Transition to Adult Care for Youth with Severe Mental Illness:
Does Continuity with Primary Care Matter?

By

Alène Ahlam Toulany, MD, FRCPC

A thesis submitted in conformity with the requirements
for the degree of Master of Science

Institute for Health Policy, Management and Evaluation
University of Toronto

Transition to Adult Care for Youth with Severe Mental Illness:
Does Continuity with Primary Care Matter?

Alène Ahlam Toulany
Master of Science
Institute for Health Policy, Management and Evaluation
University of Toronto

Abstract

Objective: To analyze the association between primary care continuity and acute mental health care services following transition to adult care.

Methods: Population-based retrospective cohort study using linked administrative health data of youth ages 12-17 with schizophrenia (SZ), eating disorders (ED), or mood and affective disorders (MAD) admitted between April 1, 2002 and April 1, 2010 in Ontario, Canada. Poisson regression models tested the association of primary care continuity and mental health outcomes after transition.

Results: Among 3183 youth with severe mental illness, the majority (n=2,052, 64.5%) received continuous primary care during the transition period. Compared with continuous care, no primary care (n=190) during transition was associated with a 52% increased risk of a mental health admission following transition (aRR 1.52, 95% CI 1.12, 2.05).

Conclusions: In the context of decreasing specialist mental health visits, ensuring adequate access to primary care during the transition period may improve outcomes in young adulthood.

Acknowledgments

I was like to first express my extreme gratitude to Dr. Astrid Guttmann, my primary supervisor, for her thoughtful mentorship, encouragement, understanding and patience though this process. Among all the paediatricians with whom I have worked, Dr. Guttmann has, *hands-down*, had the greatest impact on my academic growth. She has imparted her genuine enthusiasm and love of child health services research and provided me with numerous opportunities to expand my network of mentors and discuss my career trajectory.

I would also like to thank Dr. Thérèse Stukel and Dr. Paul Kurdyak who embodied the 'dream team' thesis committee. Together with Dr. Guttmann, their expert knowledge, guidance, and inspiration made this a truly enjoyable experience. Thank you to my brilliant mentors, Dr. Denis Daneman and Dr. Miriam Kaufman, for launching me down this career path and supporting and believing in me every step of the way. I am also very grateful for Mr. Longdi Fu's help in cutting the data and answering all of my questions about data analysis and SAS® programming.

To my family, and especially my husband, Dr. Edward Pugh, thank you for your love, kindness, unconditional support, and for cheering me on from start to finish (which included the birth of two gorgeous children, buying our first home, starting two full-time academic jobs, and a major house renovation!). To my babies, Charles and Alexandra, thank you for being my reminder to slow down and enjoy the ride and laugh so hard it hurts!

Table of Contents

List of Tables

List of Figures

List of Appendices

1.0   Introduction

Mental health disorders are a critical health issue affecting 1 in 5 adolescents and young adults in Canada at any given time[1-3]. Worldwide, it is projected that mental illness will continue to rise and become one of the five most common causes of morbidity, mortality and disability among youth in the next decade[4-6]. Children with complex health care needs are often cared for by paediatricians and paediatric specialists, such as child psychiatrists for those with mental health issues. In Canada, provincial funders mandate transfer (i.e., termination of care by paediatric services and potential re-establishment of care in adult sector) of virtually all paediatric community and hospital care to adult providers by age 18. The current configuration of distinct paediatric and adult mental health care service boundaries creates fragmentation and a barrier to continuity of care during the transition period from paediatric to adult care serices[7-10]. For adolescents and young adults with mental illness, this lack of care integration may negatively impact patient engagement and jeopardize health outcomes into adulthood. The role of primary care in providing continuity across this vulnerable transition period may represent an opportunity for intervention.

This thesis provides new knowledge on the changing patterns of health service utilization for transition-age youth (defined in this study as age 12-23) with severe mental illness. Analyzing the impact of primary care continuity during the transition period on the long-term mental health outcomes in young adulthood will provide insight into the role of primary care in supporting transition-age youth with mental illness. This has important implications for clinical care, policy and service planning and the development of best practices for health systems integration, collaborative care, and quality indicators for mental health services across the paediatric and adult care continuum.

1.1   Thesis Objectives

In a population-based cohort of youth hospitalized with severe mental illness between the ages of 12 and 17 years in Ontario, Canada, our aims were to:

1. Describe patterns of health care use (outpatient, emergency, and inpatient) before (age 12-17), during (age 17-19), and after (age 19-23) the transition period from paediatric to adult care.

2. Analyze the association of primary care continuity during the transition period from paediatric to adult care (age 17-19) and subsequent need for acute mental health care services (age 19-23).

1.2   Hypothesis

We hypothesize that the rate of outpatient mental health visits will decrease for youth with severe mental illness following transition to adult care for many reasons including the fragmentation of pediatric and adult mental health care services, lack or perceived lack of available adult resources, patient disengagement or non-adherence, and fundamental differences in treatment philosophy and approach between the two systems. As a result, we anticipate that the rate of mental health-related hospitalizations and emergency department visits will increase during the transition period and beyond as patients may not receive optimal mental health care in the outpatient setting. We also hypothesize that continuity with a primary care provider during the transition period is protective and associated with a lower risk of mental-health related hospitalizations and emergency department visits following transition to adult care.

2.0   Literature Review

2.1   Burden of Mental Illness in Youth

Most mental disorders begin in adolescence and early adulthood and are major contributors to the burden of disease in young people[5,11-13]. It is estimated that half of all lifetime cases of mental health disorders have onset by age 14 years and three-quarters by age 24[14]. Findings from the WHO's 2004 Global Burden of Disease study indicate that, worldwide and in high income countries, neuropsychiatric disorders are the major contributor to disease burden in 10 to 24 year-olds, accounting for 45% and 68% of the total years lost because of disability, respectively[5]. Moreover, 5 out of the 10 leading causes of disease burden were psychiatric in nature: unipolar depressive disorders (8.2% of total disability adjusted life years [DALYs]); schizophrenia (4.1%); bipolar disorder (3.8%); alcohol use (3.0%); and self-inflicted injuries (2.8%)[5]. These data demonstrates that, although this age group has generally been perceived as healthy, young people suffer from significant mental health morbidity. Several other large scale prospective epidemiological studies confirm this finding[15-17].

At any given time, approximately 20% of children and youth are affected by a mental health disorder that causes significant symptoms or impairment[2,3,18-20]. Anxiety, conduct, attention, depressive, and substance use disorders are among the most common[1]. In general, few young people with mental illness access services or receive appropriate care[3,21]. Data from Ontario show that only one out of every six children and youth affected with mental illness received mental health care within the previous six months[3]. Poor mental health in adolescence is strongly associated with other health, well-being, and psychosocial concerns in young adulthood, notably lower educational achievements, interpersonal problems, substance abuse, violence, and poor sexual health[18,22]. Youth with mental health problems are also at increased risk of

developing adult emotional, behavioural, and severe psychiatric disorders[22]. Given the age of onset, frequency, and protracted course, it is not surprising that mental illnesses have been characterized as the 'chronic diseases of the young'[27,28].

Mental health disorders in youth also contribute a substantial risk of suicide in an already heightened period of injury risk. In Canada, suicide is the second leading cause of death in young people aged 15–24 years[29]. Males account for almost three quarters of suicides in this age group, whereas non-fatal suicide attempts are more common in females [30,31]. The vast majority of youth with suicidal behaviors have pre-existing mental health disorders[32]. In a population-based Ontario study, approximately 80% youth who died by suicide were seen in health care settings in the year before their death, typically outpatient physician visits and/or emergency department visits[35].

2.2   Transition from Paediatric to Adult Care

The terms transfer and transition are often used interchangeably. Transition, however, represents a purposeful and planned movement from paediatric to adult care whereas transfer represents a one-time event: the termination of care by a paediatric care provider which is then re-established with an adult provider[36-38]. Successful transition is evidenced by care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive[39]. Transfer is a necessary component of successful transition.

Jurisdictions vary considerably in the age at which transfer of care from paediatric to adult services is required. In Ontario, provincial funders mandate that all paediatric hospital specialty care is transferred by age 18. In 2012, the Ministry of Health and Long-term Care introduced a change to the fee schedule which resulted in the rejection of all services billed by

paediatricians for adult patients (age ≥18). Since then, in addition to hospital care, virtually all general community paediatric care is required to transfer to adult services by age 18. With few exceptions, the Ministry will pay paediatric billing claims for adult patients if 1) the paediatrician has rendered at least on consultation or assessment in the 12 month period prior to the patient's 18th birthday, 2) ongoing management of the patient's chronic condition is necessary, and 3) the patient is less than 22 years. While the majority of youth receive their primary care by general practitioners/family physicians (GP/FPs)[40], some are cared for by paediatricians, and thus require transfer of primary care at age eighteen. In addition, the Ontario Ministry of Children and Youth Services (MCYS) fund and administer community-based mental health services delivered by non-physician providers (e.g. social workers, nurses) as well tele-psychiatry consultations with physicians up to age 18.

Transitioning adolescents with complex, chronic health care needs from paediatric to adult care settings is challenging not only for patients and their families, but also for the clinicians involved in their care[41-46]. Poor health outcomes following transition have been described for several populations such as those with sickle cell disease[47], congenital heart disease[48], diabetes mellitus[49], and organ transplantation[50,51]. Decline in health status may partly be due to an inadequately planned, interrupted, and poorly coordinated transition process[39]. It is also complicated by the tumultuous and intricate medical, social and psychological developmental changes that accompany the adolescent period[39,41]. Combined with the burden of a serious health condition, adolescence becomes a time of additional stress. Altogether, these challenges may contribute to patient disengagement/drop-out, poor treatment adherence, increase in hospitalizations and emergency room visits, and overall detrimental health outcomes[52-55]. A

recent international policy review found that few jurisdictions, however, address these transitional care issues in health or broader social policy documents[56].

There is limited evidence supporting effective transition interventions for adolescents with chronic illness[39,57-60]. Commonly used strategies in successful transition programs often include patient education, care navigators, and specific transition clinics[60]. To date, much of the emphasis in clinical practice and the transition literature focuses on specialist-to-specialist provider transition[61,62]. Very little is known on the impact and role of primary care providers in supporting the transition of youth with chronic health conditions[62]. In our recent systematic review of primary care-based transition interventions, we found only 3 studies that evaluated any kind of primary care-specific intervention, with just 1 based in a primary care setting[62]. Two used case managers to facilitate referrals to primary care, and, therefore, did not focus on primary care as the key target of intervention. The lack of evidence to guide clinical practice or policy around the role of primary care providers in the transition of youth with chronic health conditions, including mental illness, is problematic and may reflect, in part, the generally fragmented nature of the primary to specialty care interface and leadership priorities of the paediatric community[62]. Future research and policy focusing on developing and evaluating coordinated transition interventions to better integrate primary care for high need populations is needed.

Primary care is particularly important for youth because it provides an opportune setting for screening, early intervention, and coordination of services[63,64]. Primary care providers also have the capacity for long-standing relationships with youth and their families and an understanding of the context of the issues[65]. The approach in primary care also tends to be more holistic and, thereby, better integrates the social determinants of health to meet the multiple

needs of youth such as housing, school, employment, and social support[66]. The literature supports this holistic and flexible approach as being beneficial to optimizing health outcomes during transition[67,68].

2.3   Mental Health Service Transition

There is a high degree of persistent psychopathology from childhood to middle adulthood[13,69,70]. In a landmark study by Patton *et al.* (2014) evaluating patterns and predictors of persistence of mental health problems, longer duration of mental health disorder in adolescence was found to be the strongest predictor of ongoing disorder in adulthood[71]. Due to the topography of onset, course of illness, and impact of mental health disorders on functioning, most youth will require transition from paediatric to adult care services for continued management of their mental illness. There are marked differences, however, in approach and care philosophies between paediatric and adult mental health care systems[72]. Adult services typically base eligibility on diagnostic criteria, emphasize symptom management and individual responsibility for care, while paediatric services emphasize developmental approaches and family-centered care in more nurturing environments[66]. The remit of adult services is also narrower, focusing on more severely affected individuals, due to limited services and/or funding[66,68]. Continuity of services, therefore, is often hampered as paediatric and adult mental health systems are generally separate[7,73]. In Ontario, the current model of mental health service delivery for youth has been described as fragmented and fraught with gaps in service provision[74-76]. One of the primary concerns articulated in the Ministry of Child and Youth Services' policy framework on youth transitions is the lack of connection between child and adult mental health services[74,75].

Across the United Kingdom, Australia, United States and Canada, researchers are demonstrating significant gaps in systems of care between paediatric and adult mental health services[7,9,67,77]. The first systematic attempt to study the policy, process, outcome, and experience of transition for youth with mental illness demonstrated that almost half of youth "fell through the care gap" between services and those who successfully transitioned received care that was poorly planned, executed, and experienced[10]. Simply strengthening existing paediatric and adult mental health care systems may, therefore, not be enough to improve transition care. It is likely that construction of new streams of care will be needed to reduce the burden of illness and improve outcomes across this critical transition period[12]. Novel models of mental health care, overlapping with but discrete in culture and expertise from systems for children and adults, are gaining ground in Australia[11,12,78]. Although interventions aimed at improving transitions for youth with mental illness have been developed, evaluations of their effectiveness are limited[79-82]. Some evidence suggests that when care is fragmented, transition has a substantial impact on the financial demands of youth and their families[83]. These demands are likely due to increases in the cost of care, loss of private health insurance coverage, and loss of employment income and productivity[83].

Youth with severe mental illness are a particularly vulnerable group. The tasks that are essential to successful transition often depend on the very abilities that are impaired[84]. They are at increased risk of engaging in high-risk behaviour, criminal activity, dropping out of school, underemployment, homelessness, and failing to achieve important developmental tasks associated with young adulthood[85-87]. Youth with mental illness also report fears of being stigmatized for having a mental illness and needing services, poor mental health literacy, and preference for self-reliance over dependency on professionals for assistance[88]. For these reasons,

the current service configuration of paediatric and adult mental health services has been described as the weakest link in a system where it should be the most robust[12]. Youth with mental illness require developmentally appropriate services tailored to their characteristics, rather than a mere extension of either child or adult services.

To our knowledge, there has only been one study describing a large decline in total mental health service utilization at the age of emancipation for a large nationally representative sample transition-age youth (16-25 years) in the US[89]. This study showed that patterns of mental health utilization, including inpatient, outpatient, and residential care, at ages 18–19 years was about half the rate for persons aged 16–17 years. This was predominantly due to the decline in the rate of outpatient services and residential care, as opposed to inpatient. After the precipitous decline in mental health service utilization at age 18–19, a pattern of increasing inpatient, outpatient, and residential care was demonstrated, although it did not reach the rates observed before transition. By the end of the transition-age period (age 24-25), there were a third fewer patients who received mental health services as compared to the 16-17-year-old group. These findings parallel those of the National Comorbidity Survey Replication, a nationally representative community-based survey, in which 18- to 24-year-olds with mental disorders were significantly less likely to receive mental health services than adults in older age groups[90].

2.4 Continuity of Care and Health Outcomes

Continuity of care is frequently defined as "a process involving the orderly, uninterrupted movement of patients among the diverse elements of the service delivery system"[91]. Concentration of care, or a patient's usual source of care, is often used to measure continuity[92,93]. Regarded as central to the provision of quality health care, continuity has recently

been identified as a key performance measure for mental and general health services, especially in the context of primary care[91,93-99].

In adults with severe mental illness, evidence to support an association between continuity of care and improved health outcomes is sparse because of a lack of longitudinal studies, comprehensive continuity measures, and confounding of individual patient characteristics on the relationship between service process and outcomes[98,100-103]. Associations have been found, however, between continuity and improved mental health symptom scores[104,105], decreased inpatient service use[106,107], lower Medicaid costs[108], improved quality of life[98], better community functioning[98], and greater service satisfaction[98]. This suggests that efforts aimed at improving continuity in and among mental health services may be worthwhile for adults with severe mental illness. In addition, there is evidence suggesting the formal liaison of general practitioners with specialist service providers may improve functional outcomes in chronically mentally ill patients through improvements in patient concordance with treatment programs and more effective clinical practice[109].

Studies examining paediatric outcomes have shown an association between primary care physician continuity and up-to-date immunization coverage, lower emergency department use and costs, reduction in acute hospitalizations, better coordination of care, and greater patient and parent satisfaction[49,103,110-118]. Research on the impact of continuity of care on health outcomes in transition-age youth, however, is lacking. In a retrospective cohort study of 1,507 young adults with diabetes mellitus in Ontario, patients who transferred to a new allied health care team with no change in physician were 77% less likely to be hospitalized after transition than were those transferred to a new physician with either a new or no allied health care team[49]. Similarly, another retrospective cohort study of 229 young adults with diabetes demonstrated greatest

missed clinic appointments among patients who either were transferred to a young-adult clinic in a different hospital or were transferred directly to adult care[119]. In contrast, clinic attendance improved when patients transferred to a young-adult clinic within the same hospital as the paediatric clinic or to an adolescent clinic run jointly by paediatric and adult physicians[119]. These findings suggest that youth with some degree of continuity of care during the transition period experience improved health outcomes.

2.5   Ecology of Primary Care Services in Ontario

In response to a number of challenging primary health care issues such as shortages in human resources and maldistribution of physicians, patient and provider dissatisfaction, gaps in quality care, and preference of trainees to choose specialty careers, there has been significant reform to primary care service delivery in Ontario in the last decade[120]. The Ministry of Health and Long-Term Care worked closely with major stakeholders, including physician groups such as the Ontario Medical Association, to develop a number of new voluntary primary care organizational and funding models which involved patient rostering, increasing team-based allied health professional involvement, after-hours care, and financial incentives for preventative care[120,121]. The major difference between the primary care models is how physicians are reimbursed. Many of the new primary care models support inter-disciplinary teams and, therefore, some GP/FPs enrolled in these models may engage non-physician clinicians such as social works and therapists in the mental health care of youth with mental illness. GP/FPs not enrolled in a model continued to be remunerated by fee-for-service.

The majority of children and youth in Ontario have their primary care delivered by GP/FPs[40]. However, a substantial and increasing number of paediatricians also provide primary

care to children but have not been included in primary care reform and use fee-for-service for remuneration. Access to paediatricians for primary care in Ontario is limited predominantly to large urban centres[40]. Children with complex health care needs and those from higher income status are also more likely to have a paediatrician as their primary care provider[40]. When these youth reach age 18, a transition of primary care from their paediatrician to a GP/FP is needed, in addition to many also requiring specialist-to-specialist care transition for their chronic physical or mental illness.

2.6   Summary

Continuity of care is often lacking for youth with mental illness transitioning from paediatric to adult care services[122,123]. This literature review highlights the need for a more coordinated and integrated mental system for transition-age youth with severe mental illness. There is little research focusing on the pattern of health service utilization during transition for this population[89]. Even less is known on how primary care can support the mental health needs of transition-age youth and whether primary care continuity impacts long-term health outcomes. This study aims to fill an important gap in the literature for youth with severe mental illness and contribute evidence on the potential effect of primary care continuity on optimizing health during the transition years for a vulnerable youth population.

3.0   Methods

3.1   Overview of study design

This was a retrospective population-based cohort study of transition-age youth (age 12-23) using administrative health and demographic datasets housed at the Institute for Clinical Evaluative Sciences (ICES). The cohort included youth with a history of hospitalization between the ages of 12 and 17 for a severe mental illness including schizophrenia and related psychotic disorders (SZ), eating disorders (ED), and mood and affective disorders (MAD) from April 1, 2002 to April 1, 2010 in the Province of Ontario, Canada. We examined the pattern of primary and mental health care use across the transition period from paediatric to adult care, from age 17 to 19, and post-transition period, from age 19 to 23. We evaluated whether primary care continuity (continuous care, different provider, or none) during transition (age 17-19) was associated with acute mental health outcomes after transition to adult care (age 19-23). Patients were followed until their 23rd birthday or the end of the study period (March 31, 2013). The minimum duration of follow-up was 1 year. Please refer to Figure 1 for depiction of overview of study design and timeline.

Ontario legislation governing ICES allows use of health administrative data without individual patient consent for health system research, provided strict privacy guidelines, including the suppression of cell sizes under 6, are followed. Approval to complete this study was granted by the University of Toronto, Sunnybrook Health Sciences Centre, and Hospital for Sick Children Research Ethics Boards.

Figure 1: Overview of study design and timeline
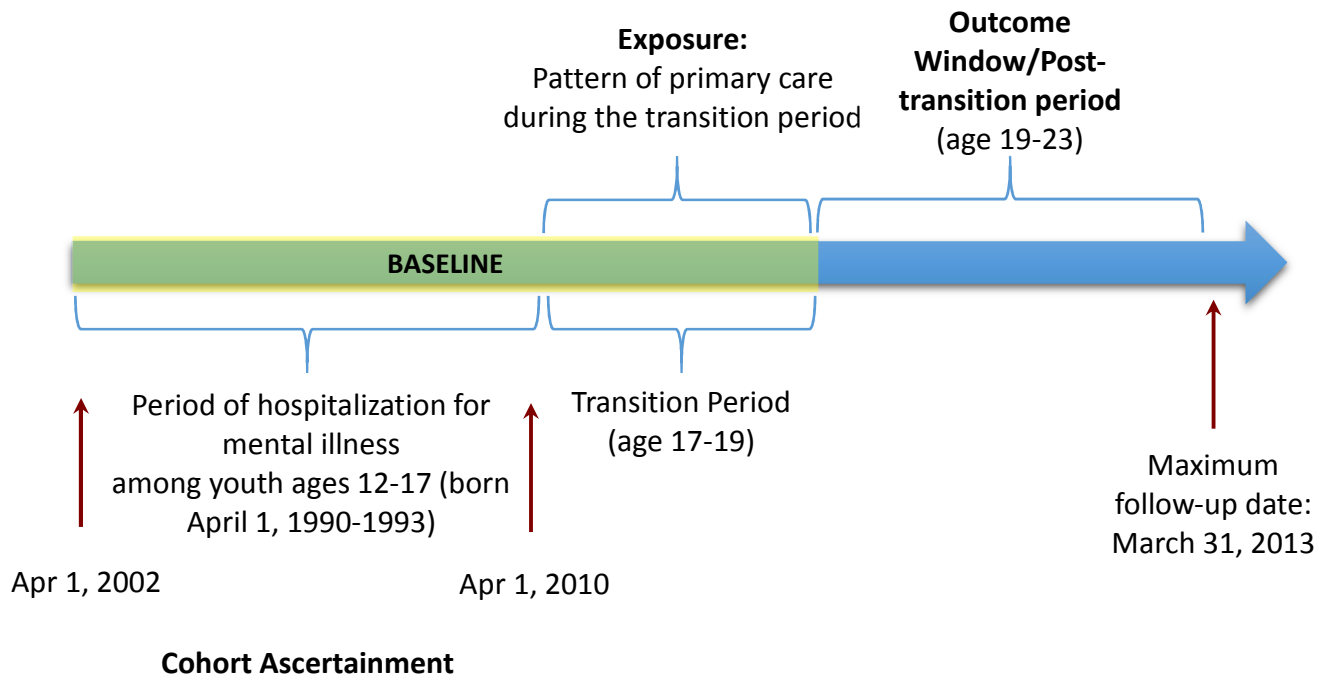
3.2   Data Sources

ICES is an independent not-for-profit research institute that receives core funding from the Ontario Ministry of Health and Long-Term Care. It encompasses much of the publicly funded administrative health services records for residents in the province of Ontario. As a prescribed entity under Ontario's Personal Health Information Protection Act (PHIPA), ICES is responsible for the confidentiality and security of all its data. Secure algorithms based on the Ontario health card number are used to assign Ontario residents with a unique encoded identifier, known as the ICES key number (IKN), used to link the data across health services databases within the ICES inventory over time.

Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD)

The Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD) captures demographic, administrative, and clinical information on hospital inpatient discharges and day surgery interventions across Canada, supplied to the Canadian Institute for Health Information (CIHI) from participating hospitals in all territories and provinces except Quebec. Data is abstracted from patient charts by trained medical staff. Ontario began using the International Classification of Diseases 10th revision (ICD-10-CA) and Canadian Classification of Health Interventions (CCI) for diagnostic and procedural coding in hospital separations reported to the DAD as early as 2002. In this study, the CIHI-DAD was used to identify the index mental health hospitalization, define the youth cohort, and ascertain outcome events.

In terms of data validity, a re-abstraction study of 14,500 discharges from 18 hospitals for from 2002/03 to 2003/04 demonstrated 67.6% agreement for coding of the most responsible diagnosis, defined as the that contributes to the greatest extent to the length of stay in hospital[124]. Overall median and interquartile ranges (IQR) for the top 50 most responsible diagnoses were: kappa 0.81 (0.70 to 0.87), sensitivity 0.82 (0.71 to 0.89), and positive predictive value 0.82 (0.74 to 0.89). Conversely, coding of comorbid diagnoses, present prior or developing during admission, was only moderate (kappa 0.56 [0.47-0.67]). The kappa values for schizophrenia, depressive episode, and bipolar affective disorder as the most responsible diagnosis were 0.94 (0.90-0.98), 0.80 (0.74-0.87), and 0.93 (0.88-0.97), respectively.

Ontario Mental Health Reporting System (OMHRS)

The Ontario Mental Health Reporting System (OMHRS) captures information submitted to CIHI on all inpatient hospitalizations to designated adult mental health beds in psychiatric facilities from 68 participating hospitals in Ontario as of October 1, 2005. Data is collected at admission, discharge, and every 3 months for patients with extended stays and includes information about mental and physical health, social support and service use sourced from a standardized assessment instrument for inpatient mental health known as the Resident Assessment Instrument–Mental Health (RAI-MH). In this study, the OMHRS was used to identify the index mental health hospitalization, define the youth cohort, and ascertain outcome events.

No validation studies for OMHRS were identified.

National Ambulatory Care Reporting System (NACRS)

The National Ambulatory Care Reporting System (NACRS) captures information on visits to hospital and community based ambulatory care, including emergency departments. Hospitals in Ontario have been submitting demographic and clinical information about emergency department presentations since 2001. In this study, the NACRS was used to identify mental health-related emergency department visits.

A re-abstraction study examining the charts for 7,500 unplanned visits to emergency departments at 15 Ontario hospitals in 2004/05 found very high agreement for demographic data but under-reporting of problems, particularly for those who presented with multiple problems where only one problem was reported to the NACRS[125]. The code describing the main problem matched between the original and re-abstracted data for 68.8% of the visits.

Ontario Health Insurance Program (OHIP)

The Ontario Health Insurance Plan (OHIP) database contains information on physician services paid within a fee-for-service system by the Ontario Ministry of Health and Long- Term Care (MOHLTC). These services include physician consultations and assessments in acute care settings, office settings, and long-term care facilities; technical and professional components of diagnostic and therapeutic procedures; surgical procedures; and laboratory services. Approximately 90-95% of physicians practicing in Ontario are enrolled in a fee-for-service mechanism while the remaining are covered by alternate funding plans, although many of these physicians submit "shadow billings" of their clinical activities. In this study, the OHIP database was used to define the exposure and determine outpatient visits. The usual provider of primary care (UPC) was determined using physician claims from OHIP, and the Client Agency Program Enrollment database of patients rostered to a GP/FP in specific primary care models.

Validity of the OHIP database has been less rigorous than for the CIHI-DAD. No validation studies of paediatric populations were identified. A re-abstraction study of 952 charts from 1999-200 in 5 academic family medicine clinics in Toronto, Ontario found administrative measures of mental health have excellent specificity and adequate sensitivity for studying mental health service use among adult populations in primary care[126].

ICES Physician Database (IPDB)

Physician specialty was determined from the ICES Physician Database (IPDB), which comprises information from the Ontario Health Insurance Plan, Corporate Provider Database (CPDB), and the Ontario Physician Human Resource Data Centre (OPHRDC) database.

Registered Persons Database (RPDB)

The Registered Persons Database (RPDB) contains demographic information for all Ontarians with a valid OHIP number. Variables obtained from the RPDB included date of birth, sex, and date of death. Data on cause of death were obtained from the Office of the Registrar General – Deaths (ORGD) database up until 2012 and classified at the Institute for Clinical Evaluative Sciences using the International Classification of Diseases, 9th revision (ICD-9).

Canadian Census Data

The 2006 Canadian Census data was used to determine neighbourhood income quintile and rural residence. Postal codes were linked to the Census to obtain mean neighbourhood income quintile, adjusted for both household and community size, for each dissemination area covering a population of 400–700.

3.3   Study Population

The study cohort was youth hospitalized >72 hours with SZ, ED, MAD between the ages of 12 and 17 years. Conditions were sorted hierarchically into mutually exclusive condition categories. At the top of the hierarchy was SZ, followed by ED and MAD.

The mental health disorders were defined on hospital discharge records in any diagnostic field, from ages 12 to 17 to try to ensure activity of the underlying mental health condition necessitating transfer to adult care services. The International Classification of Diseases, 10th Revision (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) diagnostic codes for SZ, ED, and MAD were used to construct the cohorts from CIHI-DAD and OHMRS, respectively (see Appendix A for codes).

Patients were excluded from the study if they died before age 19 or did not have continuous residency in Ontario between ages 12 to 19 years.

3.4   Outcome Variables

Primary Outcome

The primary outcome of this study was mental health-related hospitalizations measured per person years after transition to adult care services (age 19-23 years). This outcome was chosen to serve as a marker for poor disease control. To define this outcome, any mental health code (ICD-10 F00-F99) as most responsible diagnosis was used in CIHI-DAD and any discharge diagnosis was used in OMHRS. This definition is recommended by the ICES Mental Health and Addictions Data Working Group to capture hospitalizations in which the condition most responsible for the number of days or use of resources is related to mental health or addictions.

Secondary Outcomes

Secondary outcomes included 1) mental health-related emergency department visits (not resulting in a hospital admission) measured per person years and 2) all-cause mortality after transition to adult care services (age 19-23 years). Emergency department visits was chosen to serve as a marker for need for mental health services and/or difficulties related to access to care. Using the NACRS record, any mental health code (ICD-10 F10-F99) in the main diagnostic field or a firm self-harm code (ICD-10 X60-X84) in any diagnostic field was used to ascertain mental-health related emergency department visits. As per the ICES Mental Health and Addictions Data Working Group, this definition captures the majority of emergency department visits where the most clinically significant condition or greatest use of emergency department resources is mental health or addictions. The RPDB and ORGD were used to define death.

3.5   Independent Variables

Primary exposure

The primary exposure for this study was the pattern of primary care during transition from paediatric to adult care services (age 17-19). Descriptive data on the patterns of primary care visits during transition were inspected and divided into 3 exposure categories based on whether patients received care from the same (continuous care) or different primary care provider or received no primary care at all (Figure 2).

Baseline primary care provider [either GP/FP (specialty code 00) or paediatrician (specialty code 26)] was assigned at age 17. The UPC was assigned using methods from previous work[127]. Patients enrolled or rostered in a primary care model were assigned to that provider. For non-rostered individuals, an algorithm using all primary care billings for the preceding two years (age 15-17) was used to assign the physician with the highest dollar value of primary care billings for each patient. For non-rostered youth, those with no primary care were considered to have no UPC.

We defined continuous or 'same primary care' as primary care visits during transition (age 17-19) to the same usual provider of care as baseline (age 12-17) always or sometimes (at least 1 other primary care visit was to a different provider). 'Different primary care' was defined as primary care visits during transition to a primary care provider who was not the usual provider of care at baseline. 'No primary care' was defined as no primary care visits by any physician during transition.

Figure 2: Pattern of primary care during the transition period (age 17-19)

Before Transition

During Transition (age 17-19)

Primary care*
→ Different primary care
→ No primary care
→ Same primary care (Reference)

No primary care
→ (Different) primary care
→ No primary care
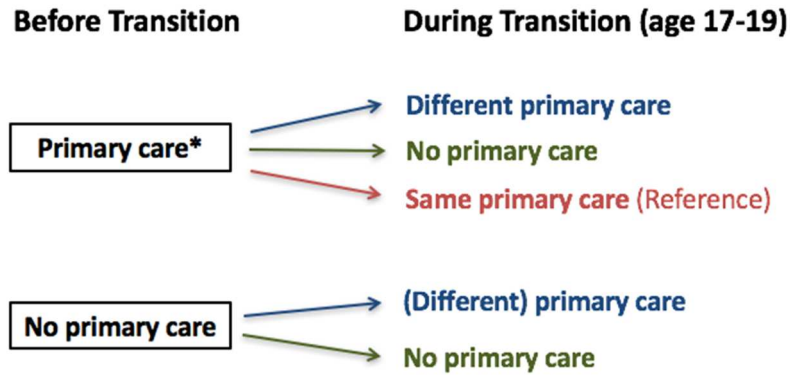
*Primary care = General Practitioner/Family Physician or Paediatrician

Covariates

Patient-level demographic, clinical, and health service use covariates were included in the analysis as potential confounders. Demographic covariates included sex, rural residence, and neighbourhood income quintile. Rural residence was defined according to Statistic Canada's classification of rural and small town (population <10,000). Neighbourhood income quintile was used as a measure of socioeconomic status. The patient's type of mental illness was considered a possible confounder as the trajectory and potential for resolution of symptoms differs among the mental health conditions. In our final models, we adjusted for mental illness co-morbidities by using 5 categories for type of mental illness: SZ alone, SZ and MAD, ED alone, ED and MAD, and MAD alone. Health service use covariates included mental health hospitalizations before transition (age 12-17), not including the index hospitalization, and during transition (age 17-19) as well as mental health outpatient visits to psychiatrists and other providers (GP/FPs and/or paediatricians) during transition (age 17-19). Mental health hospitalizations were included as a

marker of illness severity. Mental health visits by specialty was also considered a potential

marker of illness severity, disease activity, and access to care. Baseline usual provider of mental

health care [either GP/FP (specialty code 00), paediatrician (specialty code 26), or psychiatrist

(specialty code 19)] was assigned at age 17 based on the physician with the highest dollar value

of mental health billings for the preceding two years (age 15-17). Similarly, the usual provider of

mental health care [either GP/FP (specialty code 00), paediatrician (specialty code 26), or

psychiatrist (specialty code 19)] during transition was assigned at age 19 based on the physician

with the highest dollar value of mental health billings for the preceding two years (age 17-19).

Continuity of mental health care during transition (age 17-19) was also assessed for those

patients with a usual provider of mental health care at baseline and >1 visit during transition. We

defined continuity of mental health care as the percent of mental health visits during transition

compared to the baseline usual provider of mental health care and categorized as high ($\geq$75%) or

low (<75%) continuity.

3.6 Statistical Analysis

All statistics analyses were performed with SAS® version 9.4 (SAS institute, Cary, NC)

and statistical models were done using PROC GENMOD. We used p less than 0.05 as the level

of statistical significance. All tests were 2-tailed. Institutional policy required suppression of cell

sizes under 6 to ensure no risk of re-identification of patients.

Descriptive analyses

We compared descriptive patterns of health service utilization, overall and by mental

illness type, before (age 12-17), during (age 17-19), and after the transition period to adult care

(age 19-23). Due to the unequal transition time periods and variable length of follow-up among subjects (minimum follow-up 1 year), we calculated the annualized rates of hospitalizations, emergency department visits, and outpatient visits for each period before, during, and after transition by dividing the number of events by the corresponding number of person years. This ensured each time period and length of follow-up was weighted equally. Differences in mean rates of health service use across cohorts before, during and after transition were calculated using one-way analysis of variance (ANOVA) while controlling for repeated measures as each patient contributed to each time period.

Multi-collinearity

We assessed multi-collinearity of the independent variables for each outcome by examining the variance inflation factor and tolerance. Values greater than 2.5 for the variance inflation factor and less than 0.4 for tolerance were considered correlated[128]. When multi-collinearity occurred, the most clinically relevant variable was kept in the model.

Modelling Strategy

We used multivariate Poisson regression to examine the association between continuity of primary care during transition and outcomes (number of mental health-related hospitalizations and emergency department visits per person years), while adjusting for patient characteristics. Poisson regression was chosen as the study outcomes were count data, however, each observation had unequal exposure. We, therefore, accounted for variable length of follow-up with an offset parameter. When models were found to be overdispersed (i.e., observed variance greater than the mean), we specified the DSCALE parameter in the model statement to fix the

scale parameter at a value of 1 in the estimation procedure. All statistics such as standard errors and likelihood ratios were then adjusted appropriately.

Variables were selected a priori based on clinical significance or evidence from the literature. Bivariate analyses were used to determine associations between the independent and dependent variables. Our modeling approach involved a sequential addition of blocks of variables into the models. Covariates were added to the models one-by-one to examine their individual effects on the primary exposure and confounding. For example, the addition of covariates for the Poisson regression model for mental health related-admissions occurred in 6 steps as follows: sex (step 1), rural residence and income quintile (step 2), type of mental illness (step 3), mental health admissions before transition (step 4), mental health admissions during transition (step 5), and mental health visits by specialty during transition (step 6) (Appendix C). No interaction terms were tested as there were no pre-determined hypotheses on interactions. All variables were kept in the final model regardless of significance. The relationship between the independent variables were expressed as adjusted relative risks (aRRs) with 95% confidence intervals and associated p-values.

4.0   Results

4.1   Youth hospitalized with mental illness in Ontario 2002-2010

The initial cohort and flow chart of exclusions is included in Appendix B (Figure 3).

A total of 3,296 youth aged 12 to 17 had a history of hospitalization greater than 72 hours

duration for SZ, ED, or MAD from April 1, 2002 to April 1, 2010 in the Province of Ontario,

Canada. We excluded 113 youth due to death before age 19 (n=17) and non-continuous Ontario

residency from ages 12 to 19 years (n=96). The final cohort, therefore, included 3,183 youth with

severe mental illness. The majority had a diagnosis of MAD (73.2%) followed by ED (17.4%)

and SZ (9.4%). The mean age at first (index) mental health hospitalization was 14.6 years (±

1.27) for all clinical subgroups.

4.2   Baseline characteristics and health service use of the cohort (age 12-17)

Table 1 presents the overall baseline characteristics and health service use of the cohort

by type of mental illness. Girls accounted for the majority of those hospitalized for ED (92.1%,

n=510) and MAD (68.0%, n=1,584). However, boys accounted for slightly over half (57.2%,

n=171) of those admitted for SZ. Overall, most youth (88.2%, n=2,807) lived in an urban setting.

Low-income status (lowest neighbourhood income quintile) was most common among youth

with SZ (27.1%, n=81). In contrast, high-income status was most common among youth with ED

(37.9%, n=210).

Overall, the majority of youth with mental illness had a GP/FP as their usual provider of

primary care (86.1%, n=2,739). More youth with ED (16.6%, n=92) had a primary care

paediatrician than those with SZ (9.7%, n=29) and MAD (8.2%, n=192).

The mean (± SD) annualized rate (number of events/number of patient years) of primary care visits was highest among youth with ED [7.68 (± 6.76)] and lowest among youth with SZ [3.69 (± 3.02)]. Youth with ED had the highest mean annualized rates of mental health visits to any physician specialty including GP/FPs [1.80 (± 3.25)], paediatricians [3.03 (± 5.60)], and psychiatrists [3.32 (± 5.98)]. The mean annualized rates of mental health-related visits to general practitioners/family physicians, paediatricians, and psychiatrists for youth with SZ were 0.87 (± 1.21), 0.31 (± 0.61), and 3.07 (± 4.39), respectively. Youth with MAD had the lowest mean annualized rate of mental health-related visits to psychiatrists [1.89 (± 3.91)].

Overall, 1,475 (46.3%) youth had at least 1 subsequent mental-health related hospitalization after the index hospitalization in the pre-transition period (age 12-17). Youth with SZ had the highest mean annualized rate of subsequent mental health admissions [0.34 (± 0.41)], while those with MAD had the lowest [0.17 (± 0.29)]. The overall mean annualized rate of emergency department visits for all clinical subgroups was 0.12 (± 0.19).

Table 1: Baseline demographic characteristics and health service use among Ontario youth by type of mental health illness (age 12-17 years), n=3183

	Overall n=3,183	Schizophrenia* n=299	Eating Disorders n=554	Mood/Affective Disorders n=2,330
Sex, n (%)				
Female	2,222 (69.8%)	128 (42.8%)	510 (92.1%)	1,584 (68.0%)
Male	961 (30.2%)	171 (57.2%)	44 (7.9%)	746 (32.0%)
Age (years) at index hospitalization				
Mean ± SD	14.63 ± 1.27	14.70 ± 1.30	14.50 ± 1.31	14.66 ± 1.25
Neighbourhood income quintile, n (%)				
1 (lowest)	625 (19.6%)	81 (27.1%)	62 (11.2%)	482 (20.7%)
2	621 (19.5%)	50 (16.7%)	74 (13.4%)	497 (21.3%)
3	587 (18.4%)	54 (18.1%)	82 (14.8%)	451 (19.4%)
4	657 (20.6%)	71 (23.7%)	126 (22.7%)	460 (19.7%)
5 (highest)	693 (21.8%)	43 (14.4%)	210 (37.9%)	440 (18.9%)
Rurality, n (%)				
Urban	2,807 (88.2%)	263 (88.0%)	499 (90.1%)	2,045 (87.8%)
Rural	376 (11.8%)	36 (12.0%)	55 (9.9%)	285 (12.2%)
Usual provider of primary care (UPC)				
GP/FP	2,739 (86.1%)	253 (84.6%)	453 (81.8%)	2,033 (87.3%)
Paediatrician	313 (9.8%)	29 (9.7%)	92 (16.6%)	192 (8.2%)
None	131 (4.1%)	17 (5.7%)	9 (1.6%)	105 (4.5%)
Overall health service use (annualized rates)				
Primary care visits — Mean ± SD	4.94± 4.42	3.69± 3.02	7.68± 6.76	4.45± 3.52
UPC visits — Mean ± SD	2.15± 2.18	1.72± 1.85	2.46± 2.55	2.14± 2.11
Mental health-related service use (annualized rates)				
MH GP/FP visits — Mean ± SD	1.14± 1.83	0.87± 1.21	1.80± 3.25	1.01± 1.33
MH paediatrician visits — Mean ± SD	0.84± 2.69	0.31± 0.61	3.03± 5.60	0.39± 0.99
MH psychiatrist visits — Mean ± SD	2.25± 4.43	3.07± 4.39	3.32± 5.98	1.89± 3.91
Any MH admission after index event, n (%)	1,475 (46.3%)	198 (66.2%)	242 (43.7%)	1,035 (44.4%)
MH admissions — Mean ± SD	0.19± 0.32	0.34 ± 0.41	0.20 ± 0.35	0.17± 0.29
MH ED visits — Mean ± SD	0.12± 0.19	0.12 ± 0.17	0.10 ± 0.19	0.13 ± 0.20

* schizophrenia/delusional/non-organic psychotic disorder
abbreviations: SD: standard deviation; MH: mental health; ED: emergency department; GP/FP: general practitioner/family physician; UPC: usual provider of primary care

4.3   Pattern of primary care during transition (age 17-19)

Table 2 describes the pattern of primary care during transition by UPC at baseline and mental health condition. Overall, 73.3% (n=2,009) of youth with a GP/FP as their UPC before transition continued to see the same physician always or sometimes during transition whereas 22.0% (n=603) switched to a different provider. Youth with SZ, however, had the least continuity during transition with only 62.8% (n=159) receiving care from the same GP/FP and 9.1% (n=23) receiving no primary care at all. The greatest continuity during transition was observed among youth with ED with 78.3% (n=355) continuing to receive care by the same GP/FP.

Overall, transition to a GP/FP was successfully achieved by 81.2% (n=254) of youth with a paediatrician as their UPC. In addition, 64.1% (n=84) of youth with no UPC at baseline transitioned to a primary care provider between ages 17 and 19.

Table 2: Pattern of primary care during the transition period (17-19 y) old by usual provider of primary care and mental health condition, n=3,183

Usual Provider of Primary Care (12-17 y)	Primary Care During Transition (17-19 y)	Overall n=3,183	Schizophrenia^ n=299	Eating Disorders n=554	Mood/Affective Disorders n=2,330
General Practitioner/ Family Physician	No primary care	127 (4.6%)	23 (9.1%)	13 (2.9%)	91 (4.5%)
	Same primary care provider	2,009 (73.4%)	159 (62.8%)	355 (78.3%)	1,495 (73.5%)
	Different primary care provider	603 (22.0%)	71 (28.1%)	85 (18.8%)	447 (22.0%)
Total		2,739	253	453	2,033
Paediatrician	No primary care	16 (5.1%)	*	*	9 (4.7%)
	Same primary care provider	43 (13.7%)	*	*	30 (15.6%)
	Different primary care provider (GP/FP)	254 (81.2%)	24	77	153 (79.7%)
Total		313	–	–	192
None	No primary care	47 (35.9%)	*	*	41 (39.0%)
	(Different) primary care provider	84 (64.1%)	*	*	64 (61.0%)
Total		131	–	–	105

* suppressed to comply with ICES policy to ensure no risk of re-identification of subjects due to small cell size
^ schizophrenia/delusional/non-organic psychotic disorder

4.4   Usual provider of mental health care before and during transition

Table 3 shows the usual provider of mental health care in the 2 years before (age 15-17) and during (age 17-19) the transition period to adult care by type of mental illness. Overall, the proportion of youth with no mental health care provider during transition was 27.0% (n=861), as compared to 12.6% (n=401) before. Overall, 24.5% (n=779) of youth used a GP/FP as their usual provider of mental health care before transition, compared with 28.0% (n=890) during. 10.3% (n=329) of youth had paediatricians as their usual provider of mental health care, compared to only 5.7% (n=181) during transition. Youth with eating disorders, however, had the greatest proportion of mental health care delivered by a paediatrician before (25.1%, n=139) and during (14.1%, n=78) the transition period.

Psychiatrists were the predominant usual provider of mental health for all mental illness subgroups before (52.6%, n=1,674) and during (39.3%, n=1,251) the transition period. Among youth with MAD, 54.1% (n=1,261) has a psychiatrist as their usual provider of mental health before transition, compared to 37.4% (n=871) after. Among youth with SZ, 68.2% (n=204) had psychiatrists as their usual provider of mental health care before compared to 62.2% (n=186) during the transition period.

Usual Provider of Mental Health Care	Overall n=3,183		Schizophrenia* n=299		Eating Disorders n=554		Mood/Affective Disorders n=2,330	
	Before Transition, n (%)	During Transition, n (%)	Before Transition, n (%)	During Transition, n (%)	Before Transition, n (%)	During Transition, n (%)	Before Transition, n (%)	During Transition, n (%)
GP/FP	779 (24.5%)	890 (28.0%)	52 (17.4%)	51 (17.1%)	133 (24.0%)	134 (24.2%)	594 (25.5%)	705 (30.3%)
Paediatrician	329 (10.3%)	181 (5.7%)	16 (5.4%)	9 (3.0%)	139 (25.1%)	78 (14.1%)	174 (7.5%)	94 (4.0%)
Psychiatrist	1,674 (52.6%)	1,251 (39.3%)	204 (68.2%)	186 (62.2%)	209 (37.7%)	194 (35.0%)	1,261 (54.1%)	871 (37.4%)
None	401 (12.6%)	861 (27.0%)	27 (9.0%)	53 (17.7%)	73 (13.2%)	148 (26.7%)	301 (12.9%)	660 (28.3%)

Table 3: Usual provider of mental health care before (15-17 y) and during the transition period (17-19 y), n=3183

* schizophrenia/delusional/non-organic psychotic disorder

abbreviations: GP/FP: general practitioner/family physician

31

4.5   Continuity of mental health care during the transition period (age 17-19)

Table 4 shows the degree of mental health continuity during the transition period among those youth with a usual provider of mental health care at baseline (age 15-17). Overall, 50.6% (n=1,610) of youth had no visits with their usual provider of mental health care during the transition period. The highest degree of continuity was observed among youth with SZ, however, only 19.4% (n=58) saw the same provider for ≥75% of mental health visits during transition.

Table 4: Degree of continuity with usual provider of mental health care during the transition period (17-19 y) by mental illness, n=2,782

Degree of Continuity with Usual Provider of Mental Health Care during Transition	Overall n=2,782	Schizophrenia* n=272	Eating Disorders n=481	Mood/Affective Disorders n=2,029
No visits	1,610 (50.6%)	129 (43.1%)	266 (48.0%)	1,215 (52.1%)
1 visit	241 (7.6%)	24 (8.0%)	34 (6.1%)	183 (7.9%)
Low continuity°	448 (14.1%)	61 (20.4%)	103 (18.6%)	284 (12.2%)
High continuity^	483 (15.2%)	58 (19.4%)	78 (14.1%)	347 (14.9%)

* schizophrenia/delusional/non-organic psychotic disorder

° <75% of visits during transition with usual provider of mental health care

^ ≥75% of visits during transition with usual provider of mental health care

4.6   Comparison of health service use before, during and after the transition period

Table 5 describes the pattern of health service use before (age 12-17 years), during (age 17-19 years), and after the transition period (age 19-23 years) by mental illness. Mean annualized rates (number of events/number of patient years) of primary care visits were stable for youth with SZ and decreased across transition for those with ED (p<0.01). Rates of primary care visits for youth with MAD increased during transition [4.77 (± 5.01)] only to decrease to baseline rates following transition [4.45 (±4.94)] (p<0.01). The proportion of primary care visits to the usual provider of care decreased across transition for all mental health conditions.

Overall, mental health-related visit rates to GP/FPs and psychiatrists increased during transition compared to baseline. Mental health visits to GP/FPs continued to increase after transition [1.30 (± 3.42) during vs 1.58 (± 4.71) after, p<0.01], however visits to psychiatrists decreased below baseline rates [2.25 (± 4.43) before vs 2.52 (± 6.82) during vs 1.54 (± 4.36) after, p<0.01]. Youth with ED had the highest rates of mental health visits to psychiatrists before transition [3.32 (±5.98)], whereas those with SZ had the highest psychiatry visit rates during [4.43 (± 6.93)] and after transition [2.94 (± 4.58)].

Mental health admissions increased across transition for youth with SZ [0.34 (± 0.41) before vs 0.62 (± 1.34) after, p<0.01] and MAD [0.14 (± 0.46) during vs 0.19 (± 0.85) after, p<0.01], however remained stable for youth with ED. Emergency department visits increased during transition for youth with SZ [0.12 (± 0.17) before vs 0.17 (± 0.36) during, p<0.05].

Table 5: Health service use among Ontario youth with mental illness before (age 12-17), during (age 17-19), and after the transition period to adult care (age 19-23), n=3183												
	Overall n=3,183			**Schizophrenia°** n=299			**Eating Disorders** n=554			**Mood/Affective Disorders** n=2,330		
	12-17 y	17-19 y	19-23 y	12-17 y	17-19 y	19-23 y	12-17 y	17-19 y	19-23 y	12-17 y	17-19 y	19-23 y
Overall health service use (mean annualized rates ± SD)												
Primary care visits	4.94± 4.42*	5.04± 6.03*	4.41± 4.86*	3.69± 3.02	3.89± 3.89	3.77± 4.51	7.68± 6.76*	6.79± 9.56*	4.57± 4.66*	4.45± 3.52*	4.77± 5.01*	4.45± 4.94*
UPC visits	2.15± 2.18*	2.04± 2.94*	1.39± 2.58*	1.72± 1.85*	1.60± 2.53*	1.16± 2.22*	2.46± 2.55*	2.24± 3.37*	1.43± 2.57*	2.14± 2.11*	2.05± 2.87*	1.42± 2.63*
Mental health-related service use (mean annualized rates ± SD)												
MH GP/FP visits	1.14± 1.83*	1.30± 3.42*	1.58± 4.71*	0.87± 1.21^	1.22± 2.14^	1.34± 3.63^	1.80± 3.25	1.97± 4.40	1.73± 5.54	1.01± 1.33*	1.16± 3.27*	1.57± 4.61*
MH paediatrician visits	0.84± 2.69*	0.52± 3.55*	0.06± 1.01*	0.31± 0.61*	0.12± 0.54*	0.05± 0.56*	3.03± 5.60*	2.24± 8.08*	0.10± 0.98*	0.39± 0.99*	0.16± 0.93*	0.06± 1.07*
MH psychiatrist visits	2.25± 4.43*	2.52± 6.82*	1.54± 4.36*	3.07± 4.39*	4.43± 6.93*	2.94± 4.58*	3.32± 5.98*	3.71± 10.89*	1.50± 4.90*	1.89± 3.91*	1.99± 5.30*	1.37± 4.16*
MH admissions	0.19± 0.32*	0.18± 0.55*	0.23± 0.90*	0.34± 0.41*	0.49± 0.98*	0.62± 1.34*	0.20± 0.34	0.15± 0.49	0.16± 0.74	0.17± 0.29*	0.14± 0.46*	0.19± 0.85*
MH ED visits	0.12± 0.19	0.13± 0.30	0.11± 0.31	0.12± 0.17^	0.17± 0.36^	0.14± 0.31^	0.10± 0.18	0.09± 0.26	0.09± 0.31	0.13± 0.20	0.13± 0.30	0.11± 0.31

°schizophrenia/delusional/non-organic psychotic disorder

*p<0.01; ^p<0.05

abbreviations: GP/FP: general practitioner/family physician; MH: mental health; ED: emergency department; UPC: usual provider of primary care; SD: standard deviation

4.7   Outcomes

4.7.1   Death after transition among youth 19 to 23 years old

The overall number of deaths following transition was 26. This corresponds to a rate of 0.33 per 100 person years of follow-up. Data on cause of death was available for 14 youth, 64% of whom died from suicide/self-inflicted injury or motor vehicle traffic accidents.

4.7.2   Mental health-related admissions after transition among youth 19 to 23 years old

Table 6 provides results of the Poisson regression models testing factors associated with mental health-related admissions after transition among 19 to 23 year olds with SZ, ED, and MAD. In the adjusted model, compared with those who saw the same primary care provider during transition, youth with no primary care provider had a 52% increase in risk of a mental health admission (aRR 1.52, 95% CI 1.12, 2.05). There was no difference in those who saw a different versus same primary care provider during transition (aRR 1.02, 95% CI 0.88, 1.17). Compared to those with MAD, youth with SZ had a 78% higher risk (aRR 1.78, 95% CI 1.46, 2.16) of a mental health admission after transition, whereas those with ED a 32% lower risk (aRR 0.68, 95% CI 0.50, 0.92).

Compared to those with no admissions, youth with ≥3 admissions before transition had a >200% increase in risk of admission after transition (aRR 2.16, 95% CI 1.81, 2.58). Similarly, the risk of admission was >400% higher for those with ≥3 admissions during transition compared to those with none (aRR 4.35, 95% CI 3.58, 5.30). Youth with mental health visits during transition (to a psychiatrist or GP/FP and/or paediatrician) were at significantly higher risk of mental health admission after transition compared with those with no visits (aRR 3.44, 95% CI 2.62, 4.53 and aRR 2.42, 95% CI 1.79, 3.25, respectively). The association of neighbourhood

income quintile on mental health admissions after transition was inconsistent; an increased risk was observed among the lowest compared with highest income (aRR 1.47, 95% CI 1.20, 1.81) but there was no clear gradient as income increased. Female sex and rural residence were not associated with mental health admissions after transition.

Our step-wise nesting of models approach revealed that the addition of covariate 'mental health visits by specialty during transition (age 17-19)' had the strongest effect on our primary exposure (Appendix C, step 6). The aRR went from 1.08 (95% CI 0.80, 1.45) to 1.52 (95% CI 1.12, 2.05). To better understand this phenomenon, we examined the pattern of primary care continuity by mental health visits by specialty during transition (Appendix D) and by the rate of mental health-related admissions following transition (Appendix E). It became apparent that youth with no primary care provider during transition who also had no mental health visits following transition had greater than double the rate of subsequent mental health-related admissions compared with youth with the same or different primary care providers during transition. Subgroup analyses by disease category are described in Appendix F.

Table 6: Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related admission after transition (age 19-23) according to pattern of primary care during the transition period, n=3183

Variable	Unadjusted RR (95% CI)	p-value	Adjusted* RR (95% CI)	p-value
Pattern of primary care (PC) during transition				
Different PC provider	1.06 (0.91, 1.25)	0.451	1.02 (0.88, 1.17)	0.826
No PC provider	0.92 (0.66, 1.28)	0.624	1.52 (1.12, 2.05)	0.006
Same PC provider	Reference		Reference	
Sex				
Female	0.77 (0.66, 0.89)	<0.001	1.02 (0.88, 1.18)	0.797
Male	Reference		Reference	
Rural				
Yes	0.81 (0.64, 1.04)	0.103	0.93 (0.75, 1.16)	0.513
No	Reference		Reference	
Income Quintile				
1 (lowest)	1.80 (1.43, 2.27)	<0.001	1.47 (1.20, 1.81)	<0.001
2	1.30 (1.02, 1.66)	0.036	1.24 (1.00, 1.55)	0.048
3	0.99 (0.76, 1.30)	0.954	0.90 (0.71, 1.14)	0.391
4	1.75 (1.39, 2.20)	<0.001	1.43 (1.17, 1.75)	<0.001
5 (highest)	Reference		Reference	
Type of mental illness				
SZ alone	3.06 (2.51, 3.74)	<0.001	1.78 (1.46, 2.16)	<0.001
SZ & MAD	3.18 (2.50, 4.06)	<0.001	1.22 (0.97, 1.54)	0.086
ED alone	0.47 (0.34, 0.66)	<0.001	0.68 (0.50, 0.92)	0.013
ED & MAD	1.39 (1.05, 1.85)	0.023	0.90 (0.69, 1.17)	0.428
MAD alone	Reference		Reference	
Mental health admissions before transition (12-17 y)				
1	1.49 (1.22, 1.81)	<0.001	1.21 (1.01, 1.44)	0.046
2	2.37 (1.90, 2.96)	<0.001	1.49 (1.21, 1.83)	<0.001
≥3	4.96 (4.16, 5.90)	<0.001	2.16 (1.81, 2.58)	<0.001
None	Reference		Reference	
Mental health admissions during transition (17-19 y)				
1	4.90 (4.17, 5.77)	<0.001	2.98 (2.52, 3.53)	<0.001
2	5.12 (4.07, 6.44)	<0.001	2.88 (2.28, 3.62)	<0.001
≥3	9.77 (8.17, 11.69)	<0.001	4.35 (3.58, 5.30)	<0.001
None	Reference		Reference	
Mental health visits by specialty during transition (17-19 y)				
Psychiatrist (any)	6.92 (5.24, 9.14)	<0.001	3.44 (2.62, 4.53)	<0.001
General Practitioner and/or Paediatrician	2.53 (1.84, 3.46)	<0.001	2.42 (1.79, 3.25)	<0.001
No mental health visits	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, type of mental illness, mental health admissions before and during transition, and mental health visits by specialty during transition

abbreviations: SZ: schizophrenia/delusional/non-organic psychotic disorder; ED: eating disorder; MAD: mood/affective disorders

4.7.3   Emergency department visits after transition among youth 19 to 23 years old

Table 7 provides results of the Poisson regression models testing factors associated with mental health-related emergency department visits (not resulting in hospital admission) after transition to adult care among 19 to 23 year olds with SZ, ED, and MADs. In the adjusted model, pattern of primary care during transition had no effect on emergency department visits after transition. Compared with MAD, youth with SZ and co-morbid MAD and ED alone had a 34% decrease in risk of mental health-related emergency department visits after transition (aRR 0.66, 95% CI 0.48, 0.92 and aRR 0.66, 95% CI 0.51, 0.86, respectively).

Youth in the lowest income quintile had a 25% increase in risk of emergency department visit after transition compared to the those in highest income bracket (aRR 1.25, 95% CI 1.03, 1.52). As the number of mental health admissions before and during transition increased, a gradient increase in risk of emergency department visits after transition was observed compared to those with no admission history. Compared with youth with no mental health visits during transition, visits to psychiatrists and general practitioner and/or paediatricians were associated with a 69% (aRR 1.69, 95% CI 1.38, 2.06) and 48% (aRR 1.48, 95% CI 1.20, 1.84) increase in risk of emergency department visits after transition, respectively. Female sex and rural residence were not associated with mental health-related emergency department visits. Subgroup analyses by disease category are described in Appendix G.

Table 7: Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related emergency department visit after transition to adult care (age 19-23) according to pattern of primary care during the transition period, n=3183

Variable	Unadjusted RR (95% CI)	p-value	Adjusted* RR (95% CI)	p-value
Pattern of primary care (PC) during transition				
Different PC provider	1.08 (0.93, 1.25)	0.310	1.07 (0.93, 1.23)	0.369
No PC provider	0.93 (0.69, 1.25)	0.636	1.24 (0.91, 1.68)	0.167
Same PC provider	Reference		Reference	
Sex				
Female	0.93 (0.81, 1.07)	0.328	0.99 (0.86, 1.15)	0.900
Male	Reference		Reference	
Rural				
Yes	1.08 (0.88, 1.32)	0.459	1.15 (0.95, 1.40)	0.159
No	Reference		Reference	
Income Quintile				
1 (lowest)	1.36 (1.12, 1.66)	0.002	1.25 (1.03, 1.52)	0.024
2	0.95 (0.76, 1.17)	0.614	0.89 (0.72, 1.10)	0.291
3	1.06 (0.86, 1.31)	0.595	1.02 (0.83, 1.26)	0.836
4	1.06 (0.86, 1.30)	0.581	0.97 (0.79, 1.19)	0.761
5 (highest)	Reference		Reference	
Type of mental illness				
SZ alone	1.16 (0.90, 1.51)	0.257	0.84 (0.65, 1.09)	0.195
SZ & MAD	1.19 (0.86, 1.64)	0.301	0.66 (0.48, 0.92)	0.013
ED alone	0.56 (0.43, 0.73)	<0.001	0.66 (0.51, 0.86)	0.002
ED & MAD	1.26 (0.97, 1.62)	0.082	1.01 (0.78, 1.30)	0.960
MAD alone	Reference		Reference	
Mental health admissions before transition (12-17 y)				
1	1.33 (1.13, 1.58)	<0.001	1.22 (1.03, 1.44)	0.019
2	1.80 (1.47, 2.20)	<0.001	1.46 (1.19, 1.78)	<0.001
≥3	2.53 (2.12, 3.01)	<0.001	1.76 (1.45, 2.12)	<0.001
None	Reference		Reference	
Mental health admissions during transition (17-19 y)				
1	1.95 (1.62, 2.34)	<0.001	1.52 (1.26, 1.85)	<0.001
2	2.05 (1.56, 2.69)	<0.001	1.54 (1.17, 2.04)	0.002
≥3	3.90 (3.17, 4.78)	<0.001	2.77 (2.21, 3.47)	<0.001
None	Reference		Reference	
Mental health visits by specialty during transition (17-19 y)				
Psychiatrist (any)	2.25 (1.87, 2.70)	<0.001	1.69 (1.38, 2.06)	<0.001
General Practitioner and/or Paediatrician	1.54 (1.25, 1.90)	<0.001	1.48 (1.20, 1.84)	<0.001
No mental health visits	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, type of mental illness, mental health admissions before and during transition, and mental health visits by specialty during transition
abbreviations: SZ: schizophrenia/delusional/non-organic psychotic disorder; ED: eating disorder; MAD: mood/affective disorders

5.0   Discussion

5.1   Key Findings

In this large population-based cohort study of transition-age youth with severe mental illness, we have demonstrated that receipt of primary care during transition is associated with better mental health outcomes following transition to adult care. Contrary to our hypothesis, lack of continuity with a primary care provider during transition was not associated with mental health admissions or emergency department visits after transition. However, not having a primary care provider during transition was associated with a 52% higher risk of mental health admission after transition (aRR 1.52, 95% CI 1.12, 2.05) compared with those with continuous primary care (Table 6). Type of mental illness was also important. Compared to youth with MAD, those with SZ had a 78% higher risk of mental health admission following transition (aRR 1.78, 95% CI 1.46, 2.16), whereas those with ED a 32% lower risk (aRR 0.68, 95% CI 0.50, 0.92) (Table 6).

We found a two-fold increase in the proportion of youth with no mental health care during transition (27.0%, n=861), as compared to before (12.6%, n=401) (Table 3). Moreover, 50.6% (n=1,610) of youth had no continuity with their usual provider of mental health care during transition (Table 4). After transition, the rate of mental health visits varied by the type of provider and type of mental health condition. Visit rates by psychiatrists decreased significantly below baseline levels for all mental health conditions after transition [2.25 (±4.43) before vs 1.54 ± (4.36) after] (p<0.01) (Table 5). In contrast, mental-health visit rates by GP/FPs increased significantly after transition for SZ and MAD (p<0.01), but not for ED (Table 5).

No significant change was observed in the rate of mental health admissions for youth with ED. For youth with SZ, however, admissions rates increased both during and after transition

[(0.34 (± 0.41) before vs (0.49 (± 0.98) during vs 0.62 (± 1.34) after] (p<0.01) and only after

transition for youth with MAD [0.17 (± 0.29) before vs 0.14 (± 0.46) during vs 0.19 (± 0.85)

after] (p<0.01) (Table 5). Lastly, mental health-related emergency department visit rates only

increased for youth with SZ during and after transition [0.12 (± 0.17) before vs 0.17 (± 0.36)

during vs 0.14 (± 0.31) after] (p<0.05) (Table 5).

5.2   Interpretation

Our finding that no primary care during transition was associated with worse mental

health outcomes in young adulthood suggests that access to *any* primary care may be more

important than continuity of care for transition-age youth with mental illness. It is possible that

contact with a primary care provider may moderate or improve mental health symptoms in

transition-age youth. This finding has not been previously described in any transition-age

population. It is well established that adults with mental illness, particularly those with more

serious disease, have difficulty accessing primary care and often receive substandard quality of

care when they do which contributes to poor health outcomes[129-134]. Similar findings have not

been previously described among youth with mental illness.

Limited access to primary care can have significant implications for youth evident at the

personal, social, and economic levels[64]. The factors that impact access are often very different

for youth than adults. Young people identify concerns about confidentiality as the most

important barrier to their accessing health services, particularly for sensitive issues such as

mental health and substance use[63,135-139]. Although 70-90% of youth make contact with primary

care services at least once a year[137,140-142], mostly for respiratory or skin problems[143], they seek

help from family and friends for their mental health problems[144]. Other perceived barriers

include geography, inconvenient hours, lack of knowledge of what the health services offer, and unfriendly environment or staff[135,137,145,146]. In this study, it is possible that youth who had worse functioning were less capable of continuity-maintaining behaviours due to unmeasured socioeconomic and psychological barriers that made it difficult to access care, keep appointments, and prioritize and organize their own health care. These barriers to youth access have been recognized by several governments and recommendations encouraging their removal and how health services can be made more youth-friendly and developmentally appropriate have emerged[63,135,147,148].

While not having a primary care provider during transition may be problematic, most youth in this study did have a usual provider of primary care and continued to see that same provider during transition (64.5%, n=2052). The role of primary care in supporting the transition of youth with chronic health conditions, including mental illness, is often overlooked. To date, the focus in the transition literature has been on disease-specific specialist-to-specialist provider transition[61,149-155] reflecting, in part, a fragmented primary and specialist care interface. We have previously highlighted this important gap in transition care in a systematic review examining effective interventions to improve primary care involvement in transitioning young people with chronic conditions, including mental illness, to adult care[62].

The lack of substantial evidence on the role of primary care in transition care is significant as many youth with mental health problems are adequately managed in primary care. In our study, primary care providers (GP/FP and paediatricians) were the usual provider of mental health care for more than a third of youth with severe mental illness at baseline and during transition. This finding is consistent with data from the ICES Mental Health of Children and Youth in Ontario 2017 Scorecard which showed the majority of outpatient physician care

related to mental health is provided by GP/FPs with the highest visit rates among youth aged 18 to 21 years (31.8 visits per 100 population) and 22 to 24 years (39.9 visits per 100 population)[156]. Rates of outpatient visits for mental health have also increased in Ontario by 25% from 2006 to 2014, including a 55% increase in visits to paediatricians, 21% increase in visits to psychiatrists, and 16% increase in visits to primary care physicians[156]. Similarly, a recent population-based cross-sectional study examining temporal trends in mental health service use between 2006 and 2011 among children and youth found relative increases in the rates of mental health-related outpatient visits of 15.8%, with the largest absolute increase among family physician visits[157]. Mental health-related emergency department visits and hospitalizations also increased by 32.5% and 53.7%, respectively[157]. It is not clear to what extent the observed increase in acute mental health care use reflects difficulty with access to outpatient care. With this rising care need and generally poor access to psychiatry[158], the role of primary care will become increasingly important in the management of youth with mental illness.

The large burden of responsibility for youth's mental health falling on general practitioners is consistent with our findings that GP/FPs are doing more, while psychiatrists are doing less, mental health-related care for youth with severe mental illness after transition to adult care. In our study, the stark drop of psychiatrist visits and the increase in mental health admissions for youth with SZ and MAD after transition suggests a critical gap in care. This is especially true for youth with SZ whose illness is chronic and often characterized by multiple relapses over time[159].

Previous work by colleagues in the same jurisdiction did not show significant changes in cost and utilization for youth with severe mental illness following transition to adult care, however, their follow-up window was only 2 years (age 20)[160]. While the stark shift in care

philosophies and approach may be, in part, contributing to our observations, there may also be a lack of referrals to adult care. In a study of transition processes, although 80% of cases were deemed suitable, a third were not referred to adult mental health services[67]. Another explanation for the decrease in psychiatry visits, may be the natural history and prognosis of the various mental illnesses. Some of youth in our study may simply be better from their illness (e.g. MAD and ED) and not require ongoing care by a specialist psychiatrist. However, if this were true, we should not be seeing the increase rates of mental health-related admission following transition in those with SZ. For youth with ED, ambivalence about treatment and recovery is a core feature of their illness, even in the face of significant medical complications, and resistance to recovery is common[161-163]. Therefore, they may be missing or cancelling appointments and disengaging from necessary follow-up care as a means of maintaining their eating disorder[162,164]. This may be contributing to the decrease in service utilization (both outpatient and inpatient) after transition for youth with ED seen in our study. Disengagement may also result from developmental characteristics such as emerging independence, evolving family relationships, increased influence of peers, worries about confidentiality, and knowledge about and accessibility of the service proposed[123,165].

5.3   Strengths

Our study has several strengths. It is the first population-based study to explore the impact of primary care continuity on transition-age youth with mental health illness. Although reports published by the AAP, American Academy of Family Physicians (AAFP) and American College of Physicians (ACP) have recommended primary care providers and medical specialists adopt a transition planning algorithm for all youth within a medical home specific to their

clinical setting, the clinical reality and current emphasis in the transition literature focuses solely on specialist-to-specialist provider transition[166]. Our study suggests that primary care involvement in transitional care may be important for improving long-term health outcomes for youth with mental illness. This may serve as a stimulus for further study of possible primary care interventions to improve outcomes in this population.

The use of a population-based data is also rare in the transition literature and allowed us to capture a large, representative sample size to adequately power our study for our primary outcome. We also fill an important gap in the literature on the longitudinal changes in patterns of primary care across the transition period, which were examined comprehensively and accounted for in our primary exposure. Furthermore, this study builds on our knowledge of mental health service utilization among transition-age youth with severe mental illness.

5.4   Limitations

Our study has a number of limitations. As an observational study, our results demonstrate an association but do not prove causation. We studied a select population of transition-age youth with the most severe presentation of mental illness. Our inclusion criteria were limited to ICD-10 and DSM-IV-TR codes from hospitalizations for SZ, ED, and MAD, missing youth not hospitalized with these conditions. The sensitivity and specificity of diagnostic codes for these conditions have not been formally assessed. As a result, our findings may not be generalizable to patients with less severe forms of mental illness. Similar cohort studies using different samples of patients with varying degrees of mental illness are needed to confirm our findings. In addition, the current study only included youth living in Ontario and results may not be generalizable to those living in other regions. Our data are also limited to services billed to the Ontario Health

Insurance Plan (OHIP) and, thereby, reports on care provided in outpatient physician and acute care settings. It does not capture other community-level services such as mental health services offered by non-physician providers including psychologists, social workers, nurses, and other therapists. While many of the youth in this study may have relied on follow-up mental health visits with these non-physician providers, given the severity of their illness, we believe that it would also be necessary for some degree of physician involvement to help guide treatment recommendations and management. Tele-psychiatry and tele-mental health services, funded by the Ministry of Children and Youth Services for children and youth <18 years old, used for youth in remote areas with limited access to psychiatry are also not captured in this current administrative health dataset. Lastly, a small number of primary care physicians affiliated with community health centres (CHCs) do not bill by fee-for-service and, therefore, are not included in our dataset. The impact of this on our results is likely negligible as only about 1% of the population in Ontario receive care through CHCs.

Residual confounding from unknown or unmeasured covariates such as ethnic background, family composition, social supports, school related factors, therapeutic approach, or individual level income may exist. The lack of primary care association may also be confounded by youth with poor overall functioning and, thereby, less capable of adhering to recommended treatment strategies and follow-up appointments, including mental health appointments with other practitioners such as psychiatrists.

Due to provincial mandates to transfer pediatric care at age 18 years in Ontario, virtually all youth in this study with a paediatrician as their usual provider of primary care at baseline (n=313) had to change care providers during the transition period. Therefore, continuity of care during transition could not be maintained for this subgroup regardless of patient or physician

characteristics or preferences. For transition-age youth with severe mental illness, mental health care by a paediatrician may translate into worse long-term health outcomes because of this "double hit" as they require transition from both primary and secondary or specialist care. There is no data to guide these "double hit" transitions and whether they should occur simultaneously or in a sequential fashion[62].

Some youth may have maintained Ontario residency while obtaining some health services out-of-province as post-secondary students, which may have underestimated health care use after transition. It has been estimated that among the 60% of Canadians who attend post-secondary institutions, only about 10% attend out-of-province, and many still access health care in their own province[167,168]. It is, therefore, unlikely, that this had a substantial effect on our study results.

5.5   Implications and Future Directions

This study sheds light on the importance of primary care for transition-age youth with mental illness and has implications and opportunities for knowledge translation. Issues related to mental health care and access for transition-age youth is of paramount importance with the Ontario Ministry of Health. As such, our key findings will be shared with the Ontario Ministry of Child and Youth Services using a plain language summary including descriptive statistics and a measured statement around the potential role of primary care in supporting the mental health needs transition-age youth. We will also share our results with the Mental Health and Addictions Scorecard and Evaluation Framework (MHASEF) Research Team co-led by Dr. Astrid Guttmann (principal thesis supervisor) and Dr. Paul Kurdyak (thesis committee member).

While continuity of primary care during transition did not appear to influence the need for acute mental health services after transition, access to any primary care did. Ensuring adequate access to primary care may have important effects on long-term patient outcomes after transition. Transition planning, therefore, should incorporate primary care as a key element in the delivery and organization of mental health services for youth and young adults with mental illness. The level and type of primary care involvement during transition may need to differ depending on the condition. For example, for youth with uncomplicated MAD, all care across transition may be appropriately managed by the primary care provider alone. However, for youth with SZ, a shared care model between primary care and psychiatry may be needed for optimal transition care. Integration of primary and specialist mental health care may also aid in the development of system strategies that account for differences in primary care involvement and varying levels of complexity of mental health conditions. This is especially important in Ontario where a large burden of responsibility for children and youth's mental health falls on general practitioners and paediatricians[156,169,170].

The current fragmentation of mental health services indicate that an actively collaborative approach must be adopted in work in this area. Further studies examining interventions in primary care settings for youth with mental illness are needed. Interventions should aim to better integrate primary care and specialist mental health care and improve continuity of care during the transition period. Evaluations should focus on long-term health outcomes and cost-effectiveness of these interventions. Furthermore, it would be helpful to identify which patients with mental illness are most in need of, or likely to benefit from, enhanced transition support or shared primary and specialist care model.

Transition planning is a complex health system issue and should be a shared responsibility between the paediatric and adult care providers. Primary care and specialist adult mental healthcare providers engaged at both the policy and service levels are needed in order to support a successful model of transition for youth with mental illness. Future work with longer observation periods and replication of our study design in other jurisdictions will further explain the trajectories of youth with severe mental illness as they cross into the adult healthcare system.

6.0   Conclusions

Patterns of mental healthcare use for young adults with childhood-onset severe mental illness appear very different than the patterns exhibited during their youth. After transition to adult care, outpatient visits to psychiatrists decrease for all mental health conditions while mental health-related admissions increase for youth with SZ and MAD, but not for ED. Primary care providers appear to be moderating this gap in care by seeing more of these young adults for mental health-related issues after transition. Not having a primary care provider during transition increases the risk of mental health-related admissions after age 19. Therefore, timely and appropriate access to effective primary care during the transition period and beyond may help improve outcomes into adulthood for transition-age youth with severe mental illness.

7.0   References

1.   Waddell C SC. *Prevalence of mental disorders in children and youth: a research update prepared for the British Columbia Ministry of Children and Family Development, Mental Health Evaluation & Community Consultation Unit, Department of Psychiatry, Faculty of Medicine, The University of British Columbia.* 2002 2002.

2.   Shaffer D, Fisher P, Dulcan MK, et al. The NIMH Diagnostic Interview Schedule for Children Version 2.3 (DISC-2.3): description, acceptability, prevalence rates, and performance in the MECA Study. Methods for the Epidemiology of Child and Adolescent Mental Disorders Study. *J Am Acad Child Adolesc Psychiatry.* 1996;35(7):865-877.

3.   Offord DR, Boyle MH, Fleming JE, Blum HM, Grant NI. Ontario Child Health Study. Summary of selected results. *Can J Psychiatry.* 1989;34(6):483-491.

4.   *U.S. Department of Health and Human Services. (2000). Report of the Surgeon General's conference on children's mental health: A national action agenda. Washington, DC: U.S. Government Printing Office.*

5.   Gore FM, Bloem PJ, Patton GC, et al. Global burden of disease in young people aged 10-24 years: a systematic analysis. *Lancet.* 2011;377(9783):2093-2102.

6.   *European Commission. 2003. The Health Status of the European Union. Narrowing the health gap.Luxemburg: European Communities.*

7.   Singh SP. Transition of care from child to adult mental health services: The great divide. *Curr Opin Psychiatry.* 2009;22(4):386-390.

8.   Singh SP. Journey from child to adult mental health care: A view from the bridge. *Australian and New Zealand Journal of Psychiatry.* 2012;46:55.

9.   Singh SP, Paul M, Ford T, Kramer T, Weaver T. Transitions of care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): a study of protocols in Greater London. *BMC Health Serv Res.* 2008;8:135.

10.   Singh SP, Paul M, Ford T, et al. Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *Br J Psychiatry.* 2010;197(4):305-312.

11.   McGorry P, Hazell P, Hickie I, et al. The 'youth model' in mental health services. *Australasian psychiatry : bulletin of Royal Australian and New Zealand College of Psychiatrists.* 2008;16(2):136-137.

12.   McGorry PD. The specialist youth mental health model: strengthening the weakest link in the public mental health system. *Med J Aust.* 2007;187(7 Suppl):S53-56.

13.   Kim-Cohen J, Caspi A, Moffitt TE, Harrington H, Milne BJ, Poulton R. Prior juvenile diagnoses in adults with mental disorder: Developmental follow-back of a prospective-longitudinal cohort. *Arch Gen Psychiatry.* 2003;60(7):709-717.

14.   Kessler RC, Chiu W, Demler O, Walters EE. PRevalence, severity, and comorbidity of 12-month dsm-iv disorders in the national comorbidity survey replication. *Arch Gen Psychiatry.* 2005;62(6):617-627.

15.   Wasserman D, Carli V, Wasserman C. Saving and empowering young lives in Europe (SEYLE): a randomized controlled trial. *BMC Public Health.* 2010;10:192.

16.   Ford T, R. G, H. M. The British Child and Adolescent Mental Health Survey 1999: the prevalence of DSM-IV disorders. *J Am Acad Child Adolesc Psychiatry.* 2003 42(10):1203-1211

17.   Oldehinkel AJ, Verhulst FC, Ormel J. Mental health problems during puberty: Tanner stage-related differences in specific symptoms. The TRAILS study. *J Adolesc.* 2011;34(1):73-85.

18.   Reinherz HZ, Giaconia RM, Lefkowitz ES, Pakiz B, Frost AK. Prevalence of psychiatric disorders in a community population of older adolescents. *J Am Acad Child Adolesc Psychiatry.* 1993;32(2):369-377.

19.   Roberts RE, Attkisson CC, Rosenblatt A. Prevalence of psychopathology among children and adolescents. *Am J Psychiatry.* 1998;155:715-725.

20.   Perou R, Bitsko RH, Blumberg SJ, et al. Mental health surveillance among children-- United States, 2005-2011. *MMWR supplements.* 2013;62(2):1-35.

21.   Kataoka SH, Zhang L, Wells KB. Unmet need for mental health care among U.S. children: variation by ethnicity and insurance status. *Am J Psychiatry.* 2002;159(9):1548- 1555.

22.   Patel V, Flisher A, Hetrick S, McGorry P. Mental health of young people: a global public-health challenge. *The Lancet.* 2007;369(9569):1302-1313.

23.   Bruffaerts R, Demyttenaere K, Borges G, et al. Childhood adversities as risk factors for onset and persistence of suicidal behaviour. *Br J Psychiatry.* 2010;197(1):20-27.

24.   Scott KM, Von Korff M, Angermeyer MC. Association of childhood adversities and early-onset mental disorders with adult-onset chronic physical conditions. *Arch Gen Psychiatry.* 2011;8:838-844.

25.   Kessler RC, Angermeyer M, Anthony JC. Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry.* 2007;6:168-176.

26.   Kessler RC, McLaughlin KA, Green JG. Childhood adversities and adult psychopathology in the WHO World Mental Health Surveys. *Br J Psychiatry.* 2010;197(5):378-385.

27.   Insel TR, Fenton WS. Psychiatric epidemiology: it's not just about counting anymore. *Arch Gen Psychiatry.* 2005;62(6):590-592.

28.   Consortium. TWWMHS. Prevalence, Severity, and Unmet need for Treatment of Mental Disorders in the World Health Organization World Mental Health Surveys. *JAMA : the journal of the American Medical Association.* 2004;291:2581-2590.

29.   Skinner R, McFaull S. Suicide among children and adolescents in Canada: trends and sex differences, 1980-2008. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.* 2012;184(9):1029-1034.

30.   Silverman MM, Berman AL, Sanddal ND, O'Carroll P W, Joiner TE. Rebuilding the tower of Babel: a revised nomenclature for the study of suicide and suicidal behaviors. Part 2: Suicide-related ideations, communications, and behaviors. *Suicide & life-threatening behavior.* 2007;37(3):264-277.

31.   Rhodes A. Youth suicide in Canada: distinctions among boys and girls. *Healthcare quarterly (Toronto, Ont).* 2013(1710-2774 (Print)).

32.   Nock MK, Green JG, Hwang I, et al. Prevalence, correlates, and treatment of lifetime suicidal behavior among adolescents: results from the National Comorbidity Survey Replication Adolescent Supplement. *JAMA psychiatry.* 2013;70(3):300-310.

33.   Rhodes AE, Bethell J, Spence J, Links PS, Streiner DL, Jaakkimainen RL. Age-sex differences in medicinal self-poisonings: a population-based study of deliberate intent and medical severity. *Soc Psychiatry Psychiatr Epidemiol.* 2008;43(8):642-652.

34.   Kessler RC, Berglund P, Borges G, Nock M, Wang PS. Trends in suicide ideation, plans, gestures, and attempts in the United States, 1990-1992 to 2001-2003. *JAMA : the journal of the American Medical Association.* 2005;293(20):2487-2495.

35.   Rhodes AE, Khan S, Boyle MH, et al. Sex differences in suicides among children and youth: the potential impact of help-seeking behaviour. *Can J Psychiatry.* 2013;58(5):274-282.

36.   Blum RW. Transition to adult health care: Setting the stage. *J Adolesc Health.* 1995;17(1):3-5.

37.   Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health.* 1993;14(7):570-576.

38.   Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health.* 2003;33(4):309-311.

39.   Kaufman MP, J. Transition to adult care for youth with special health care needs. *Paediatrics & child health.* 2007;12(9):785-793.

40.   Guttmann A, Schultz SE, L. J. *Primary Care for Children. In: Jaakkimainen L, Upshur R, Klein-Geltink JE, Leong A, Maaten S, Schultz SE, Wang L, editors. Primary Care in Ontario: ICES Atlas. Toronto: Institute for Clinical Evaluative Sciences.* 2006.

41.   Amaria K, Stinson J, Cullen-Dean G, Sappleton K, Kaufman M. Tools for addressing systems issues in transition. *Healthcare quarterly (Toronto, Ont).* 2011;14 Spec No 3:72-76.

42.   McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford, England).* 2007;46(1):161-168.

43.   Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics.* 2005;115(1):112-120.

44.   Shaw TM, DeLaet DE. Transition of adolescents to young adulthood for vulnerable populations. *Pediatrics in Review.* 2010;31(12):497-505.

45.   Tucker LB, Cabral DA. Transition of the adolescent patient with rheumatic disease: issues to consider. *Rheumatic diseases clinics of North America.* 2007;33(3):661-672.

46.   Wong LH, Chan FW, Wong FY, et al. Transition care for adolescents and families with chronic illnesses. *J Adolesc Health.* 2010;47(6):540-546.

47.   Blinder MA, Vekeman F, Sasane M, Trahey A, Paley C, Duh MS. Age-related treatment patterns in sickle cell disease patients and the associated sickle cell complications and healthcare costs. *Pediatr Blood Cancer.* 2013;60(5):828-835.

48.   Heery E, Sheehan AM, While AE, Coyne I. Experiences and Outcomes of Transition from Pediatric to Adult Health Care Services for Young People with Congenital Heart Disease: A Systematic Review. *Congenit Heart Dis.* 2015;10(5):413-427.

49.   Nakhla M, Daneman D, To T, Paradis G, Guttmann A. Transition to adult care for youths with diabetes mellitus: findings from a Universal Health Care System. *Pediatrics.* 2009;124(6):e1134-1141.

50.   Samuel SM, Nettel-Aguirre A, Hemmelgarn BR, et al. Graft failure and adaptation period to adult healthcare centers in pediatric renal transplant patients. *Transplantation.* 2011;91(12):1380-1385.

51.   Annunziato RA, Emre S, Shneider B, Barton C, Dugan CA, Shemesh E. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatr Transplant.* 2007;11(6):608-614.

52.   Nakhla MM, Daneman D. Transitions in the care of children and youth with Type 1 diabetes. *Diabetes Management.* 2012;2(6):537-547.

53.   Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics.* 2004;113(3 Pt 1):e197-205.

54.   Tomlinson P, Sugarman ID. Complications with shunts in adults with spina bifida. *BMJ (Clinical research ed).* 1995;311(7000):286-287.

55.   Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. *Pediatric nephrology (Berlin, Germany).* 2000;14(6):469-472.

56.   Hepburn CM, Cohen E, Bhawra J, Weiser N, Hayeems RZ, Guttmann A. Health system strategies supporting transition to adult care. *Arch Dis Child.* 2015;100(6):559-564.

57.   Kennedy A, Sawyer S. Transition from pediatric to adult services: are we getting it right? *Curr Opin Pediatr.* 2008;20(4):403-409.

58.   Rapley P, Davidson PM. Enough of the problem: a review of time for health care transition solutions for young adults with a chronic illness. *Journal of clinical nursing.* 2010;19(3-4):313-323.

59.   McQuillan RF, Toulany A, Kaufman M, Schiff JR. Benefits of a transfer clinic in adolescent and young adult kidney transplant patients. *Canadian journal of kidney health and disease.* 2015;2:45.

60.   Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: A systematic review. *Arch Dis Child.* 2011;96(6):548-553.

61.   Callahan ST, Winitzer RF, Keenan P. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. *Curr Opin Pediatr.* 2001;13(4):310-316.

62.   Bhawra J, Toulany A, Cohen E, Moore Hepburn C, Guttmann A. Primary care interventions to improve transition of youth with chronic health conditions from paediatric to adult healthcare: a systematic review. *BMJ Open.* 2016;6(5):e011871.

63.   Tylee A, Haller DM, Graham T, Churchill R, Sanci LA. Youth-friendly primary-care services: how are we doing and what more needs to be done? *Lancet.* 2007;369(9572):1565-1573.

64.   Dadich A, Jarrett C, Robards F, Bennett D. Enhancing youth health in primary care: lessons learned from general practitioners. *Health communication.* 2014;29(6):619-628.

65.   O'Brien D, Harvey K, Howse J, Reardon T, Creswell C. Barriers to managing child and adolescent mental health problems: a systematic review of primary care practitioners' perceptions. *Br J Gen Pract.* 2016;66(651):e693-707.

66.   Randall, G. E., Mulvale, G. M., Wakefield, P. A., Embrett, M. G., Barr, N. G., Miatello, A. M., Longo, C. J., Nguyen, T. D., Di Rezze, B. M., Vania, D. K., & McRae, S. A. (2016). Mapping the policy to practicelandscape for youth mental health in Ontario: A report from the "youth to adult transitions in health care – the case of mental health

services in Ontario" research team. McMaster University: Hamilton, Ontario, Canada., Statistics.

67. Singh SP, Paul M, Ford T, et al. Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. *Br J Psychiatry.* 2010;197(4):305-312.

68. Lamb C, Murphy M. The divide between child and adult mental health services: points for debate. *The British journal of psychiatry Supplement.* 2013;54:s41-44.

69. Rutter M, Kim-Cohen J, Maughan B. Continuities and discontinuities in psychopathology between childhood and adult life. *J Child Psychol Psychiatry.* 2006;47(3-4):276-295.

70. EJ C, S M, A E, al e. Prevalence and development of psychiatric disorders in childhood and adolescence. *Arch Gen Psychiatry.* 2003;60:837-844.

71. Patton GC, Coffey C, Romaniuk H, et al. The prognosis of common mental disorders in adolescents: a 14-year prospective cohort study. *Lancet.* 2014.

72. Mulvale GM, Nguyen TD, Miatello AM, Embrett MG, Wakefield PA, Randall GE. Lost in transition or translation? Care philosophies and transitions between child and youth and adult mental health services: a systematic review. *Journal of mental health (Abingdon, England).* 2016:1-10.

73. Davis M, Sondheimer DL. State child mental health efforts to support youth in transition to adulthood. *J Behav Health Serv Res.* 2005;32(1):27-42.

74. Ministry of Children and Youth Services: Ontario's Policy Framework for Child and Youth Mental Health. A Shared Responsibility. Queen's Printer for Ontario. 2006.

75. *Ministry of Child and Youth Services. Draft Child and Youth Mental Health Service Framework.* 2013.

76. *Office of the Provincial Advocate for Children and Youth for Ontario. Statement on Child and Youth Mental Health in Ontario. Report.* 2011.

77. Melissa A. Vloet SD, Mario C. "We Suffer from Being Lost"*: Formulating Policies to Reclaim Youth in Mental Health Transitions. *Healthcare Quarterly.* 2011;14(Special Issue 2):32-38.

78. McGorry P, Purcell R. Youth mental health reform and early intervention: encouraging early signs. *Early Interv Psychiatry.* 2009;3(3):161-162.

79. McGorry P, Bates T, Birchwood M. Designing youth mental health services for the 21st century: examples from Australia, Ireland and the UK. *The British journal of psychiatry Supplement.* 2013;54:s30-35.

80. Paul M, Street C, Wheeler N, Singh SP. Transition to adult services for young people with mental health needs: A systematic review. *Clin Child Psychol Psychiatry.* 2015;20(3):436-457.

81. Embrett MG, Randall GE, Longo CJ, Nguyen T, Mulvale G. Effectiveness of Health System Services and Programs for Youth to Adult Transitions in Mental Health Care: A Systematic Review of Academic Literature. *Adm Policy Ment Health.* 2016;43(2):259-269.

82. Di Rezze B, Nguyen T, Mulvale G, Barr NG, Longo CJ, Randall GE. A scoping review of evaluated interventions addressing developmental transitions for youth with mental health disorders. *Child Care Health Dev.* 2016;42(2):176-187.

83. Barr NG, Longo CJ, Embrett MG, Mulvale GM, Nguyen T, Randall GE. The transition from youth to adult mental health services and the economic impact on youth and their families. *Healthcare management forum.* 2017;30(6):283-288.

84.   Vander Stoep A. Transition to adulthood for adolescents with psychiatric disorder. *Dissertation Abstracts International: Section B: The Sciences and Engineering.* 1998;58(12-B):6482.

85.   Vander Stoep A, Beresford SA, Weiss NS, McKnight B, Cauce AM, Cohen P. Community-based study of the transition to adulthood for adolescents with psychiatric disorder. *Am J Epidemiol.* 2000;152(4):352-362.

86.   Davis M, Vander Stoep A. The transition to adulthood for youth who have serious emotional disturbance: Developmental transition and young adult outcomes. *Journal of Mental Health Administration.* 1997;24(4):400-427.

87.   Health Canada. *A Report on Mental Illness in Canada.* October 31, 2013 2002.

88.   Gulliver A, Griffiths KM, Christensen H. Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry.* 2010;10:113.

89.   Pottick KJ, Bilder S, Vander Stoep A, Warner LA, Alvarez MF. US patterns of mental health service utilization for transition-age youth and young adults. *J Behav Health Serv Res.* 2008;35(4):373-389.

90.   Kessler RC, Demler O, Frank RG, et al. Prevalence and treatment of mental disorders, 1990 to 2003. *The New England journal of medicine.* 2005;352(24):2515-2523.

91.   Bachrach LL. Continuity of care for chronic mental patients: a conceptual analysis. *Am J Psychiatry.* 1981;138(11):1449-1456.

92.   Breslau N, Haug MR. Service delivery structure and continuity of care: a case study of a pediatric practice in process of reorganization. *J Health Soc Behav.* 1976;17(4):339-352.

93.   Wei X, Barnsley J, Zakus D, Cockerill R, Glazier R, Sun X. Evaluation of a diabetes management program in China demonstrated association of improved continuity of care with clinical outcomes. *Journal of clinical epidemiology.* 2008;61(9):932-939.

94.   Joyce AS, Wild TC, Adair CE, et al. Continuity of care in mental health services: toward clarifying the construct. *Can J Psychiatry.* 2004;49(8):539-550.

95.   Starfield B. *Primary care: balancing health needs, services and technology.* 2nd ed. New York, NY: Oxford University Press; 1998.

96.   Crawford MJ, de Jonge E, Freeman GK, Weaver T. Providing continuity of care for people with severe mental illness- a narrative review. *Soc Psychiatry Psychiatr Epidemiol.* 2004;39(4):265-272.

97.   Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *BMJ (Clinical research ed).* 2003;327(7425):1219-1221.

98.   Adair CE, McDougall GM, Mitton CR, et al. Continuity of care and health outcomes among persons with severe mental illness. *Psychiatr Serv.* 2005;56(9):1061-1069.

99.   Bindman J, Johnson S, Wright S, et al. Integration between primary and secondary services in the care of the severely mentally ill: patients' and general practitioners' views. *Br J Psychiatry.* 1997;171:169-174.

100.   Adair CE, McDougall GM, Beckie A, et al. History and measurement of continuity of care in mental health services and evidence of its role in outcomes. *Psychiatr Serv.* 2003;54(10):1351-1356.

101.   Sytema S, Micciolo R, Tansella M. Continuity of care for patients with schizophrenia and related disorders: a comparative south-Verona and Groningen case-register study. *Psychol Med.* 1997;27(6):1355-1362.

102. Stephen Puntis, Jorun Rugkåsa, Alexandra Forrest, Amy Mitchell, Tom Burns. Associations Between Continuity of Care and Patient Outcomes in Mental Health Care: A Systematic Review. *Psychiatr Serv.* 2015;66(4):354-363.

103. Christakis DA, Wright JA, Koepsell TD, Emerson S, Connell FA. Is greater continuity of care associated with less emergency department utilization? *Pediatrics.* 1999;103(4 Pt 1):738-742.

104. Lehman AF, Postrado LT, Roth D, McNary SW, Goldman HH. Continuity of care and client outcomes in the Robert Wood Johnson Foundation program on chronic mental illness. *The Milbank quarterly.* 1994;72(1):105-122.

105. Olfson M, Mechanic D, Boyer CA, Hansell S. Linking inpatients with schizophrenia to outpatient care. *Psychiatr Serv.* 1998;49(7):911-917.

106. Sytema S, Burgess P. Continuity of care and readmission in two service systems: a comparative Victorian and Groningen case-register study. *Acta Psychiatr Scand.* 1999;100(3):212-219.

107. Sytema S, Burgess P, Tansella M. Does community care decrease length of stay and risk of rehospitalization in new patients with schizophrenia disorders? A comparative case register study in Groningen, The Netherlands; Victoria, Australia; and South-Verona, Italy. *Schizophr Bull.* 2002;28(2):273-281.

108. Chien CF, Steinwachs DM, Lehman A, Fahey M, Skinner EA. Provider Continuity and Outcomes of Care for Persons with Schizophrenia. *Mental health services research.* 2000;2(4):201-211.

109. Mitchell G, Del Mar C, Francis D. Does primary medical practitioner involvement with a specialist team improve patient outcomes? A systematic review. *Br J Gen Pract.* 2002;52(484):934-939.

110. Guttmann A, Manuel D, Dick PT, To T, Lam K, Stukel TA. Volume matters: Physician practice characteristics and immunization coverage among young children insured through a universal health plan. *Pediatrics.* 2006;117(3):595-602.

111. O'Malley AS. Current evidence on the impact of continuity of care. *Curr Opin Pediatr.* 2004;16(6):693-699.

112. Christakis DA, Mell L, Koepsell TD, Zimmerman FJ, Connell FA. Association of lower continuity of care with greater risk of emergency department use and hospitalization in children. *Pediatrics.* 2001;107(3):524-529.

113. Christakis DA, Wright JA, Zimmerman FJ, Bassett AL, Connell FA. Continuity of care is associated with well-coordinated care. *Ambulatory pediatrics : the official journal of the Ambulatory Pediatric Association.* 2003;3(2):82-86.

114. Christakis DA, Wright JA, Zimmerman FJ, Bassett AL, Connell FA. Continuity of care is associated with high-quality careby parental report. *Pediatrics.* 2002;109(4):e54.

115. Brousseau DC, Meurer JR, Isenberg ML, Kuhn EM, Gorelick MH. Association between infant continuity of care and pediatric emergency department utilization. *Pediatrics.* 2004;113(4):738-741.

116. McBurney PG, Simpson KN, Darden PM. Potential cost savings of decreased emergency department visits through increased continuity in a pediatric medical home. *Ambulatory pediatrics : the official journal of the Ambulatory Pediatric Association.* 2004;4(3):204-208.

117. Becker MH, Drachman RH, Kirscht JP. A field experiment to evaluate various outcomes of continuity of physician care. *Am J Public Health.* 1974;64(11):1062-1070.

118. Breslau N. Continuity reexamined: differential impact on satisfaction with medical care for disabled and normal children. *Medical care.* 1982;20(4):347-360.
119. Kipps S, Bahu T, Ong K, et al. Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabet Med.* 2002;19(8):649-654.
120. Glazier RH, Klein-Geltink J, Kopp A, Sibley LM. Capitation and enhanced fee-for-service models for primary care reform: a population-based evaluation. *CMAJ Canadian Medical Association Journal.* 2009;180(11):E72-81.
121. Hutchison B, Glazier R. Ontario's primary care reforms have transformed the local care landscape, but a plan is needed for ongoing improvement. *Health affairs (Project Hope).* 2013;32(4):695-703.
122. de Girolamo G, Dagani J, Purcell R, Cocchi A, McGorry PD. Age of onset of mental disorders and use of mental health services: needs, opportunities and obstacles. *Epidemiol Psychiatr Sci.* 2012;21(1):47-57.
123. Paul M, Ford T, Kramer T, Islam Z, Harley K, Singh SP. Transfers and transitions between child and adult mental health services. *British Journal of Psychiatry - Supplementum.* 2013;54:s36-40.
124. Juurlink D, Preyra C, Croxford R, et al. Canadian Institute for Health Information Discharge Abstract Database: A Validation Study. Toronto: Institute for Clinical Evaluative Sciences. 2006.
125. *CIHI Data Quality Study of Ontario Emergency Department Visits for Fiscal Year 2004-2005- Executive Summary. Ottawa.* 2008.
126. Steele LS, Glazier RH, Lin E, Evans M. Using administrative data to measure ambulatory mental health service provision in primary care. *Medical care.* 2004;42(10):960-965.
127. Guttmann A, Klein-Geltink, J., Kopp, A., Cairney, J. Uptake of the New Fee Code for Ontario's Enhanced 18-Month Well Baby Visit: A Preliminary Evaluation. Toronto: Institute for Clinical Evaluative Sciences; 2011.
128. O'Brien R. A caution regarding rules of thumb for variance inflation factors. *Qual Quant.* 2007;41:673-690.
129. Bradford DW, Kim MM, Braxton LE, Marx CE, Butterfield M, Elbogen EB. Access to medical care among persons with psychotic and major affective disorders. *Psychiatr Serv.* 2008;59(8):847-852.
130. Ross LE, Vigod S, Wishart J, et al. Barriers and facilitators to primary care for people with mental health and/or substance use issues: a qualitative study. *BMC Family Practice.* 2015;16:135.
131. Vigod SN, Kurdyak PA, Stewart DE, Gnam WH, Goering PN. Depressive symptoms as a determinant of breast and cervical cancer screening in women: a population-based study in Ontario, Canada. *Arch Womens Ment Health.* 2011;14(2):159-168.
132. Benjamin-Johnson R, Moore A, Gilmore J, Watkins K. Access to medical care, use of preventive services, and chronic conditions among adults in substance abuse treatment. *Psychiatr Serv.* 2009;60(12):1676-1679.
133. Newcomer JW, Hennekens CH. Severe mental illness and risk of cardiovascular disease. *JAMA : the journal of the American Medical Association.* 2007;298(15):1794-1796.
134. Kurdyak P, Vigod S, Calzavara A, Wodchis WP. High mortality and low access to care following incident acute myocardial infarction in individuals with schizophrenia. *Schizophr Res.* 2012;142(1-3):52-57.

135. McPherson A. Adolescents in primary care. *BMJ (Clinical research ed).* 2005;330:465-467.
136. Sanci LA, Sawyer SM, Kang MS, Haller DM, Patton GC. Confidential health care for adolescents: reconciling clinical evidence with family values. *Med J Aust.* 2005;183(8):410-414.
137. Booth ML, Bernard D, Quine S, et al. Access to health care among Australian adolescents young people's perspectives and their sociodemographic distribution. *J Adolesc Health.* 2004;34(1):97-103.
138. Ford CA, Millstein SG, Halpern-Felsher BL, Irwin CE, Jr. Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. A randomized controlled trial. *JAMA : the journal of the American Medical Association.* 1997;278(12):1029-1034.
139. Kari J, Donovan C, Li J, Taylor B. Adolescents' attitudes to general practice in north London. *Br J Gen Pract.* 1997;47(415):109-110.
140. Elliott BA, Larson JT. Adolescents in mid-sized and rural communities: foregone care, perceived barriers, and risk factors. *J Adolesc Health.* 2004;35(4):303-309.
141. Klein JD, McNulty M, Flatau CN. Adolescents' access to care: teenagers' self-reported use of services and perceived access to confidential care. *Arch Pediatr Adolesc Med.* 1998;152(7):676-682.
142. Zimmer-Gembeck MJ, Alexander T, Nystrom RJ. Adolescents report their need for and use of health care services. *J Adolesc Health.* 1997;21(6):388-399.
143. Churchill R, Allen J, Denman S, Williams D, Fielding K, von Fragstein M. Do the attitudes and beliefs of young teenagers towards general practice influence actual consultation behaviour? *Br J Gen Pract.* 2000;50(461):953-957.
144. Boldero J, Fallon B. Adolescent help-seeking: what do they get help for and from whom? *J Adolesc.* 1995;18(2):193-209.
145. Donovan C, Mellanby AR, Jacobson LD, Taylor B, Tripp JH. Teenagers' views on the general practice consultation and provision of contraception. The Adolescent Working Group. *Br J Gen Pract.* 1997;47(424):715-718.
146. Access to health care for adolescents and young adults. *J Adolesc Health.* 2004;35(4):342-344.
147. WHO. Adolescent friendly health services: an agenda for change. Geneva: WHO, 2002.
148. Bailey S. Bridging the Gaps: Health Care for Adolescents. *Council Report CR114, June 2003, Royal College of Paediatrics and Child Health, £10, 60 pp.* 2003;27(10):397-397.
149. Pinzon JL, Jacobson K, Reiss J. Say goodbye and say hello: the transition from pediatric to adult gastroenterology. *Can J Gastroenterol.* 2004;18(12):735-742.
150. Eleftheriou D, Isenberg DA, Wedderburn LR, Ioannou Y. The coming of age of adolescent rheumatology. *Nature reviews Rheumatology.* 2014;10(3):187-193.
151. Lyons SK, Libman IM, Sperling MA. Clinical review: Diabetes in the adolescent: transitional issues. *The Journal of clinical endocrinology and metabolism.* 2013;98(12):4639-4645.
152. Young S, Murphy CM, Coghill D. Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry.* 2011;11:174.

153. Sawicki GS, Ostrenga J, Petren K, et al. Risk Factors for Gaps in Care during Transfer from Pediatric to Adult Cystic Fibrosis Programs in the United States. *Annals of the American Thoracic Society.* 2017.

154. Gray WN, Schaefer MR, Resmini-Rawlinson A, Wagoner ST. Barriers to Transition From Pediatric to Adult Care: A Systematic Review. *J Pediatr Psychol.* 2017.

155. Campbell F, Biggs K, Aldiss SK, et al. Transition of care for adolescents from paediatric services to adult health services. *The Cochrane database of systematic reviews.* 2016;4:Cd009794.

156. MHASEF Research Team. The Mental Health of Children and Youth in Ontario: 2017 Scorecard.Toronto, ON: Institute for Clinical Evaluative Sciences; 2017.

157. Gandhi S, Chiu M, Lam K, Cairney JC, Guttmann A, Kurdyak P. Mental Health Service Use Among Children and Youth in Ontario: Population-Based Trends Over Time. *Can J Psychiatry.* 2016;61(2):119-124.

158. Kurdyak P, Stukel TA, Goldbloom D, Kopp A, Zagorski BM, Mulsant BH. Universal coverage without universal access: a study of psychiatrist supply and practice patterns in Ontario. *Open medicine : a peer-reviewed, independent, open-access journal.* 2014;8(3):e87-99.

159. Emsley R, Chiliza B, Asmal L, Harvey BH. The nature of relapse in schizophrenia. *BMC Psychiatry.* 2013;13(1):50.

160. Cohen E, Gandhi S, Toulany A, et al. Health Care Use During Transfer to Adult Care Among Youth With Chronic Conditions. *Pediatrics.* 2016;137(3):e20152734.

161. Geller J, Drab DL. The readiness and motivation interview: a symptom-specific measure of readiness for change in the eating disorders. *Eur.* 1999;7(4):259-278.

162. Dimitropoulos G, Tran AF, Agarwal P, Sheffield B, Woodside B. Navigating the transition from pediatric to adult eating disorder programs: perspectives of service providers. *Int J Eat Disord.* 2012;45(6):759-767.

163. Fisher M. The course and outcome of eating disorders in adults and in adolescents: a review. *Adolescent medicine (Philadelphia, Pa).* 2003;14(1):149-158.

164. Dimitropoulos G, Tran AF, Agarwal P, Sheffield B, Woodside B. Challenges in making the transition between pediatric and adult eating disorder programs: a qualitative study from the perspective of service providers. *Eat.* 2013;21(1):1-15.

165. Zwaanswijk M, Van der Ende J, Verhaak PF, Bensing JM, Verhulst FC. Factors associated with adolescent mental health service need and utilization. *J Am Acad Child Adolesc Psychiatry.* 2003;42(6):692-700.

166. American Academy of P, American Academy of Family P, American College of P, Transitions Clinical Report Authoring G, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics.* 2011;128(1):182-200.

167. Canada. S. 2003 Youth in Transition Survey (YITS), Cohort A. http://www.univcan.ca/universities/facts-and-stats/. Accessed December 12, 2016.

168. Canada. S. Postsecondary Student information System, 2012. Available at: http://www.statcan.gc.ca/pub/81-004-x/2007002/9989-eng.htm. Accessed December 12, 2016.

169. Offord DR, Boyle MH, Fleming JE. Ontario Child Health Study. Summary of selected results. *Can J Psychiatry.* 1989;34(6):483-491.

170.   Myers KM, Valentine JM, Melzer SM. Child and adolescent telepsychiatry: utilization and satisfaction. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association.* 2008;14(2):131-137.

8.0   Appendices

Appendix A

Diagnostic codes used to identify the cohort with severe mental illness

Condition	DSM-IV	DSM-IV description (OMHRS)	ICD-10	ICD-10 description (DAD/NACRS)
Schizophrenia, delusional and non-organic psychotic disorders	295.10	Schizophrenia, disorganized type	F20	Schizophrenia (excluding F20.4: Post-schizophrenic depression)
	295.20	Schizophrenia, catatonic type	F22	Persistent delusional disorders
	295.30	Schizophrenia, paranoid type	F23	Acute and transient psychotic disorders
	295.40	Schizophreniform disorder	F24	Induced delusional disorder
	295.60	Schizophrenia, residual type	F25	Schizoaffective disorders
	295.70	Schizoaffective disorder	F28	Other nonorganic psychotic disorders
	295.90	Schizophrenia, undifferentiated type	F29	Unspecified nonorganic psychosis
	297.10	Delusional disorder		
	297.30	Shared psychotic disorder		
	298.80	Brief psychotic disorder		
	298.90	Psychotic disorder NOS		
Eating disorders	307.10	Anorexia Nervosa	F50.0	Anorexia nervosa
	307.51	Bulimia Nervosa	F50.1	Atypical anorexia nervosa
	307.50	Eating Disorder NOS	F50.2	Bulimia nervosa
			F50.3	Atypical bulimia nervosa
			F50.8	Other eating disorders
			F50.9	Eating disorder, unspecified
Mood and affective disorders	293.83	Mood disorder due to general medical condition	F30	Manic episode
	296.0x	Bipolar I disorder, single manic episode	F31	Bipolar affective disorder
	296.2x	Major depressive disorder, single episode	F32	Depressive episode
	296.3x	Major depressive disorder, recurrent	F33	Recurrent depressive disorder

296.4x	Bipolar I disorder, most recent episode manic	F34	Persistent mood [affective] disorders
296.5x	Bipolar I disorder, most recent episode depressed	F39	Unspecified mood [affective] disorder
296.6x	Bipolar I disorder, most recent episode mixed		
296.70	Bipolar I disorder, most recent episode unspecified		
296.80	Bipolar disorder NOS		
296.89	Bipolar II disorder		
296.90	Mood disorder NOS		
300.40	Dysthymic disorder		
301.13	Cyclothymic disorder		

Appendix B

Figure 3: Creation of the youth with severe mental illness cohort

709,384 patients born between April 1, 1990 and
March 31, 1993 in Ontario, Canada

Exclusions

706,088 no history of mental health admission

96 non-continuous Ontario residency anytime
between age 12 and 19

17 died before age 19

Study population analyzed

3,183 hospitalized with schizophrenia/delusional/non-organic psychotic disorder, eating
disorder, or mood/affective disorder

Appendix C

Stepwise nesting of Poisson regression models for outcome mental health-related admissions after transition (age 19-23) according to pattern of primary care during transition

Step 1: Addition of sex				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	1.06 (0.91, 1.25)	0.451	1.05 (0.89, 1.23)	0.564
No PC provider	0.92 (0.66, 1.28)	0.624	0.86 (0.62, 1.19)	0.366
Same PC provider	Reference		Reference	
Sex				
Female	0.77 (0.66, 0.89)	0.001	0.76 (0.65, 0.89)	<0.001
Male	Reference		Reference	

Step 2: Addition of rural residence and income quintile				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	1.06 (0.91, 1.25)	0.451	1.04 (0.88, 1.22)	0.653
No PC provider	0.92 (0.66, 1.28)	0.624	0.86 (0.62, 1.19)	0.364
Same PC provider	Reference		Reference	
Sex				
Female	0.77 (0.66, 0.89)	0.001	0.77 (0.66, 0.90)	<0.001
Male	Reference		Reference	
Rural				
Yes	0.81 (0.64, 1.04)	0.103	0.79 (0.62, 1.01)	0.055
No	Reference		Reference	
Income Quintile				
1 (lowest)	1.80 (1.43, 2.27)	<0.001	1.80 (1.43, 2.26)	<0.001
2	1.30 (1.02, 1.66)	0.036	1.29 (1.01, 1.65)	0.041
3	0.99 (0.76, 1.30)	0.954	0.99 (0.75, 1.29)	0.920
4	1.75 (1.39, 2.20)	<0.001	1.75 (1.39, 2.20)	<0.001
5 (highest)	Reference		Reference	

Step 3: Addition of type of mental illness

Variable	Unadjusted RR (95% CI)	p-value	Adjusted* RR (95% CI)	p-value
Pattern of primary care (PC) during transition				
Different PC provider	1.06 (0.91, 1.25)	0.451	0.98 (0.84, 1.15)	0.794
No PC provider	0.92 (0.66, 1.28)	0.624	0.82 (0.59, 1.13)	0.217
Same PC provider	Reference		Reference	
Sex				
Female	0.77 (0.66, 0.89)	0.001	0.97 (0.82, 1.13)	0.670
Male	Reference		Reference	
Rural				
Yes	0.81 (0.64, 1.04)	0.103	0.80 (0.63, 1.02)	0.069
No	Reference		Reference	
Income Quintile				
1 (lowest)	1.80 (1.43, 2.27)	<0.001	1.53 (1.22, 1.93)	<0.001
2	1.30 (1.02, 1.66)	0.036	1.18 (0.93, 1.50)	0.176
3	0.99 (0.76, 1.30)	0.954	0.90 (0.69, 1.17)	0.446
4	1.75 (1.39, 2.20)	<0.001	1.55 (1.24, 1.94)	<0.001
5 (highest)	Reference		Reference	
Type of mental illness				
SZ alone	3.06 (2.51, 3.74)	<0.001	2.91 (2.36, 3.59)	<0.001
SZ & MAD	3.18 (2.50, 4.06)	<0.001	3.07 (2.41, 3.91)	<0.001
ED alone	0.47 (0.34, 0.66)	<0.001	0.49 (0.35, 0.69)	<0.001
ED & MAD	1.39 (1.05, 1.85)	0.023	1.42 (1.06, 1.89)	0.018
MAD alone	Reference		Reference	

abbreviations: SZ: schizophrenia/delusional/non-organic psychotic disorder, ED: eating disorder, MAD: mood/affective disorders

Step 4: Addition of mental health admission before transition (age 12-17)

Variable	Unadjusted RR (95% CI)	p-value	Adjusted* RR (95% CI)	p-value
Pattern of primary care (PC) during transition				
Different PC provider	1.06 (0.91, 1.25)	0.451	0.95 (0.82, 1.11)	0.522
No PC provider	0.92 (0.66, 1.28)	0.624	0.87 (0.64, 1.19)	0.374
Same PC provider	Reference		Reference	
Sex				
Female	0.77 (0.66, 0.89)	0.001	0.99 (0.85, 1.16)	0.948
Male	Reference		Reference	
Rural				
Yes	0.81 (0.64, 1.04)	0.103	0.82 (0.65, 1.03)	0.094
No	Reference		Reference	
Income Quintile				
1 (lowest)	1.80 (1.43, 2.27)	<0.001	1.43 (1.15, 1.78)	0.001
2	1.30 (1.02, 1.66)	0.036	1.15 (0.91, 1.46)	0.229
3	0.99 (0.76, 1.30)	0.954	0.87 (0.68, 1.13)	0.295
4	1.75 (1.39, 2.20)	<0.001	1.49 (1.20, 1.85)	<0.001
5 (highest)	Reference		Reference	
Type of mental illness				
SZ alone	3.06 (2.51, 3.74)	<0.001	2.63 (2.14, 3.24)	<0.001
SZ & MAD	3.18 (2.50, 4.06)	<0.001	1.77 (1.38, 2.25)	<0.001
ED alone	0.47 (0.34, 0.66)	<0.001	0.57 (0.41, 0.79)	<0.001
ED & MAD	1.39 (1.05, 1.85)	0.023	1.00 (0.75, 1.32)	0.986
MAD alone	Reference		Reference	
Mental health admissions before transition (12-17 y)				
1	1.49 (1.22, 1.81)	<0.001	1.36 (1.13, 1.65)	0.001
2	2.37 (1.90, 2.96)	<0.001	2.16 (1.73, 2.68)	<0.001
≥3	4.96 (4.16, 5.90)	<0.001	4.04 (3.38, 4.84)	<0.001
None	Reference		Reference	

abbreviations: SZ: schizophrenia/delusional/non-organic psychotic disorder, ED: eating disorder, MAD: mood/affective disorders

Step 5: Addition of mental health admission during transition (age 17-19)

Variable	Unadjusted RR (95% CI)	p-value	Adjusted* RR (95% CI)	p-value
Pattern of primary care (PC) during transition				
Different PC provider	1.06 (0.91, 1.25)	0.451	0.97 (0.85, 1.12)	0.725
No PC provider	0.92 (0.66, 1.28)	0.624	1.08 (0.80, 1.45)	0.628
Same PC provider	Reference		Reference	
Sex				
Female	0.77 (0.66, 0.89)	0.001	0.99 (0.86, 1.15)	0.915
Male	Reference		Reference	
Rural				
Yes	0.81 (0.64, 1.04)	0.103	0.87 (0.70, 1.08)	0.199
No	Reference		Reference	
Income Quintile				
1 (lowest)	1.80 (1.43, 2.27)	<0.001	1.40 (1.14, 1.73)	0.001
2	1.30 (1.02, 1.66)	0.036	1.22 (0.98, 1.52)	0.074
3	0.99 (0.76, 1.30)	0.954	0.86 (0.68, 1.09)	0.216
4	1.75 (1.39, 2.20)	<0.001	1.40 (1.14, 1.72)	0.001
5 (highest)	Reference		Reference	
Type of mental illness				
SZ alone	3.06 (2.51, 3.74)	<0.001	1.88 (1.54, 2.30)	<0.001
SZ & MAD	3.18 (2.50, 4.06)	<0.001	1.31 (1.04, 1.66)	0.021
ED alone	0.47 (0.34, 0.66)	<0.001	0.66 (0.49, 0.90)	0.008
ED & MAD	1.39 (1.05, 1.85)	0.023	0.96 (0.74, 1.25)	0.769
MAD alone	Reference		Reference	
Mental health admissions before transition (12-17 y)				
1	1.49 (1.22, 1.81)	<0.001	1.24 (1.04, 1.49)	0.018
2	2.37 (1.90, 2.96)	<0.001	1.65 (1.34, 2.03)	<0.001
≥3	4.96 (4.16, 5.90)	<0.001	2.34 (1.95, 2.80)	<0.001
None	Reference		Reference	
Mental health admissions during transition (17-19 y)				
1	4.90 (4.16, 5.77)	<0.001	3.91 (3.32, 4.60)	<0.001
2	5.11 (4.07, 6.43)	<0.001	3.62 (2.87, 4.56)	<0.001
≥3	9.77 (8.17, 11.68)	<0.001	5.70 (4.69, 6.92)	<0.001
None	Reference		Reference	

abbreviations: SZ: schizophrenia/delusional/non-organic psychotic disorder, ED: eating disorder, MAD: mood/affective disorders

Step 6: Addition of mental health visits by specialty during transition (age 17-19)

Variable	Unadjusted RR (95% CI)	p-value	Adjusted* RR (95% CI)	p-value
Pattern of primary care (PC) during transition				
Different PC provider	1.06 (0.91, 1.25)	0.451	1.02 (0.88, 1.17)	0.826
No PC provider	0.92 (0.66, 1.28)	0.624	1.52 (1.12, 2.05)	0.006
Same PC provider	Reference		Reference	
Sex				
Female	0.77 (0.66, 0.89)	<0.001	1.02 (0.88, 1.18)	0.797
Male	Reference		Reference	
Rural				
Yes	0.81 (0.64, 1.04)	0.103	0.93 (0.75, 1.16)	0.513
No	Reference		Reference	
Income Quintile				
1 (lowest)	1.80 (1.43, 2.27)	<0.001	1.47 (1.20, 1.81)	<0.001
2	1.30 (1.02, 1.66)	0.036	1.24 (1.00, 1.55)	0.048
3	0.99 (0.76, 1.30)	0.954	0.90 (0.71, 1.14)	0.391
4	1.75 (1.39, 2.20)	<0.001	1.43 (1.17, 1.75)	<0.001
5 (highest)	Reference		Reference	
Type of mental illness				
SZ alone	3.06 (2.51, 3.74)	<0.001	1.78 (1.46, 2.16)	<0.001
SZ & MAD	3.18 (2.50, 4.06)	<0.001	1.22 (0.97, 1.54)	0.086
ED alone	0.47 (0.34, 0.66)	<0.001	0.68 (0.50, 0.92)	0.013
ED & MAD	1.39 (1.05, 1.85)	0.023	0.90 (0.69, 1.17)	0.428
MAD alone	Reference		Reference	
Mental health admissions before transition (12-17 y)				
1	1.49 (1.22, 1.81)	<0.001	1.21 (1.01, 1.44)	0.046
2	2.37 (1.90, 2.96)	<0.001	1.49 (1.21, 1.83)	<0.001
≥3	4.96 (4.16, 5.90)	<0.001	2.16 (1.81, 2.58)	<0.001
None	Reference		Reference	
Mental health admissions during transition (17-19 y)				
1	4.90 (4.17, 5.77)	<0.001	2.98 (2.52, 3.53)	<0.001
2	5.12 (4.07, 6.44)	<0.001	2.88 (2.28, 3.62)	<0.001
≥3	9.77 (8.17, 11.69)	<0.001	4.35 (3.58, 5.30)	<0.001
None	Reference		Reference	
Mental health visits by specialty during transition (17-19 y)				
Psychiatrist (any)	6.92 (5.24, 9.14)	<0.001	3.44 (2.62, 4.53)	<0.001
General Practitioner and/or Paediatrician	2.53 (1.84, 3.46)	<0.001	2.42 (1.79, 3.25)	<0.001
No mental health visits	Reference		Reference	

abbreviations: SZ: schizophrenia/delusional/non-organic psychotic disorder, ED: eating disorder, MAD: mood/affective disorders

Appendix D

Pattern of primary care continuity by mental health visits by specialty during the transition period (age 17-19), n=3183

Pattern of primary care (PC) during transition	Pattern of mental health visits by specialty during transition		
	GP/FP and/or Paed., n (%)	Psychiatrist (any), n (%)	None, n (%)
Different PC provider	216 (6.8%)	445 (14.0%)	280 (8.8%)
No PC provider	−	49 (1.5%)	137 (4.3%)
Same PC provider	671 (21.1%)	938 (29.5%)	443 (13.9%)

− N/A due to suppression of cell sizes under 6
abbreviations: GP/FP: general practitioner/family physician, Paed: paediatrician

Appendix E

Rate of mental health-related admissions (per person years) following transition (19-23 y) according to pattern of primary care and mental health visits by specialty during the transition period (17-19 y), n=3183

Pattern of primary care (PC) during transition	Rate of mental health admissions per person years		
	MH visits to GP/FP and/or Paed.	MH visits to Psychiatrist (any)	No MH visits
Different PC provider	0.18	0.39	0.05
No PC provider	0	0.44	0.11
Same PC provider	0.13	0.37	0.04

abbreviations: GP/FP: general practitioner/family physician, Paed.: paediatrician, MH: mental health

Appendix F: Subgroup analyses by disease category for outcome mental health-related admissions after transition (age 19-23) according to pattern of primary care during transition

Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related admission after transition to adult care (age 19-23) for youth with **schizophrenia°** according to pattern of primary care during transition, n=3183				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	1.35 (0.92, 1.98)	0.128	1.34 (0.92, 1.95)	0.126
No PC provider	1.41 (0.77, 2.59)	0.268	2.22 (1.18, 4.17)	0.014
Same PC provider	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, comorbid mood/affective disorder, mental health admissions before and during transition, and mental health visits by specialty during transition

°Schizophrenia/delusional/non-organic psychotic disorder

Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related admission after transition to adult care (age 19-23) for youth with **eating disorders** according to pattern of primary care during transition, n=3183				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	0.78 (0.50, 1.21)	0.266	0.64 (0.45, 0.91)	0.014
No PC provider	1.47 (0.66, 3.28)	0.342	5.25 (2.50, 11.01)	<0.001
Same PC provider	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, comorbid mood/affective disorder, mental health admissions before and during transition, and mental health visits by specialty during transition

Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related admission after transition to adult care (age 19-23) for youth with **mood/affective disorders** according to pattern of primary care during transition, n=3183				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	0.92 (0.77, 1.11)	0.406	0.93 (0.79, 1.10)	0.389
No PC provider	0.74 (0.50, 1.09)	0.128	1.45 (1.01, 2.08)	0.045
Same PC provider	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, mental health admissions before and during transition, and mental health visits by specialty during transition

Appendix G: Subgroup analyses by disease category for outcome mental health-related emergency department visits after transition (age 19-23) according to pattern of primary care during transition

Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related emergency department visits after transition to adult care (age 19-23) for youth with **schizophrenia°** according to pattern of primary care during transition, n=3183				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	1.09 (0.70, 1.69)	0.711	1.22 (0.78, 1.90)	0.385
No PC provider	1.45 (0.76, 2.78)	0.258	1.93 (0.94, 3.96)	0.072
Same PC provider	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, comorbid mood/affective disorder, mental health admissions before and during transition, and mental health visits by specialty during transition
°Schizophrenia/delusional/non-organic psychotic disorder

Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related emergency department visits after transition to adult care (age 19-23) for youth with **eating disorders** according to pattern of primary care during transition, n=3183				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	0.62 (0.40, 0.95)	0.027	0.58 (0.40, 0.84)	0.004
No PC provider	0.73 (0.27, 1.96)	0.538	1.64 (0.67, 4.00)	0.276
Same PC provider	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, comorbid mood/affective disorder, mental health admissions before and during transition, and mental health visits by specialty during transition

Unadjusted and adjusted Poisson regression with relative risk (RR) of mental health-related emergency department visits after transition to adult care (age 19-23) for youth with **mood/affective disorders** according to pattern of primary care during transition, n=3183				
Variable	**Unadjusted RR (95% CI)**	**p-value**	**Adjusted* RR (95% CI)**	**p-value**
Pattern of primary care (PC) during transition				
Different PC provider	1.16 (0.99, 1.35)	0.063	1.14 (0.98, 1.32)	0.098
No PC provider	0.91 (0.65, 1.26)	0.562	1.18 (0.85, 1.65)	0.324
Same PC provider	Reference		Reference	

*Adjusted for pattern of primary care during transition, sex, rurality, income quintile, mental health admissions before and during transition, and mental health visits by specialty during transition