Lambert M, Penney C, Porter J, Rubenstein D, Sabourin V, Thériault C, Warren M. (2019, Nov). *Patient engagement and partnership for a case management intervention for patients with chronic diseases and complex care needs.* Poster presentation (accepted) at NAPCRG Conference (Toronto, ON). [Peer reviewed; Personal contribution: content analysis; Audience: Researchers and decision makers].

McKenna, M., Arsenault, H., Cassidy, M., Elnihum, S., Holland, M., Peterson, S., Reza, M., & Sawani, E. (2019, May). *Stoking the Fire: Teaching and learning interdisciplinarity in an interdisciplinary context.* E-abstract, Department of Interdisciplinary Studies, UNB, Saint John, Canada. Poster presentation (accepted) at 26th Annual UNB Graduate Studies Conference (Fredericton, NB). [Peer reviewed; Personal contribution: co-author – literature review; Audience: Researchers and graduate students].

Cassidy M (2019, Apr. 9). *A Navigation Centre For Children and Youth with Complex Care Needs In New Brunswick.* Together We Care Conference at Marco Polo Pavilion (Saint John, NB). [Lead Presenter - Invited]. Audience: Hundreds of community stakeholders, government, region wide community service providers.

C. Other Publications/Reports

Doucet S, Doherty D, Luke A, Cassidy M, Schwarz C (2020, Dec). *Case Management project*. Selected and featured in '12 Days of Research' campaign. Atlantic Health Exploration and Discovery (AHEAD) Committee.

Cassidy M. (2016, May). *An Interprofessional Diabetes Health Team Proposal Project: How to Improve Facilitating Patient Care Transitions from Hospital to Home via Role Clarification.* Context: Capstone interdisciplinary project for Master of Education - Health Professions (UNB).

D. Peer Review Activities

2023 **Peer Reviewer** (Journal), Western Journal of Nursing Research. Context: Peer-reviewed scholarly clinical nursing journal. Audience: nursing researchers and clinical practitioners. 1 review in progress.

2021 **Peer Reviewer**, University of New Brunswick 27th Annual Graduate Student Conference (May 2021). Context: Designed for multi-disciplinary graduate student research. Audience: students and community. 4 reviews completed.

2021 **Peer Reviewer** (Journal), Healthy Populations Journal. Healthy Populations Institute. Dalhousie University. 1 review completed.

2020 **Peer Reviewer**, University of New Brunswick Graduate Student Conference (May 2020). Context: Designed for multi-disciplinary graduate student research. Audience: students and community. 4 reviews completed.

2020 **Peer Reviewer,** NAPCRG Conference. Context: 48th NAPCRG Annual Meeting (Nov 2020) – San Francisco Hilton, Audience: Global primary care researchers. 5 reviews completed.

E. Research in Progress

Cassidy M., Gander S. (2020-Present). *A Comparison of Prenatal Exposures in Children with and without a Diagnosis of Autism Spectrum Disorder.* For submission to the **Canadian Pediatric Society.**

Cassidy M. (2020-Present). *Qualitative Interviewing Guide: Best Practice Tips for Novice Researchers with Priority Populations.* For submission to **Atlantic Student Research Journal.**

Section III - TEACHING

A. Undergraduate and Relevant Courses

2022	**Performance Measurement Methodology** (PuMP), Government of New Brunswick (EECD department) to directors and their teams
2022	**Lean Six Sigma Methodology**, Government of New Brunswick (department wide) to Yellow Belt candidates
2020	**Instructional design & technical support,** PriCARE research program national Case Management training program
2018 - 2019	**Lecturer**, MBA program, University of New Brunswick Course title: Effective Communications (MBA 7510, SJ1M3)
2018 - 2021	**Teacher** & Acting Vice-Principal (Local Permit) Anglophone South District (South) K-12
2016 - 2017	**Instructional Lead,** Southern NB Certified Diabetes Educators group
2017	**Co-Instructor**, Horizon Health, taught new insulin order set & designed new hypoglycemia prevention tool deliverable for 13,000 staff
2015 - 2016	**Instructor**, Craving Change National Health Program

B. Undergraduate Summer Students Supervised

2019 Sara Kim (Undergraduate Student – McGill)

C. Graduate Courses Taught

MBA Program Lecturer (2018 – 2019)***:*** Taught "Effective Communications" to diverse International group. 1 term/fall session, 30 students.

D. Graduate Student Committees

UNB Student disciplinary committee (2019-2020): Member

E. Teaching Awards

Nominated for prestigious Allan P Stuart Award of Teaching Excellence to honour persons who are representative of outstanding teaching achievement for MBA 7510 (SJM13) "Effective Communications" course 2018 (*ineligible for award criteria due to not enough course sections taught*).

SECTION IV - ACADEMIC SERVICE

A. UNB Departmental/Faculty/Campus/University Service

2020-22 **Senate Member (Elect),** University of New Brunswick

2020- **Exam Invigilator**, University of New Brunswick (MBA 7404 finance course)

2019- **Graduate Student Representative**, Student disciplinary committee

2019 **UNB Graduation Ceremony, Volunteer,** facilitated pre-ceremony proceedings

1999 **Coordinator UNB Student Resource Centre** & staff – UNB Fredericton

1997 **SPARC Member,** promoted UNB recruitment at both regional and international events

B. Courses/Certificates/Diplomas

PuMP Performance Measurement Process – Certified (APMG International) (Jun 2023)

Lean Six Sigma Black Belt (GNB) (Nov 2022)

Coaching with the G.R.O.W. model (Adroit training, Fredericton) (May

2022) PROSCI® Change Practitioner Certified (Oct 2021)

Program Evaluation, Logic Models & Data Collection Certified (NB-IRDT & NB SPOR) (May 2019)

Data Science (Harvard EdX Courses) (Apr 2019)

- RBasics; Visualization; Probability; Inference & Modeling; Wrangling & Linear Regression

Young Adults with Chronic Conditions Optimizing Treatment and Transition from Pediatric to Adult Care (Harvard Medical School Course, Boston, MA) (Mar 2019)

Diploma in University Teaching (University of New Brunswick) (Apr 2018)

SHRM Certificates in Human Resources (Skillsoft – 24 CP courses) (Mar

2018) Board Effectiveness for Women (LearnSphere) (Jan 2018)

Harvard Manage Mentor (Harvard Management Certificate Program) (2014-2017)

- 44 Modules addressing Critical Management Issues

Project Management Certificates (PMI -16 CAPM courses 6th Ed.) (Skillsoft) (Dec 2017)

Diploma in Social Media Marketing (Alison) (Oct 2017)

Diploma in Information Technology Management & Health Care IT (Alison) (2017)

Instructional Methods in Health Professions Education Certificate (University of Michigan) (Dec 2015)

Canadian Compendium of Pharmaceutical Education (2004-2008)

- Courses included; accreditation, cardiology, metabolism, diabetes and healthcare in Canada

C. Community Service & External Committees

NB Social Pediatrics program (Sept 2019-2020):

- Active member of 'Strengthening Families' weekly course program for families and youth at risk in Saint John priority neighbourhoods
- Mentored youth at risk (e.g., activities included enhancing individualized literacy and social skills)

UNB Promise Partnership for youth at risk (Saint John priority communities) (Sept 2019-2020)

- Weekly mentoring of at risk elementary aged youth (e.g., focus on improving individualized literacy skills)

Bee Me Kidz (2019)

- Conducted group learning and awareness sessions for families and youth at risk (at Glen Falls & Nick Nicolle Centres)

Canadian Mental Health Association (May 2019)

- Prepared food for vulnerable populations at the SJ Community Food basket as part of Mental Health awareness activities

Big Brothers Big Sisters (July 2017-2018)

- Pre-launch volunteer support for Annual Big Book fundraising event

New Horizons Community Theatre - Chris Saunders Elementary (2017)

- Supported youth actors during live community theatre performances

NB Kinesiology Association - President, Board of Directors (2014-2015)

- Led provincial team to achieve provincial goals of increased awareness
- Researched and developed innovative online learning module for allied health stakeholders
- Developed curriculum for successful annual member conference (Moncton, NB)
- Designed first member survey
- Created communications strategy

Ronald McDonald House NS (2014)

- Successfully organized fundraiser attaining all items on their 'WishList' for sick children and their families, while exceeding donation expectations
- Promoted event on social media
- Worked with community business partners to accept collected items

Heart and Stroke Foundation of NS (2003)

- Provided communications support for major fundraising events (e.g., Big Bike Ride)
- Produced published media deliverables for event promotion & brand awareness

Children's Wish Foundation (2000)

- Coordinated 'Parade of Wishes' logistics, volunteers, and related activities (Fredericton, NB)

Memberships:

- GNB Project Management Community of Practice Group (2021-)
- GNB Process Improvement Facilitator Community of Practice Group (2021-)
- GNB Business Intelligence and Analytics (2021-)
- North American Primary Care Research Group (2020-)
- NB Teachers Association (2020-2021)
- UNB Communications and Marketing Association Group (2018-)
- QUEST-SJ Research Group (2018-)
- Canadian Association of Medical Educators (2017-)
- Canadian Obesity Network (2016-)
- Certified NB Kinesiologist, *ID #NB14072* (2014-2016)
- Public Relations Society Executive, Mount St. Vincent University (2002-2003)