Young People's Mental Health Service Use and Pathways to Care

Kathleen MacDonald
Department of Psychiatry, Faculty of Medicine
McGill University, Montreal
August 2021

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of

Doctor of Philosophy

Dedication

This thesis is dedicated to my parents, Richard and Francine, for their wonderful support.

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Abstract

Introduction

The majority of psychiatric conditions emerge before the age of 25, and mental illness is the largest contributor to burden of disease in young people. Still, many youth with mental health problems remain untreated, or face delayed detection, long waitlists and multiple help-seeking contacts before obtaining mental health services. Early access to appropriate care can minimise the negative outcomes associated with mental illnesses, yet many gaps remain in our understanding of how young people come to access mental health services. The overall objective of this thesis was to examine and understand young people's mental health service use and pathways to care across the continuum of mental health disorders, with a specific focus on youth involved in child welfare services.

Methods

Four studies were conducted. Study I, a systematic review, was conducted following PRISMA guidelines. Studies on pathways to mental health services for 11-30-year olds were identified through electronic databases searches. Study II, a qualitative meta-synthesis, was conducted to summarize the perspectives of youths and their carers on navigating mental health systems. Five electronic databases were searched using the same inclusion criteria as in Study I. Study III examined mental health service utilization and pathways to care for youth aged 11-18 during the period of their involvement with child welfare services in Montreal, Quebec. Data was collected retrospectively from medical charts. Logistic regression was conducted to compare patterns of service use, controlling for socio-demographic, childhood adversity, and placement variables. Study IV was an examination of trajectories to the Emergency Room, including reasons for and initiators of contact, for child welfare-involved youth. Building on data collected for Study III, this study used latent class analysis to distinguish trajectories to the ER based on pathway characteristics and Kaplan-Meier time-to-event curves to determine differences in recurrence of ER use based on trajectory type.

Results

Study I, our systematic review, included forty-five studies from 26 countries. Youths' pathways to mental healthcare were complex, involved diverse contacts, and, sometimes, undue treatment delays. Across contexts, families, general practitioners and ERs featured prominently in pathways. Study II synthesized 31 qualitative studies with recurring themes including the importance of mental health literacy, and the role of structural barriers and social support in finding help. Complex pathways, waitlists, eligibility criteria, and fragmented care were commonly cited issues. Study III demonstrated that youth involved in child welfare services had multiple contacts with mental health services. The predominant setting used for mental health care was the ER. High numbers of placements were the strongest predictor of using multiple mental health settings. Study IV established that youth with a history of sexual abuse, of parental mental illness, and of being placed outside of their family home, were more likely to receive mental health services from an ER. Further, three distinct trajectories to the ER were found. Of these, the trajectory with police as main initiators of contact with the ER, for substance use or externalizing behaviours, was least likely to result in a recurrent ER visit.

Conclusions

Our four projects confirm that across diagnoses, settings, and contexts, youth and carers have difficult experiences accessing mental health care. Multiple factors are pivotal in helping youth obtain services, especially familial support. For young people at heightened risk of mental illness, such as those involved with child welfare services, current practices are not meeting their needs and increased collaboration between service settings is crucial. Despite the importance of early, accessible outpatient care for young people, many youth end up at the ER for mental health concerns.

Résumé

Introduction

La majorité des problèmes de santé mentale se manifestent avant l'âge de 25 ans, et les troubles mentaux représentent les principales causes de morbidité et d'invalidité chez les adolescents. Pourtant, les problèmes de santé mentale des jeunes sont souvent détectés et traités tardivement. Alors que l'accès rapide à des soins appropriés peut minimiser les conséquences négatives associées aux troubles mentaux, les trajectoires individuelles des jeunes en recherche d'aide ne sont pas bien étudiées. L'objectif global de cette thèse était d'examiner l'utilisation de services en santé mentale des jeunes et les trajectoires pour s'y rendre, avec une attention particulière sur les jeunes en contexte du système de protection de la jeunesse.

Méthodes

Quatre études ont été menées. Une revue systématique a été menée portant sur les trajectoires aux soins en santé mentale pour des jeunes de 11-30 ans. La deuxième étude, une métasynthèse qualitative, a été menée afin de résumer les perspectives des jeunes et de leurs familles sur leurs cheminements à travers le système de santé mentale. L'étude III a examiné l'utilisation des services de santé mentale des jeunes pendant de leur suivi en protection de la jeunesse. Les données ont été recueillies de façon rétrospective à partir de dossiers médicaux. L'étude IV portait sur les trajectoires menant à L'Urgence pour des problèmes de santé mentale, pour les jeunes en protection de la jeunesse. S'appuyant sur les données collectées pour l'étude III, cette étude a utilisé une analyse de classe latente pour distinguer les trajectoires vers l'Urgence en fonction des caractéristiques systémiques et une analyse Kaplan-Meier pour déterminer les différences dans la récurrence de l'utilisation de l'Urgence en fonction du type de trajectoire.

Résultats

L'étude I répertorie quarante-cinq études provenant de 26 pays. Les trajectoires des jeunes en recherche de soins de santé mentale étaient complexes et impliquaient des contacts divers. À travers les contextes, les familles, les médecins de famille et les salles d'urgence figuraient de façon prédominante dans les trajectoires. L'étude II résume 31 études ayant des thèmes récurrents, notamment l'importance de la littératie en santé mentale et le rôle des barrières systémiques et du soutien social dans la recherche d'aide. Des trajectoires complexes, de longues listes d'attente, des critères d'admissibilité et des soins fragmentés étaient des obstacles fréquemment cités. L'étude III a démontré que les jeunes impliqués dans les services de protection de la jeunesse avaient de multiples contacts avec les services de santé mentale, y compris les services d'urgence, hôpitaux, le secteur privé, et les écoles. Le service prédominant était L'Urgence. L'étude IV a démontré que les jeunes ayant des antécédents d'abus sexuel, de problématiques de santé mentale chez leurs parents,et un historique de placements étaient plus susceptibles de recevoir des services de santé mentale à L'Urgence. De plus, trois trajectoires distinctes vers l'Urgence ont été identifiées. Parmi celles-ci, la trajectoire impliquant la police était la moins susceptible d'entraîner une visite récurrente à l'Urgence.

Conclusions

Nos quatre études confirment que peu importe la nature du trouble de santé mentale, le milieu de vie ou le contexte géographique, les jeunes et leurs familles ont de la difficulté à accéder aux services en santé mentale. Plusieurs facteurs peuvent avoir un rôle déterminant pendant la recherche d'aide des jeunes, en particulier, le soutien familial. Pour les jeunes à risque accru de problèmes de santé mentale, tels que ceux impliqués dans les services de protection de la jeunesse, les pratiques actuelles ne répondent pas à leurs besoins et une collaboration accrue entre les secteurs de santé est cruciale. Malgré l'importance des soins précoces et accessibles pour les jeunes, de nombreux jeunes se retrouvent à l'Urgence pour des problèmes de santé mentale.

Acknowledgements

First and foremost, I would like to thank my supervisor Dr. Srividya Iyer, who was an inspiration before undertaking this PhD and is now an invaluable mentor, and a friend. Your guidance, patience, encouragement and optimism were instrumental in helping me complete this doctorate and for making the process so enjoyable. It is rare to find a someone whose prominent intellect and wisdom are equally matched by their compassion, integrity and generosity, and who leads by empowering those around her. I am so grateful to have had your support throughout the different stages of my PhD journey over these last six years.

To the members of my thesis committee: Dr. Ashok Malla, Dr. Shalini Lal and Dr. Kelly Anderson. You have been so supportive, encouraging and have provided such great insights on my projects over the years. I am very thankful for your mentorship.

To Dr. Lise Laporte and Dr. Lyne Desrosiers of the Centre de Jeunesse de Montréal. Our collaboration over the years has meant so much to me and was truly one of the highlights of my PhD. Thank you for all of our discussions, our long and numerous meetings, and for being such positive people. Merci beaucoup!

Throughout the years, I have been lucky enough to work alongside some of the brightest and kindest fellow graduate students on whom I relied more than I can say. To Dr. Gerald Jordan, Megan Pope, Dr. Franz Veru, Miriam Kinkaid, Helen Martin, Madeline Doyle, Matthew Peters, Sarah McIlwaine, Nina Fainman-Adelman, and Kayleigh Munn - thank you for your support and for creating such great memories of my time at Burland. Huge thanks to Kevin, whose transition from older brother to co-worker felt surprisingly natural. I am so grateful for the incredible insights you provided into my work over the years, but, most importantly, grateful that we got to play lunchtime ball hockey together for a couple of years.

PEPP-Montréal is family I am so proud to be a part of. To Dr. Ashok Malla, who boldy envisioned this program - thank you. Dr. Jai Shah, Dr. Ridha Joober, Emily Meadows and the whole clinical and research staff - thank you for creating such an inclusive and stimulating environment. I would be a very different person had I not come to work at PEPP in 2013. I learned so much from the ACCESS Open Minds project and am grateful for the colleagues and friends I made there. Thank you for all that you do.

Thank you to my parents, my siblings Lisa and Kevin, and my great friends and family for their years of encouragement and interest in my work. Thank you to Charlie, for being the very best of all possible distractions.

And most of all, thank you to Jamie. While completing this PhD certainly represents a great achievement in my life, our happy family is what I will always be most proud of. Thank you for sharing parenting duties (e.g., taking Chacha on so many long bike rides) and for your overall support as I finished this work. I am very grateful.

Acknowledgments related to the production of this thesis

I am thankful for the financial support received over the course of my PhD, including a doctoral award from the Fondation de Recherche du Quebec- Santé, in partnership with the Quebec Support Unit for Patient-Oriented Research (Unité SRAP, 2017-2021) ; an ACCESS Open Minds Doctoral Studentship (2017-2021); the McGill-Glasgow Travel award (2017) ; the McGill Psychiatry Department Graduate Excellence in Mental Health Fellowship (2016) ; a Recruitment Excellence Fellowship from McGill University (2015); and funding received from Dr. Srividya Iyer's Canadian Institutes of Health Research (CIHR) Foundation grant.

The projects involving youth protection services in Montreal, QC, were made possible due to funding from the ACCESS Open Minds, Strategy for Patient-Oriented Research (SPOR)

network funded by the Canadian Institutes of Health Research and the Graham Boeckh Foundation.

I further would like to acknowledge the contributions of various individuals in the collection of data used in my doctoral work. Ms. Nina Fainman-Adelman played a vital role as the second, independent reviewer for both literature reviews included in this thesis *(Manuscripts I & II)*. I would like to acknowledge the work of numerous research assistants at the Centre de Jeunesse de Montréal for their rigorous chart reviewing and data extraction over the years 2015-2017. Their diligence made these projects *(Manuscripts III & IV)* possible. Finally, I would like to thank Dr. Gerald Jordan for his feedback on this dissertation.

Contributions of Authors

This dissertation comprises seven chapters and four manuscripts. I, Kathleen MacDonald, was responsible for the conception and writing of all components of this thesis. I am the first author on all four included manuscripts.

Manuscript I. Pathways to Mental Health Services for Young People: a Systematic Review.
Published in : *Social Psychiatry and Psychiatric Epidemiology*, 2018

I conceived this project in collaboration with my supervisor, Dr. Srividya N. Iyer, in response to considerable gaps of knowledge regarding pathways to care for young people. I determined that an ideal first step would be to conduct a systematic review of the state of the research literature. We contacted Dr. Kelly K. Anderson, an expert in the field, for input on how to best adapt our review to fit our research questions. Nina Fainman-Adelman was recruited to work on data collection and analysis. I conceived the research question, developed the search strategy in collaboration with co-authors, and led all data collection and analysis. I wrote the manuscript for this study which was subsequently revised and edited by all co-authors. The specific contributions of each co-author are listed below.

- **Kathleen MacDonald** was involved in the conception of the project, the development of its protocol, in data collection, data analysis and interpretation, and in writing the manuscript.
- Nina Fainman-Adelman was involved in the collection of data, data analysis, and provided feedback on interpretation and manuscript.
- Kelly K. Anderson was involved in the conception of the project, provided support in developing the methodology, and provided crucial feedback on the manuscript.
- Srividya N. Iyer was involved in the conception of the project, developing the methodology, data collection and analysis, and manuscript feedback.

Manuscript II. Experiences of Pathways to Mental Health Services for Young People and their Carers: a Qualitative Meta-Synthesis Review
Published in : *Social Psychiatry and Psychiatric Epidemiology*, 2020

I formulated this project in collaboration with Dr. Srividya N. Iyer, following the publication of the previous manuscript, a review of quantitative literature. In realizing that a large subset of the literature had been excluded due to its qualitative nature, we felt that efforts should be made to synthesize and review this group of relevant studies. I concluded that a qualitative meta-synthesis review was the appropriate methodology to complement our earlier efforts. Dr. Manuela Ferrari, an expert in qualitative research, provided key inputs regarding methodology. Data was collected with Nina Fainman-Adelman, and analyzed by myself, Manuela Ferrari, and Srividya Iyer. I wrote the manuscript for this study which was subsequently revised and edited by Drs. Ferrari and Iyer. The specific contributions of each co-author are listed below.

- **Kathleen MacDonald** was involved in the conception of the project, the development of its protocol, in data collection, data analysis and interpretation, and in writing the manuscript.
- Manuela Ferrari provided support in developing the methodology, data analysis, and provided crucial feedback on the manuscript.
- Nina Fainman-Adelman was involved in the collection of data.
- Srividya N. Iyer was involved in the conception of the project, developing the methodology, data collection and analysis, and manuscript feedback.

Manuscript III. Patterns of Mental Health Service Utilization and Pathways to Care for Youth Involved in Child Welfare Services in Quebec, Canada.
Prepared for journal submission, 2021

This manuscript is the result of a collaborative effort between myself, Dr. Srividya Iyer, and Drs. Laporte and Desrosiers of the Centre de Jeunesse de Montreal. We first conceived a large-scale research project requiring extensive data collection based on chart review methodology, and collectively co-developed the data extraction list. I was involved in pilot-testing the data extraction list, while training and supervising research assistants during data collection was ensured by Dr. Laporte and Dr. Desrosiers. Following data collection, I devised the specific research questions addressed by this manuscript, selected the appropriate statistical methodology, and was solely responsible for data preparation and analysis. I wrote the manuscript, and all co-authors provided feedback and edits. The specific contributions of each co-author are listed below.

- **Kathleen MacDonald** was involved in the conception of the project, data analysis and interpretation, and in writing the manuscript.
- Lise Laporte was involved in the conception of the project, supervising the collection of data, and provided feedback on interpretation and manuscript.
- Lyne Desrosiers was involved in the conception of the project, supervising the collection of data, and provided feedback on interpretation and manuscript.
- Srividya N. Iyer was involved in the conception of the project, developing the methodology, data interpretation, and manuscript feedback.

Manuscript IV. Emergency Room Utilization for Mental Health Problems by Youth involved with Child Welfare Services
Prepared for journal submission, 2021

This project arose from key findings emerging following the completion of the previous manuscript. In analyzing results from our child welfare dataset, I uncovered a key finding regarding the use of emergency services by youth in child protection services. I determined that this issue required further investigation. I outlined new research questions and conducted supplementary analyses, which resulted in this manuscript. As such, I was solely responsible for the conception of this project, as well as data preparation and analysis. I wrote the manuscript for this study, and all co-authors provided edits and feedback. The specific contributions of each author are listed below.

- **Kathleen MacDonald** was involved in the conception of the project, data analysis and interpretation, and in writing the manuscript.
- Lise Laporte was involved in supervising the collection of data, and provided feedback on interpretation and manuscript.
- Lyne Desrosiers was involved in supervising the collection of data, and provided feedback on interpretation and manuscript.
- Srividya N. Iyer was involved in the conception of the project, data interpretation, and manuscript feedback.

Contributions to Original Knowledge

This thesis comprises four original scientific manuscripts, published or prepared for publication, for which I am the lead author. Together, they represent a novel lens into the mental health service utilization and individual pathways to care of young people across various contexts. Specific original contributions to the field include :

I. The first published systematic review on pathways to care across the continuum of mental health disorders among youth. While multiple reviews have been conducted on the topic of pathways to care in the field of early psychosis, no review had been conducted for youth mental health problems across the continuum. Further, we also undertook the first qualitative meta-synthesis on this same topic, in order to provide overviews of the state of both quantitative and qualitative literature. While there have been increasing numbers of qualitative research reports on youth mental health pathways to care, this meta-synthesis is the first attempt to summarize such literature.

From these studies, we established the difficulties encountered by youth seeking mental health services across the world, including the numbers and types of care providers accessed along their pathways to care; as well as the appraisals of such complex pathways to care by youth and their families.

II. From these two reviews, we established a gap in knowledge pertaining to pathways to care for youth in vulnerable conditions, whose risk for mental disorders and access to care may differ from general or clinical populations. To begin addressing this gap, we sought to establish service utilization and pathways to care for youth within child welfare settings, an understudied population, particularly in Canada. While previous research has investigated service use in this population using administrative databases, to our knowledge, no study had specifically looked at individual patterns of mental health service use during the entire period of child welfare involvement. As such, our publication on mental health service use in child welfare services in Quebec was the first to yield a number of findings, including the predominance of Emergency Rooms in providing mental healthcare for these youth; as well as the breadth of service settings accessed by young people during their involvement within the child welfare system.

III. The next original contribution to the field was the determination of specific pathways to the ER by youth in child welfare, using latent class analysis. This type of analysis has been used to identify subgroups of youth with similar mental health symptoms or sociodemographic characteristics, and to determine the association of such subgroups with service use. To our knowledge, our study was the first to employ this methodology to distinguish trajectories based on characteristics along the pathway to care, thus demonstrating that common systemic or external factors often lead to ER use, in addition to known individual-level factors.

IV. Finally, the overall scope of this thesis demonstrates that pathways to youth mental health care are complex, and are impacted by governing healthcare systems, existing intersectoral collaborations (or lack thereof), and policy measures ensuring equitable access to care. This lens is a novel approach in the field of youth mental health service utilization, whose focus has often been on individual factors promoting or impeding service use.

*

A note on language

The World Health Organization defines ‘youth’ as individuals aged 15-24; and ‘young people’ as individuals aged 10-24. The United Nations define ‘youth’ as the period between ages of 15-24. Youth mental health services often cater to individuals between the ages of 11-25.

In recognition of the various definitions used across different settings, we have aimed to broadly refer to individuals aged 10-25 interchangeably as ‘youth’, ‘young people’, or ‘adolescents and young adults’.

Introduction

There are more young people in the world than ever before – 1.2 billion, 15% of the world's population[1]. Already at its apex in modern history, the youth population will continue to increase. Estimates suggest that by 2032, over 2 billion people will be aged between 10-19 years, driven largely by populations in low- and middle-income countries, already home to more than 90% of today's youth [2].

Modern medical advances have improved outcomes for, and even eradicated, many diseases that once posed a great threat to young people – malaria, polio, HIV/AIDS – , and improvements in sanitation and childhood nutrition mean that more young people can expect to live to their 25th birthday than at any other time in history. At present, throughout most of the world, adolescence and young adulthood is viewed as a time of relatively prosperous physical health, with low incidence of disease burden and mortality. Though the impacts of physical ailments is decreasing in this population, trends suggest that the burden of mental health problems may be increasing. At the very least, the visibility of the mental health burden in youth is providing a picture of affliction at rates higher than ever considered before.

Epidemiological studies from the late 1990s and early 2000s unearthed major findings regarding the developmental trajectory of mental disorders. Namely, all major mental health disorders – schizophrenia, mood disorders, personality disorders, substance use- typically have their onset before an individual turns 24 [3]. In fact, 75% of all mental health problems emerge in one's teenage and young adult years, with a significant proportion of 15-24 year olds experiencing a mental health problem at any one time.

Left untreated, mental health issues are linked to numerous negative long-term consequences, including poor treatment outcomes, lower rates of remission, and higher likelihood of complex symptomatology. Aside from the negative health impacts, untreated mental illness in young people also affects the formation of their personal identities, their relationships, and the attainment of their vocational and educational goals. Mental disorders, precisely because of their peak onset during young adulthood and their long-term impacts on the most productive years of ones' life, also pose an increasingly large threat to the gross domestic product of nations. For these reasons, the impacts of mental health problems are felt not only at the individual level, but at a societal level as well. Given these individual, societal and economic costs, a strong focus on early intervention in this age group has the potential to generate enormous benefits to both youth and society.

Despite this, access to mental health services for young people is poor. Help is sometimes left unsought, with help-seeking barriers including stigma, lack of knowledge about mental health and available services, or concerns about confidentiality. In other cases, help is desired, but inaccessible: external barriers are common, including long waitlists, financial costs, services restricted on age or diagnostic categories. Often, young people must navigate an increasingly complex healthcare system and interact with numerous professionals across different sectors before reaching appropriate services. These complex pathways to care delay treatment and impact youth and families' experiences of seeking help. Given this, poor engagement of young people in psychiatric services is widespread, with high rates of treatment attrition even when youth do access care. In sum, the confluence of high rates of disorders coupled with a gap in treatment has caused a youth mental health 'crisis' [4], resulting in high levels of impairment, distress, and suicidality.

A decade ago, the World Health Organization predicted that by 2020, *"mental disorders will become one of the five most familiar ailment causing dismalness, mortality, and dysfunction among youths."* [5]. Today, findings from the same organization confirm their prediction: mental health disorders are among the primary contributors to disease burden and mortality in the world's youth population. It is clear that mental health problems will be one of this generation's greatest challenges. These trends suggest an urgent need for new solutions in the provision of care of youth with mental health problems, and for new research efforts to improve the understanding of youths' access to mental health services and for new strategies to ensure that services are easily accessible, appropriate, and meet the needs of youth.

Chapter 1. Literature Review

Section 1. Portrait of Mental Disorders Among Youth

1.1 Prevalence

Epidemiological research, originally established for the study of infectious diseases, can be used to specify the distribution of disorders in the general population, typically based on rates of prevalence (number of existing cases in a defined population during a specified period) and incidence (number of new cases of a disorder in a defined population during a specified period). The application of epidemiological tools to the field of psychiatry led to many key developments in our understanding of rates, frequencies, and age of onset distributions of mental health disorders. In the early 1980s, the first large-scale psychiatric epidemiological surveys were conducted in a number of countries including the United States, United Kingdom, and France, and an international consortium was created by the World Health Organization in 1998 to conduct comparative analysis across different contexts. For the first time, these surveys provided a glimpse into the occurrence of mental disorders in random samples representative of the general population. Often, survey methodology is based on self-reported concerns or diagnoses, or structured clinical interviews. Most commonly, prevalence estimates refer to either 12-month prevalence, an estimate of disorder prevalence over the previous year, or point-prevalence, an estimate of disorder prevalence at the time of the interview. Although there is substantial variation in survey results depending on the methodological characteristics of the studies, these surveys, taken together, have offered us the best estimates of the burden of mental disorders amongst young people.

Numerous reviews have attempted to quantify the prevalence of mental health disorders among youth. In 1991, a first review collated findings from 38 studies published between 1965-1990, and estimated a median prevalence rate of adolescent mental disorders of 13%, with estimates ranging from 3-30% [6]. In the late 1990s, a new review identified 52 studies and calculated a median prevalence rate of 15% for adolescents [7]. These reviews noted that the heterogeneity in methodologies between studies were a major limitation in estimating true pooled-prevalence rates across contexts.

In the most recent review of its kind, published in 2015, the authors used strict inclusion criteria including the use of standardized assessment methods to derive diagnosis. Their meta-analysis of 41 epidemiological surveys from around the world estimated a pooled 12-month prevalence of mental disorders for young people of 13.4% [8]. Anxiety disorders have been found to be the most frequent condition in youth, with 12-month prevalence of 6.5%, followed by disruptive disorders (5.7%), and mood disorders (2.6%). In terms of specific countries, nationally representative epidemiological research from the United States indicated that the 12-month prevalence of mental disorders was 40 % among 13–17 year olds [9]. In Australia, the National Survey of Mental Health and Wellbeing revealed that 26 % of 16–24 year olds had experienced an anxiety, affective, or substance use disorder in the past 12 months [10]. In Ontario, Canada , youth had an estimated prevalence of mental disorders equal to 14.3% [11].

In contextualizing 12-month prevalence rates, the researchers in the one study concluded, *"Only a small percentage of young people meet criteria for a DSM disorder at any given time, but most do by young adulthood. As with other medical illness, psychiatric illness is a nearly universal experience"*[12].

Epidemiological samples often exclude specific populations, such as those living in institutions (prisons, hospitals) or marginalized populations (homeless, refugees, in foster care). In fact, many vulnerable groups are poorly represented in epidemiological research, despite the fact that they may be at particularly high risk for mental illness. For youth in marginalized contexts, specific historical (e.g., colonization, cultural suppression) and environmental (poverty, adverse childhood events, social/material deprivation, stress) circumstances constitute important social determinants of health, which can have significant impacts on mental health and wellbeing. This is clearly represented in the estimates of mental health disorders among some disadvantaged youth. For example, youth living in poverty have been found to be two or three times more likely to develop mental health problems compared to medium- and high income youth [13]. High rates of mental health problems have also been revealed among Indigenous youth across the world [14, 15], and in Canada, rates of suicide are reported to be five to seven times higher for certain First Nations youth living on reserves compared to the general youth population [16]. Estimates of mental health problems among youth involved with child welfare services range from 25-50% [17], almost four times higher than youth with no such involvement. Finally, the intersection of youth homelessness and mental health is significant. A survey of homeless youth in the United States found that 45% had reported mental health problems in the past year [18]. In a Canadian study on youth homelessness, over 85% of homeless youth had experienced a mental health crisis, and over 40% had reported at least one suicide attempt [19].

The experience of multiple forms of marginalization is common and increasingly recognized. The cycle of marginalization is difficult to disentangle, especially as exposure to certain stresses, including maltreatment, instability, or violence, has lasting effects of mental distress, which itself can contribute to increased likelihood of experiencing further marginalization. Indigenous youth and visible minority groups are overrepresented within the child welfare system, which has been linked to systemic issues such as racial bias in reporting and decision-making, as well as a lack of culturally appropriate services [20-22]. Children involved in child welfare are also at higher risk of becoming homeless once they reach adulthood, with the vast majority of homeless young adults reporting the involvement of welfare services during their childhood [19]. For many, the experience of marginalization is both a risk factor for mental health problems as well as a consequence of periods of mental ill health.

Comorbidity

Psychiatric comorbidity, the simultaneous or sequential presence of multiple disorders over a given period [23], is widespread, even in young people. The presence of comorbid disorders is related to increased severity of disease [24-27] and the potential for long-term negative outcomes including longer [28], and more severe [29] episodes of illness, higher frequency of suicide, greater utilization of mental health services [30], and greater impacts on social functioning [31]. There is some evidence that comorbidity of mental disorders is more frequent in adolescence than during adulthood [32]. In a large-scale epidemiological survey from the UK, 20% of youth who had received a mental health diagnosis had more than one diagnosed disorder [33]. In Australia, 30% of youth who experienced mental illness in the past year had more than two diagnosable disorders [34]. Some have suggested that the development of a psychiatric disorder is itself a risk factor for subsequent development of another psychiatric comorbidity [25, 35, 36].

The most prevalent comorbidity in youth has been found between disruptive disorders (oppositional defiant or conduct disorders) and attention deficit–hyperactivity disorders (ADHD). Another common comorbidity is the experience of depression and anxiety, and some studies have found that between 50% and 66% of young people with depression have a comorbid psychiatric disorder [37]. Marginalized groups tend to have increased risk of comorbid psychopathology. A study from the United States revealed that nearly 20% of youth who had been involved in foster care had three or more current psychiatric problems, compared to 3% of their peers not involved in foster care system [38].

Age of onset

As described previously, age-of-onset distribution studies revealed that most mental disorders — anxiety, depression, substance use, eating disorders, and suicidal ideation and psychosis —have their peak period of incidence in adolescence and young adulthood [3, 39]. In fact, half of all lifetime cases of mental disorders have their onset by 14 years of age, and three quarters by 24 years of age [26]. A recent meta-analysis reported that the peak age of onset across all mental disorders was 14.5 years (IQR 11-34) [39]. Age of onset distributions do vary across types of mental disorder, with impulse-control disorders presenting at the earliest ages, with a median age of onset between 7 and 9 years old for ADHD, and 80% of all lifetime ADHD cases beginning by age 11. Anxiety disorders are also characterized by an early onset, with median age in the range of 7-14 years old. Mood and substance disorders tend to occur later and have wider ranges of onset (median age 29-43 and 18-29, respectively) [3].

Burden of disease

Over the past few decades, psychiatric epidemiologists have shifted their focus from prevalence and incidence studies and have increasingly investigated the impacts and burden of mental disorders on society. The concept of disability-adjusted life years (DALYS) is one such example, which seeks to estimate of the reduction of life expectancy attributable to disability caused by a specific disease. In one study looking specifically at 15-24 year olds, mental disorders contributed 60–70% of their total DALY [40]. Further, five of the top ten causes of disability-adjusted life-years among young people were directly related to mental health or substance use [40].

In addition to disability, mental disorders contribute substantially to the mortality rates in young populations – in fact, in many regions, adolescence and young adulthood is increasingly seen as a stage of increased risk of suicide. Suicide is a leading cause of death among young people in China and India, and the second cause of death in many other countries, including Canada [41].

Prevalence trends

The extent to which the prevalence of youth mental health problems has been increasing in the past few years is a matter of some debate, with studies investigating this issue reporting contradictory findings. Some studies have shown increased prevalence in self-reported mental health concerns among young people over the past 10 years [40, 42, 43] while others showed increases among female adolescents but not males [44], increases in males alone [45], or no change in prevalence [46, 47]. In Canada, the prevalence of self-reported suicidal ideation and attempts decreased among adolescent males from 1998 to 2010 [46]. In Ontario specifically, rates of mental health visits for self-harm decreased for youths aged 13–17 years between 2003 and 2009 but rose over the subsequent decade [48]. A US study reported an increase in the past-year prevalence suicidal ideation and suicide attempts from 2008 to 2017 among youth [49].

The inconsistencies observed in the literature may reflect methodological differences between studies, while other discrepancies may be explained by different prevalence rates across countries or settings. In all cases, retrospective studies can be afflicted with recall bias, and comparative cross-sectional studies may confound cohort effects with age effects.

What is more easily quantifiable is the fact that the provision of mental health services to youth has been rising. In 1998, 9% of youth aged 12-17 in the USA reported having used mental health outpatient services in the past year. By 2012, this proportion rose to 14% in the same population [50]. In Canada, mental health-related emergency department visits, hospitalisations and outpatient visits among youth increased from 2006 to 2011 [51], including a 66% increase in emergency department visits, and a 55% increase in hospitalizations of children and youth due to mental health concerns [52]. Hospitalizations due to self-harm increased by 90% between 2009-2014 [53]. These findings align with data from the United States, where hospitalization rates for youth mental health problems grew by 24% between 2007-2010 [54, 55], and by 80% for mood disorders specifically, between 1997-2010 [56].

One can view service utilization as a proxy measure of need, thus suggesting that a rise in service use is reflective of a probable rise in prevalence. Other interpretations are possible, such a shift in attitudes leading towards increased help-seeking, in part due to anti-stigma and mental health literacy interventions. Certainly, the rise in Emergency Room use suggests that needs are not being adequately met in primary care or community services, or that youth are preferring to access care within ER services, potentially due to perceived or real ability to receive services more rapidly in this setting [57].

With emerging evidence clearly demonstrating the burden and consequences of mental health problems among young people, the following section will address why youth are specifically vulnerable to the development of mental health problems, covering both biological and social determinants of mental health.

1.2 The vulnerability of youth

The period of adolescence represents both a biological and social construct. On one hand, distinct neurobiological and hormonal changes occur during this period. At the same time, shaped by cultural and social expectations, this period also represents a distinct stage of educational and employment opportunities, the occurrence of romantic and sexual relationships, potentially harmful substance use, and transitions towards housing and financial independence. The confluence of these circumstances creates a critical period for the development of mental health disorders.

a. Biological vulnerability

The transition to adulthood is characterized by distinct biological, physical and psychological developments which contribute to youths' unique vulnerability to the onset of mental illness. It is understood that during early adolescence, brain maturation processes, coupled with the hormonal changes linked to puberty, have significant impacts on behavioural and emotional regulation linked to youth psychopathology.

Historically, the brain was thought be fully developed by the period of adolescence. Advances in neurobiology and brain imaging in the late 1990s and early 2000s led to an understanding that, in fact, many key areas of the brain and its connectivity continue to mature well into a person's mid-twenties [58, 59]. In reality, the period of adolescence is marked by increased brain plasticity, meaning that adolescent brains are exceedingly adaptable and have heightened responsiveness to environmental influences [60].

The human brain contains trillions of cortical synapses, structures in neurons that permit the transmission of chemical and electrical signals between cells. During early childhood, the number of cortical synapses in the brain is at its peak, which allows for early learning, memory formation and adaptation skills to emerge. These synapses, and the circuits they form, are not static features but instead undergo frequent remodeling in response to external stimuli (e.g., stress, drugs, disease) as well as normal developmental processes. Throughout adolescence and young adulthood, many synapses are eliminated through a process of synaptic pruning. This pruning does not occur in a widespread fashion, but is localized within certain areas. Specifically, the most extensive synaptic pruning occurs in neural systems subserving high cognitive functions – reasoning, emotional regulation, risk versus reward appraisal, and motivation.

It has been hypothesized that anomalies in this brain maturation process may play a role in the development of certain mental disorders. Notably, schizophrenia has been associated with an overactive maturation process and grey matter loss [61], as have depression and post-traumatic stress disorder [62]. Environmental context, including chronic stress and substance use, has also been shown to impact the maturation process and has been linked to increased susceptibility to mental health problems including anxiety and depression [63-65].

Early adversity, such as abuse and neglect, can also impact structural and functional brain development. In a systematic review, brain regions found to be affected by abuse and neglect included areas responsible for higher cognitive functions such as self-regulation, decision-making, emotional and behavioural regulation (e.g., the prefrontal cortex, amygdala, anterior cingulate cortex). These brain changes may represent responses to early experiences of stress and may be associated with an increased risk of mental health problems during adolescence and young adulthood [66].

Advances in neurobiology have elicited biological mechanisms for many aspects of human brain activity, including executive function, attention, memory, motivation and social behaviours. There is evidence that many mental illnesses may derive from some variation in underlying neurological processes. However, much remains unknown about the role of brain processes in the development of mental disorders, and this complexity is partly due to the interplay between biological, genetic, and other factors. In particular, vulnerability to mental illness is accentuated by the social environment in which people live. The next section will cover social factors leading to increased vulnerability to mental health problems among youth.

b. Social vulnerability

> *"We look forward to the day when enough will be known about sociocultural factors to allow prevention in a public health sense through deliberate change in the human environment"*
>
> —Alexander Leighton, 1959 [67]

In addition to biological vulnerabilities associated with adolescence and young adulthood, youth experience a range of particular social circumstances linked to increased susceptibility to mental health problems.

Research on the social determinants of physical health was advanced, in part, by Link and Phelan's pioneering work describing social determinants as 'fundamental causes' of physical illness, and led to numerous advances in the societal-level interventions to improve population health [68]. Globally, social determinants of health are the conditions in which individuals "are born, grow, live, work, and age" [69] . These determinants include access to and quality of education, food, sanitation, nutrition, employment, housing, and other opportunities. These factors drive many health inequalities among disadvantaged populations, such as life expectancy, child mortality, and burden of disease.

The study of social determinants is critical to the history of psychiatry. Over the years, research into the social determinants of mental health has concluded that core social factors impacting mental health include discrimination, adverse early life experiences, poor education, job insecurity, income inequality, and neighborhood deprivation; housing instability, and poor access to health care [70].

Youth are not absolved from these conditions; in fact, the multiple transitions encountered through the period of young adulthood, including transitioning to financial and housing independence, and changes in education or employment status, represent unique opportunities for social factors to affect youths' health and well-being.

Recent societal changes such as the widening of income inequality have placed numerous families and youth at the lowest end of the socio-economic ladder [71]. There is evidence that poverty contributes to mental health problems among children [72] and that these effects can be reduced by family income supplements [73]. Food insecurity has also been associated with mental health symptoms among children [74] and adolescents [75].

Economic inequality greatly impacts young people, who are disproportionally affected by unemployment and lack of opportunities to improve their economic standing. The current economic climate poses specific challenges for young people, with high rates of youth unemployment and increasing employment instability reported around the world. This may be due to rises in short-term employment opportunities, the student debt crisis, and delayed retirement of the aging population [76] ,which prevents youth from establishing stable careers. Further, in the context of the COVID-19 pandemic, early studies have shown an increase in high school drop-out rates [77], and unemployment among youth [78]. This is significant as youth not in employment, education or training (NEET status) have increased likelihood of mental health problems, in some cases up to twice as likely as their non-NEET peers [79, 80].

Youth also face discrimination over racial or gender identities which are consistently linked to serious mental illness [81]. Young people with intersecting disadvantages are at even higher risk, with ethnic minority LGBTQ+ youth reporting poorer mental health than their non-visible minority LGBTQ+ peers [82]. The experience of poverty among transgender populations has also been linked to increased self-harm, depression, and suicide attempts [81].

Importantly, social determinants and mental health symptoms can act in a reciprocal relationship. The experience of mental health problems can subsequently impact social conditions, including dropping out of work or school, homelessness, relationship instability, and economic uncertainty [83, 84]. This is especially salient for young people as multiple social determinants intersect with traditional transitions and life choices, thus affecting how youth navigate educational, employment, opportunities and can affect future careers, housing situations, or improvements in socio-economic standing. As such, youth experiencing mental health problems may be at further risk of increased social inequities.

c. Resilience

It is important to note that the majority of youth, even those who face multiple risk factors, remain in good mental health. Protective factors can play a large role mitigating risk of mental health problems in youth, with good evidence for the proactive role of social support, involvement in community, low levels of conflict, and personal characteristics [85, 86]. These protective processes are linked to the concept of resilience. A recent shift has gone from conceptualizing resilience as a product of individual characteristics to an ecological process resulting from the interaction between individual and their environment, including the availability of resources and the capacity of persons to find and use such resources [87]. Resilience has thus been defined by Ungar and colleagues,

> *"In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their wellbeing, and their capacity individually and collectively to negotiate for these resources to be provided and experienced in culturally meaningful ways."* [88]

It has been noted that a large focus is still placed on emotional regulation or coping strategies in the promotion of resilience, despite evidence showing that such capacities are unlikely to sustain positive mental health outcomes in the absence of other structural systems – such as familial support, housing, and health and social services. Recent studies have shown that for vulnerable youth faced with multiple adversities, the provision of strong systems of care, including access to psychosocial services, can often lead to positive outcomes irrespective of youths' personal traits such as motivation or regulation [89, 90].

1.3 The Importance of Early Intervention in Youth Mental Health

A basic tenet of healthcare is the importance of early detection and treatment of serious health conditions, as most interventions have their highest rates of success in early stages of disease. Historically, mental healthcare has lagged behind in this regard, with a long history of treatment of mental disorders occurring in adult-centered institutions or asylums, and revolved around reactive, paternalistic care. Despite an increased focus on community mental healthcare , which emerged from the deinstitutionalized efforts of the 1960s and 1970s, early intervention in mental health is still significantly underfunded [91].

Early intervention (EI) in psychiatry aims to prevent, or at the least delay, the onset of a serious mental illness and to minimise the associated damage to an individual's health and functioning. When left untreated, mental health issues are linked to numerous negative long-term outcomes, including poor treatment outcomes, lower rates of remission, and higher likelihood of complex symptomatology [92]. Young people with mental health problems often have poor academic performance and are at increased risk of dropping out of school [93, 94]. Untreated mental illness in youth also affects the formation of personal identity, relationships, social functioning and is linked to lower quality of life [12, 95-99].

Too often, mental health problems in youth lead to early loss of life. Suicide is the second leading cause of death for youth between the ages of 10 and 24 in the United States [100] and Canada [101], and among those who die by suicide, more than 90% had at least one diagnosable mental health disorder. Suicide is a leading cause of death in young people in countries such as China and India [102, 103].

There is evidence that such adverse outcomes can be prevented through early intervention and early management [92, 104-106]. Youth often present symptoms of mental health problems before reaching the threshold of a diagnosable psychiatric disorder. Often, distress or functional impairments can be first signs of a need for support [107]. Timing of interventions at this stage, even brief interventions such as single-session interventions [108], can be crucial in altering the trajectory of symptoms and preventing the severity of a disorder [109]. However, current mental health services are not designed to intervene at this crucial timepoint, the emergence of symptoms. Services are often designed following the traditional physical health system (pediatric vs adult), with few services specifically tailored for the 11-25 age range during which more disorders are known to emerge, meaning many youth in need of care fall through a gap in the system.

Youth with mental health problems frequently first seek care within primary care services, often at their general practitioner's (GP) office. A 2016 survey of general practitioners reported that 78% of GPs reported seeing more young people with mental health problems compared to five years prior [110]. However, detection and management of mental health problems in primary care can be difficult [111]. Youth present symptoms of mental disorders that are transient, and at times difficult to differentiate from typical adolescent trajectories. Further, even if the presence of a mental health problem is identified, general practitioners often feel ill equipped to provide necessary treatment themselves, yet links between primary and specialist services are often fraught. A recent review concluded that the paucity of specialist providers for youth mental health was the most common barrier cited by GPs in the management of youth mental health problems [111]. Even when specialist services exist, wait times tend to be long, and many GPs express concerns about the risk to youth whom they refer to specialist care [110]. Further, only a minority will be eligible, as strict eligibility criteria often restrict services to severe or persistent disorders most commonly seen in older adults. At the early stages of illness, most youth will not present with clear-cut, severe symptoms required to meet criteria for these services, and only a minority of young people below the age of 18 report accessing specialized services [91].

The pediatric cut-off at age 18 means that a significant gap in care often occurs right at the peak of onset of many disorders, and thus youth face both a high risk of mental health problems coupled with the greatest chance of falling through the cracks [112]. In the UK, less than 5% of young people make an optimal transition to adult mental health services [113], with most youth describing a transition process that was inadequately planned and communicated [113, 114]. Even when referred to adult services, young people often disengage from treatment, or endorse negative mental health outcomes including feeling anxious about the transition to adult care [113-116].

Given these gaps in care, a reform in the delivery of mental health services, with a focus on early intervention, has long been awaited. Progress in community-based, early intervention services for youth first made strides in the field of psychosis, driven by a vision for a hopeful future for youth in early phases of psychotic disorders. These programs focused on the early identification of youth in need, and dedicated resources to both clinical and functional recovery. The progresses made in early intervention for psychosis services dramatically changed the landscape of the field, leading to a substantial reform in the structure of psychosis treatment in a broad range of settings globally. EI services for psychosis are now widely available in multiple countries, including Australia, UK, Denmark, and Canada;

and funding for these types of services is increasing as their ability to return on investments is progressively recognized [91, 117-119].

Buoyed by the success of EI programs for psychosis, and the evidence generated by the research into positive clinical and functional outcomes, a wider application of early intervention services for the full range of mental disorders experienced by young people is now emerging. Over the last decade, the reform of youth mental services has gained momentum worldwide [109, 120, 121].

Youth ‘one-stop shops’, catering to 11–25-year-olds, include integrated, multifaced services such as mental health, vocational, and educational support, are now in emergence in various countries, including Australia (headspace), Ireland (Jigsaw), Denmark, Netherlands (@ease) and Canada (ACCESS Open Minds, Foundry, Youth Wellness Hubs Ontario). Through these endeavours, the evidence base and support for widespread implementation of early intervention in youth mental health is mounting. In particular, new evidence is being generated for the effectiveness of early treatment in preventing negative outcomes. The reduction of durations of untreated illness through early identification and quick-access efforts have long been shown to positively impact outcomes in psychosis [122-124], and similar evidence is now rising for major depressive disorder, bipolar disorder, panic disorder, generalized anxiety disorder, and obsessive–compulsive disorder [125-127]. Non-specific interventions such as those addressing emotional self-regulation, problem-solving, social support, conflict, loneliness and other difficulties, as well as certain app or web-based interventions (‘e-interventions’)[128, 129], have had promising results.

Given the known individual, societal and economic costs of mental illness in young people, as well as the rates of mental disorder and the fact that most cases emerge during this age period, it is unsurprising that early intervention for this population has the potential to generate enormous benefits for society. Substantial progress has been made in developing youth-specific services which shift the paradigm for mental health service delivery to a model focused on prevention, early intervention, and the provision of services which are engaging for young people. Yet, despite these promising advances, considerable gaps remain in both the availability and accessibility of services as well as our understanding of youths' pathways to care. Youth-specific mental health services are still an exception in most healthcare jurisdictions, and their effectiveness is the subject of ongoing research. Youth across many contexts still face multiple barriers to accessing appropriate care, as reviewed in the next section.

Section 2. Mental Health Service Use & Pathways to Care

2.1 Treatment gap

As described in the previous chapter, the prevalence and burden of mental disorder in adolescence and young adulthood, and the established importance of intervening early in the development of mental health problems are increasingly recognized. Yet, there remains a large gap between the needs of this group and their service use rates [41].

Estimates of treatment need vary by disorder and by definitions of treatment. In a nationally representative survey, 44% of Canadians over age 15 with mental health needs reported their needs was unmet [130]. In the USA, several recent large-scale studies examining service use in youth specifically have consistently reported that as few as 20% of youth receive services for their mental health needs [131, 132]. For youth with serious mental illness, it has been estimated that less than 50% receive any form of treatment [133].

In terms of specific disorders, data from the United States indicated that rates of treatment in the past year for youth age 19 to 25 with a mood disorder was of about 35%, and about 14% for anxiety disorders [134]. In another study from the USA, young adults aged 18-25 had the lowest treatment rate for diagnosed depression (46.9%) compared to any other age group [135]. Specialist services, such as psychiatrists, are even harder to access, with some estimates suggesting only 5% of youth in need receive specialist care [136].

Some of the treatment gap in youth mental health is explained by reluctance to seek help. A survey of German adolescents indicated that only 18% of youth with diagnosable anxiety disorders, and 23% with diagnosable depressive disorders, had ever sought help [137]. In line with these findings, a large scale study from Norway indicated that 34% of youth with high levels of depression and anxiety had sought help in the past 12 months [138]. Barriers to help-seeking include stigma, mental health literacy (i.e., an unawareness that they problem they are experiencing is related to mental, or can be aided by mental health services) [139]. Youth have also endorsed negative attitudes about services and have had concerns about confidentiality, impeding their desire to seek services [140].

Crucially, not all unmet needs occur because a person is reluctant to seek mental health services. In fact, young people report that mental health is one of the greatest concerns for themselves and their peers [141] and are increasingly using novel forms of services, including websites and apps, to seek information and treatment [129]. Population-based surveys have consistently shown that the vast majority of individuals with mental health problems do eventually make contact with services [50, 142, 143].

What appears to be more common, rather than youth not seeking help, is that youth face multiple barriers to care once they do decide to seek services. In the next section, we will outline some of the barriers to care leading to treatment delays for mental health problems in youth.

2.2 Delays to Treatment

In 1938, physicians Pack and Gallo introduced the concept of health treatment delays, simply defined as the interval between the onset of symptoms and the first visit to a physician.

Studies into these delays has been extensive, especially within the field of cancer research [144].In psychiatry, treatment delay research was amplified with the advent of the early intervention movement for psychosis, as a greater emphasis was placed on the important of reducing such delays [124, 145].

In addition to age of onset studies which pioneered an understanding of the developmental trajectories of mental disorders, surveys on treatment initiation demonstrated the profound delays which are often incurred between onset of mental health problems and initial treatment. For the large majority of individuals who eventually reached mental health services, these delays were found to be in the range of multiple years, even decades. An international study of 15 countries led by the World Health Organization found that the median delay to treatment ranged from 6-8 years for mood disorders, to up to 20 years for social phobia and social anxiety disorders [146].

These patterns are concerning given that treatment delays represent unnecessary periods of distress for patients and their families. In addition, there is evidence that such delays may also compromise the potential for recovery once treatment is initiated [147, 148]. As described above, commonly-cited contributors to unmet needs for health services include poor accessibility, availability, and acceptability of care [149]. To begin addressing this problem, it is important to first understand the patterns and actors involved in the help-seeking process. Studies have specifically investigated the pathway from help-seeking to treatment initiation [150]. There are multiple ways to conceptualize this pathway. A simplified illustration is depicted in Figure 1, adapted from Andersen's Model of Total Patient Delay [151], as well as Bechard-Evans et al.'s work on components of duration of untreated psychosis [150]. Of note, this linear depiction of the steps to treatment may not be representative of individual pathways to services. Individuals' dynamic pathways to care are often circuitous, reflecting both individual and social choices, and will be described in greater detail in Section IV.

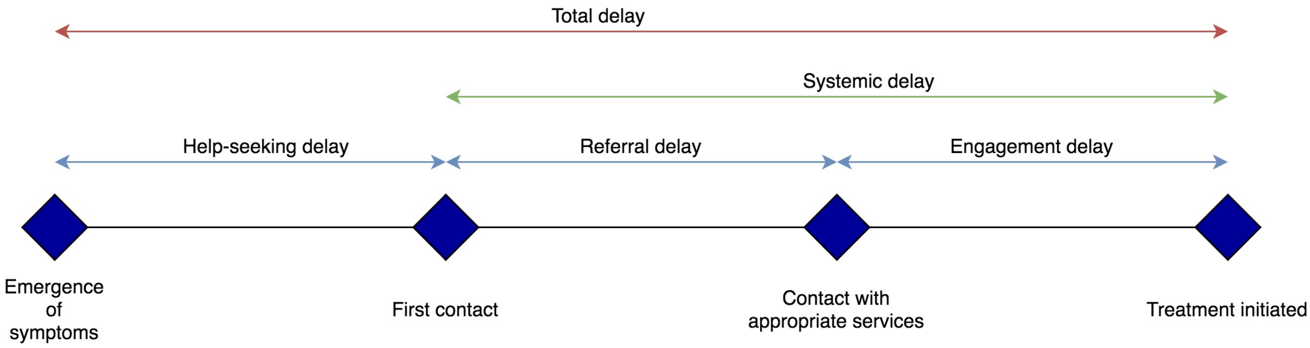

Figure 1. Treatment Delays

a) Help-seeking delays represent the time between the onset of mental health problems and the first help-seeking attempt. This is a critical early step which is dependent on the awareness of signs and symptoms of mental disorders; recognition that the problem may warrant help ; and the availability of these sources of help [140].

A large proportion of research, especially regarding youth, has focused on this first component (help-seeking delays). A systematic review of barriers and facilitators to help-seeking in young people identified major contributors to these delays, including low rates of mental health literacy (i.e., not recognizing signs and symptoms of psychological distress or not knowing where and how to access help), a preference for self-reliance, and perceived stigma and embarrassment [152]. Facilitators, though still mostly under-researched, included encouragement from others and positive past experiences with mental health services. When youth first experience symptoms of mental health problems, they often turn to family and friends first, rather than seeking professional help by themselves [140]. As such, parents are known to play a large role in helping their young one reach services when needed. For these reasons, social support is a major factor in the length of help-seeking delays.

b) Systemic delays refer to the total amount of time between the initial help-seeking contact and treatment initiation. Even once an individual and/or their carers have initiated the process of seeking help for a mental health problem, further delays may be encountered before receiving proper treatment. In many cases, this delay represents a failing at the level of the available services and healthcare systems. This delay can be as long, or sometimes longer, than the help-seeking delay. Engagement delays describes the time that it takes for the young person to begin treatment even once the contact with the appropriate health providers has been established. Often, the available treatment options are described by youth as non-engaging, and attrition from treatment is common.

Despite the emphasis on help-seeking delays in the promotion of mental health service use for young people, the contribution of systemic delays to the overall experience of obtaining care for mental health problems is significant. An effective response to mental health problems does not depend solely on timely initiation of help-seeking at the level of the individual or their carers, but also depends on a rapid and appropriate response on the part of the mental health system.

On major component of systemic delays occurs after an individual has made contact with services. The referral delay often includes waiting times which occur between contacting a service and being offered treatment. Literature on mental health waitlists is limited, in part due to the lack of mandatory tracking and reporting of waiting times in psychiatry, even though these types of reports are mandatory for other health services such as cardiac procedures and surgeries. Two decades ago in Canada, a specific project aimed to document such data, and youth mental health was highlighted as one of the five clinical disciplines with the longest waitlists [153]. A study from 2011 that surveyed child and adolescent mental health services agencies in Canada revealed that the estimated mean wait time for an initial assessment was 109.5 days [154].

The impacts of long waitlists are multifold. First and foremost, mental health problems can worsen with longer delays, and youth are at increased risk for harm and hospitalization during the period of time they were on a waitlist for treatment. Studies have shown that longer wait times mean that youth and families are less likely to attend appointments once they are made available [155-157]. It has been estimated that up to one-third of youth do not attend the initial appointment after being placed on a waitlist and that this non-attendance increases in likelihood once the waitlist has surpassed eight weeks [158] or six months [157]. Even if youth and families do engage with treatment following waitlist delays, there is evidence that the waiting time decreases motivation for treatment and expectations of outcomes [159].

Importantly, in a study on parental help-seeking for youth with mental health problems, it was found that half the families currently on a waitlist for mental health problems were simultaneously seeking help with other agencies. Families reported having contacted five different agencies during their time on a waitlist [136]. These studies have important ramifications for system organization and allocation of resources [136, 160]. A final, but not insignificant, concern is that for most waitlist data, the measurement provided is the delay until a first evaluation. Whether wait times to treatment are even more extended, especially in settings where assessments and treatments are provided by different teams, and where there are additional delays post-assessment, is typically unknown.

In addition to waitlists, another major contributor to systemic delays is the complexity of the healthcare system and the ineffective navigation often required in order to reach services. A study of parents of youth with mental health problems in Ontario highlighted that parents contacted multiple providers, across multiple sectors, in their search for help, with 65% of parents having contact with 3 or more sectors [160]. Over the years, the knowledge that substantial delays are experienced following the first help-seeking contact contributed to major interest in the mode and routes by which young people access help - their pathways to care.

Defined as the *"sequence of contacts with individuals and organizations prompted by the distressed person's efforts, and those of his or her significant others, to seek help, as well as the help that is supplied in response to such efforts."*[161], pathways to care represent a natural following point in the study of treatment delays and access to care. Rogler and Cortes (1993) introduced the concept of a help-seeking pathway to describe how people navigate mental health systems. Pathways to care do not occur randomly, but instead intersect with social, cultural and systemic factors which shape both their direction and duration [161]. The study of pathways to care is often used to highlight specific nodes causing treatment delays.

2.3 Pathways to Care

While contemporary research into pathways to psychiatric care has a recent history stemming from the work of Rogler and Cortes, the history of pathways to care research in a larger sense is rooted in anthropological and sociological traditions.

In 1955, American sociologist John A. Clausen and psychologist Marian Radeke-Yarrow published a series of papers in a special edition of the *Journal of Social Issues.* These works, based out of the National Institute Mental Health (NIMH), aimed to describe, for the first time, the impact of mental illness on families. These reports were based on intensive interviews with a small number of families in which the husband was hospitalized for mental illness. In so doing, Clausen and Yarrow undertook what is assumed by many to be the first accounts of pathways to care for mental health issues, and outlined key questions that remain relevant in health service research to this day.

> *"Who defines and who assists in defining the nature of the patient's difficulty? What persons, lay or professional, enter into the process of dealing with the patient and getting him to treatment? What persons, beliefs or circumstances either facilitate or hinder effective action in getting the patient to psychiatric treatment [...]?"* Clausen and Yarrow,
> Path to a Mental Hospital, 1955, p. 25[162]

The first empirical research on pathways to care, led mostly by sociologists, tended to describe critical actors (such as clergy, police, lawyers, and medical practitioners) who influenced the process of seeking and obtaining care [162-165]. Through the 1950s and 1960s, researchers framed the use of health services as a part of the illness career – defined in 1961 by Goffman's seminal work Asylums [166] as the progressions of actions to rectify a health problem. During this period, researchers in the field of medical anthropology took an interest in examining the differences in pathways to mental health care in Western and non-Western countries, mostly focusing on the use of 'alternative healers' (e.g, shamans, curanderos, homeopaths) [167, 168] in an attempt to differentiate individuals who sought services from these healers from the 'medicalized' help-seekers in the Western countries.

By the 1970s, anthropologists had shifted their focus from the stricter medical models of care to the concept of "hierarchies of help-seeking" [168], revealing that individuals, even in Western countries, routinely moved from one type of health provider to another [169]. This approach shifted the focus from service use as an individual one-time construct to a socially constructed 'pattern of decisions'. A recognition followed that despite healthcare organization frameworks, the paths taken by individuals in search of care did not systematically coincide with these predetermined structures. Individual choices instead reflected personal and socialized constructions about the illness , about treatment, and about services.

In the early 1990s, recognizing that the organization of mental health care in low- and middle income countries was failing to meet the needs of their populations, the World Health Organization (WHO) undertook a large, multinational study to examine the pathways to psychiatric care of patients across eleven different countries. Dubbed the Pathway Study [170], this project was conducted under the auspices of the WHO's studies on the Epidemiology of Mental Disorders, and had the specific aim to help inform mental health service organization in economically developed and developing countries. Results from the Pathway Study showed that nature of pathways varied substantially depending on context and resource availability. In regions with access to different types of mental health services, patients took a more direct route from the community to specialized care. However, in areas with few services, patients took a wide variety of different pathways that often included traditional or faith healers.

Various cross-cultural studies have since emerged using the same methodology as the seminal WHO Pathways study. These studies have found that large percentages of patients with psychiatric illness are seen by traditional healers at the beginning of their pathway to treatment, and that these individuals are often delayed in received specialized treatment or medical services [171-173]. In contrast, studies based in high income countries found that generally, general practitioners were also found to play a key role in the identification of mental illness and acted as gatekeepers for accessing treatment in psychiatric settings [174-176].

It is imperative to note that most of the aforementioned studies were conducted through the lens of psychiatric institutions, i.e., they were often conducted within hospital settings, and employed a retrospective timeline interview to ascertain how patients came to use such services. As such, the knowledge garnered through these studies was limited in terms of the severity, nature, and end-point of the individuals whose pathways they chose to study.

In addition to cross-cultural studies of pathways to care, much of the contemporary research on pathways to care stems from the field of first-episode psychosis. The early intervention movement of the 1980s and 1990s was a catalyst to the emergence of evidence for the negative consequences associated with long delays to treatment [124, 145, 177, 178]. This led to initiatives to reduce these delays, requiring an in-depth understanding of the individual pathways and barriers experienced prior to accessing specialized psychosis services, and to several studies exploring pathways to care in first-episode psychosis. A review of pathways to early intervention services found that general practitioners were the most common points of first contact, but the most frequent referral source to psychosis services were Emergency Rooms [179]. This review found inconsistent evidence regarding the effects of gender, colour/ethnicity and socio-economic indicators both on the point of first contact and the referral source to specialized care.

Just like the cross-cultural studies on pathways to psychiatric care were based with the lens of psychiatric institutions, research on pathways to care in early intervention for psychosis also uses a delineated, defined 'end point' from which to look back on retrospectively. This is especially achievable because in early psychosis, the symptoms are relatively clearly defined and the setting of appropriate care is known.

Pathways to care research across the continuum of youth mental health problems is more challenging because a clear, optimal 'end point' representing appropriate care can be difficult to define. Still, recent studies have begun tackling this important issue. One qualitative study with caregivers of youth with mental health problems described parents' frustrations with how services were organized [180]. The authors of the study described the child and youth mental health system as a "more like a labyrinth or a tangled web than a pathway" (Boydell et al., 2006, p. 187). Other studies have explored pathways to care across specific disorders such as ultra-high risk for psychosis [181], ADHD [182], and integrated youth mental health services [183].

In summary, the history of pathways to care research emerged from the anthropological and sociological tradition and the construct of an illness career in the 1960s and 1970s, and was followed by a push by large-scale organizations in an effort to improve service delivery. Further, the drive to eliminate delays to treatment in the field of early intervention for psychosis led to a plethora of research within this field. Yet, a large gap remains in our knowledge of how youth access the care and services they require when faced with mental health challenges across the broad range of issues that can affect youth.

In studying youths' trajectories of mental health service utilization, it is important to have an understanding of the health care systems in which these services are established. The following section covers a brief outline of mental health service organization across different jurisdictions worldwide, with a specific focus on the provision of child and adolescent mental health services within these areas.

Section 3. Child and Adolescent Mental Health Services (CAMHS)

The last few decades have seen dramatic changes in approaches to mental health care delivery. The 1960s and 1970s were marked by the de-institutionalisation movement, radically shifting the focus of psychiatry from asylums and institutes to community-based care. This shift occurred across many countries in a ripple effect. Since that shift, the complexity of providing care across a vast array of settings (inpatient, outpatient, community, primary care, etc.,) and involving many professionals (e.g., primary care physicians, specialist physicians, counselors, psychologists, psychotherapists) has been a challenge for mental health systems across the world.

Globally, expenditure for mental healthcare varies widely. The median mental health expenditure by country has been calculated to be about 2% of total health spending, ranging from about 0.5% in lower income countries and 5% in higher income countries [184]. A calculation of expenditure imbalance (i.e., the proportion of funds allocated to mental health compared to the extent of disability they cause) found that in the United States and Canada, the burden of mental disorders was between 2.5-2.7 times higher than the proportion of healthcare costs allocated to mental health services [185]. The expenditure imbalance was even more pronounced in low- and middle-income countries.

The organization of mental health services often occurs across tiers of service. Within primary care, or Tier 1, service providers include general practitioners, school nurses, teachers, social workers and community organizations. Tier 2, or secondary care services, is often comprised of specialist professionals such as clinical or educational psychologists, nurse specialists, or pediatricians. Third-level services represent specialist care for more severe or complex disorders, and are often comprised of teams of providers, including psychiatrists, in an outpatient setting. Tier 4 services are highly specialized, such as residential or inpatient care.

3.1 Accessing tiers of service

The ways in which young people access healthcare across these different tiers varies widely depending on countries' healthcare models. In Denmark, Finland, and the UK, individuals are registered with a general practitioner (GP) based on their neighborhood postal code, ensuring that all individuals have automatic access to primary care physicians. In Canada, New Zealand, Australia and much of Europe, individuals can register with any general practitioner. In the latter case, access to a general practitioner can be difficult, and the lack of GP access has been decried in many jurisdictions, such as in Canada and in Quebec specifically.

Access to a general practitioner is crucial across many of these countries as their overall model of care is based on a gatekeeper system, which positions primary care physicians between individuals and specialist care. Access to specialist care is often only permitted through initial identification of need and referral by a GP. The main goal of gatekeeper models of care is to facilitate access to specialist care by restricting use to those in need.

In other countries, such as the US, India, Greece, Spain and, until recently, Germany, individuals can access specialist care directly, bypassing the role of primary care gatekeepers. At times, this access is predicated on out-of-pocket payments or higher insurance co-payments, leading to some questions of access equity. A review comparing healthcare models described that individuals in the USA were twice as likely to see a specialist in the previous 12 months compared to those in UK which operates on a gatekeeper model [186]. A different study indicated that specialist service use was disproportionately higher among high-earners individuals vs low-income individuals, and that while this inequity was highest in countries with direct access to specialist services, it was also true of countries employing a gatekeeper system within a publicly funded healthcare context. [187].

3.2 CAMHS within primary care

Many youth with mental health problems, irrespective of healthcare model, will first encounter services within the primary care sector. Schools and general practitioners are often play a determining role in identifying youth at risk and providing initial support.

General practitioners are ideally placed to address emerging mental health issues as young people often have regular access a GP office and may have experience presenting with other health ailments [188-191]. Still, despite the valuable opportunity for primary care physicians to identify and engage youth with mental problems, detection and treatment of mental disorders within these settings is often lacking [192, 193]. Previous research identified certain barriers experienced by GPs when treating mental health problems in young people, including the reluctance to diagnose mental health conditions [194], limited treatment options [195] and limited resources (i.e., time) [196] to effectively manage these conditions.

Many young people also describe receiving mental health support from their schools. Advantages of school-based services include ease of access, specifically through the removal of barriers such as transportation and parental need to take time away from work [197]. Some youth view schools-based services as less stigmatizing setting for receiving mental health services. Still, challenges exist in the provision of care. Many school-based interventions focus primarily on promotion of positive mental health and prevention [198], with few resource dedicated to treatment and even fewer to the provision of evidence-based interventions. Schools may not benefit from robust links with medical services, and schools often preferred to provide services in-house [177], perhaps due to difficulties referring to specialist or medical services [199] . Youth themselves at times describe that receiving mental health services in schools is actually more stigmatizing as their peers are aware of their issues and confidentiality concerns are common [181].

Both GPs and schools describe a difficulty in connecting with specialist care. This suggests that while some young people may benefit from services provided within primary care, others, with more complex or evolving needs, may find themselves falling through the cracks as the services provided for them are unable to meet their needs and unable to connect them with services that can.

3.3 CAMHS within specialist services

Within psychiatry, the formation of the subspeciality of child psychiatry is a relatively recent advancement, stemming from the establishment of the first dedicated unit by Leo Kanner in 1930, following seminal work from him and others specifying the developmental and psychopathology of children. Even more recently has the concept of adolescent psychiatry emerged within child psychiatry discipline, leading to the reform of many groups as 'child and adolescent psychiatry'.

Accessing specialist services such as child and adolescent psychiatry can be difficult irrespective of type of healthcare system. In countries employing a gatekeeper model of care, factors that determine who is referred to specialist CAMHS by GPs is not well understood. Referrals tend to be linked to symptom severity, though specifically to symptoms of antisocial or externalizing behaviours [200]. Often, parents' request for a referral is an important determinant in reaching specialist care [200]. As described previously, in countries where direct access to specialist is available, at a cost, issues of equity have been raised, with insurance and income being primary drivers of whether young people will access services [187]. Overall, requiring referrals to specialty mental health care services can create additional barriers to care [201]. Reducing referral requirements may also encourage service providers in primary and secondary care sectors to more efficiently direct youth to appropriate mental health services and reduce delays to treatment.

Moving forward

As noted above, there is increasing momentum in the transformation of youth mental health services to address some of the gaps and problems in delivery of care. Given geography, political and diversity within mental health systems, the implementation of such transformation is likely to only be successful if adapted to context and culture. Still, some evidence is being generated for commonalities across successful youth mental health service settings. There is good evidence that the optimal mental health treatment setting for children and adolescents is a non-restrictive, community-based environment [202]. Other studies looking at best-practices within youth mental health service reforms indicated the importance of a) youth and family co-design b) system targeting to youth 12-25 c) integration of mental health, physical health, substance use, and vocational support. d) A single "one stop shop" e) elimination of transitions such as those between child-adolescent and young adult services. A systematic review of common elements across "youth-friendly" mental health services concluded with the following definition :

> *"A youth-friendly mental health and substance use service is one that is accessible, appealing, flexible, confidential and integrated, where youth feel respected, valued, and welcome to express themselves authentically, without discrimination of any kind; it is a developmentally and culturally appropriate service that mandates youth participation in service design and delivery, to empower youth and help them gain control over their lives."*[203]

Section 4. Mental Health Utilization & Pathways to Care

> *"In a perfect world, the mere presence of symptoms would be sufficient for people to desire and obtain treatment. Since this is not the case, knowing who receives care or who has a propensity to seek care informs us about what happens to people with mental health problems"*

Bernice Pescosolido and Carol A. Boyer , How Do People Come to Use Mental Health Services, 1999, p.395[204]

The use of mental health services is often conceptualized as the result of individual behaviour. Several theoretical service utilization models have been developed to help understand this type of behaviour, and its relation to an individual's use of healthcare services. The first such help-seeking models were developed to address adult help-seeking for physical health ailments.

1960s and 1970s

The Health Belief Model (HBM) [205] focused on the influence of an individual's attitudes and beliefs on their decision to seek formal medical care. This model was later categorized as a 'socio-cognitive' model as its places importance on the role of thoughts and perception in the help-seeking process. This was followed by Anderson et al.'s 'socio-behaviour model' (SMB) [206], which shifted the focus from thoughts and cognition to the role of various structural factors in service utilization. Anderson's model, considered one of the most influential models of health care utilization, and certainly one of the most widely used, identified three stages of help-seeking: identification of the problem, the decision to seek services, and the selection of a service. Andersen's model then proposed three sets of factors which are used to predict the use of services: predisposing (e.g, gender, age, race, beliefs), enabling (e.g., income, access to care, family support) and need (e.g., presence and severity of a health condition, perceived need)

1980s

Andersen's model and the studies that followed it demonstrated the importance of cultural and social factors in the demand for services. Ethnographic studies from the 1970s and 1980s made important contributions in this regard, including the emergence of the concept of Explanatory Models, developed by Arthur Kleinman in the 1980s [207]. According to Kleinman, explanatory models of illness were the conceptions about the disease, and about treatment, that will define which service sectors are utilized during the help-seeking process.

1990s

These theoretical models tended to be rooted in a need to find out whether people were using medical, vs non-medical, sources of help – and why. This conceptualization of utilization as simply the decision to use a medical services has been suggested to reflect a ”medical model bias” [208].

In line with this medical bias, Goldberg and Huxley described a framework for pathways to psychiatric care which identifies sequential filters through which a patient passes to reach specialist care [209]. To move sequentially from one level to another, individuals are assumed to pass through filters. Since these filters are selectively permeable, some individuals are more likely to pass through than others. The filters refer to (a) problem recognition by the individual and his decision to consult a GP, (b) problem recognition by the GP, (c) referral to mental health care by the GP, and (d) admission to in-patient mental health care. The model assumes that patients generally initiate care at the level of primary care and are subsequently referred to psychiatric specialists, thus is primarily useful for gatekeeper-models of healthcare organization. The effectiveness the model also depends on symptom presentation, the primary care provider’s ability to recognize need for mental health treatment, and the ability of GPs to refer to specialist care.

Limitations:The models described above differ in scope and emphasis, but have key elements in common. First, help-seeking is represented as a stage-like process, beginning with emergence and recognition of a problem, and followed by a decision to seek services. Second, this process of help-seeking is affected by a variety of factors, from factors at the individual level (beliefs, attitudes) to structural levels (e.g., access to care, availability of services). However, some limitations exist in these conceptualizations of help-seeking and service utilization. First, these models all view the formal medical system as the primary actor in the help-seeking process. Yet, empirical evidence on pathways to care, especially in the field of mental health, paints a much more complex picture of the types and sequence of contacts made by an individual experiencing mental health problems. For instance, many patients have been shown to seek help from outside the formal medical system outlined in Goldberg and Huxley's model. In addition to primary care providers and hospitals, help-seeking pathways may involve such diverse contacts as emergency services, social services, the criminal justice system, school counsellors, and religious figures. Noteworthy contacts along the pathway to care, including police, ambulatory, or judicial services, are not accounted for in Goldberg and Huxley model. Further, all models rely on the assumption that individuals are making rational decisions about service utilization, and that this decision is entirely voluntary, and all models rely on a first stage of problem recognition by the individual. Yet, even the earliest work on pathways to care demonstrated that problem recognition is not always the first step to service utilization. In Clausen and Yarrow's work, wives were the instigator of care, and often the patient, their husband, did not recognize a need for care until long after the treatment had been commenced.

Finally, the models are considered inflexible, not adequately representing the reality of fluid pathways to, and across services. These limitations were addressed by subsequent models developed in the decades that followed.

2000s-present

New models emerged as researchers began to rethink the failure of utilization models to explain whether and why individuals accessed formal treatment systems. This effort focused on reconceptualizing the underlying assumptions and processes that shaped utilization patterns, including the role of individual choice in entering services and the possibility of multitude of entrances into the healthcare system. One of these models, Network Episode Model (NEM), [210] shifts away from the focus on individual roles to a community-based perspective on health service use. The NEM, which builds on the Anderson's socio-behavioural model,focuses on patterns of use and considers service use a dynamic process, as opposed to linear. This includes the assumption that individuals can be in different places in the help-seeking process, simultaneously. For example, individuals can already be in services when they recognize a need for help or identify a problem.

The Network Episode Model expands upon the classic medical models and argues that seeking help is a social process shaped by networks including the community, family, friends, social services and treatment systems [211]. The NEM also marked a return of the concept of the illness career, described previously, whereby help-seeking as a dynamic process occurring over the course of a lifetime, or illness episode. Finally, the authors of the NEM suggest that individual, voluntary choice is not the only entry way into services. This concept has been subsequently confirmed through their own studies, in which 50% of mental health service users had come to the services by choice, one quarter had entries to care linked to coercive methods, and one-quarter had 'muddled through' (i.e., had no clear narrative as to how they ended up receiving care.) These types of entries to care have similarly been found in youth narratives of pathways to care [212-214], reviewed in Chapter IV of this thesis. Over time, the NEM was revised (the Revised NEM -III, [215]) and expanded upon to include a focus on youth, and on the role of gatekeepers' help-seeking efforts on youths' behalf (Gateway Provider Model, [216]).

Limitations: While the NEM addressed many of the shortcomings of previous theoretical models, some have criticized the model as being conceptually sound, but difficult to test empirically. To address this, in 2012, Munson and colleagues developed theory of mental health service utilization among young adults (Framework Of Mental Health Utilization by Young People, [217]). The conceptual model integrated concepts from both the Network-Episode Model and a health behavior change theory, the Unified Theory of Behavior (UTB). This new model specified determinants of intention to use services, as well as contextual dimensions, including quality of relationships between youth, service providers, and families, and

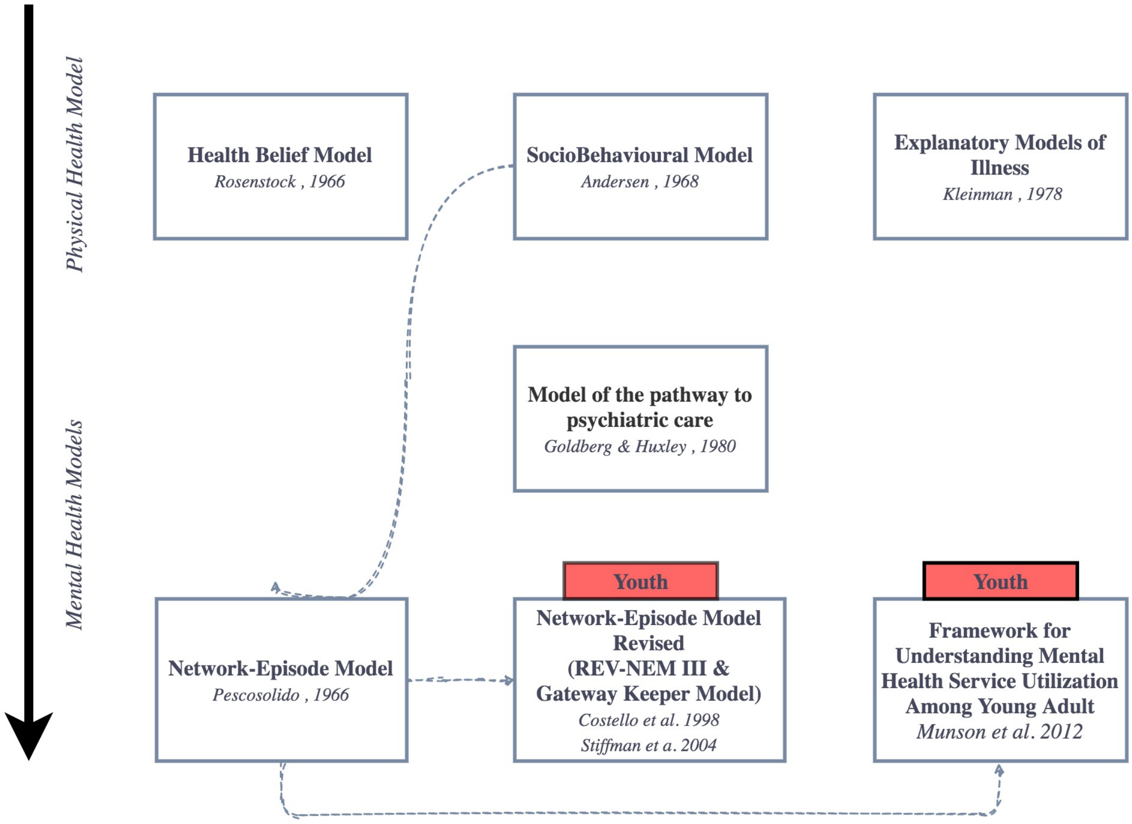

Figure 2. Health Service Utilization Frameworks

the availability of services, which influence youths' service use and allowed for more directed empirical tests. Recent studies have employed Munson et al.'s framework to examine how the social world affects service use, in different youth populations including youth in systems of care [218] and in early psychosis settings [219].

In summary, these theoretical models (See Figure 2) and the empirical research stemming from them represent service use for mental health care using two distinct approaches. The first approach explores characteristics of service users and non-users, typically of traditional medical services. Such profiles of users can be used to predict patterns of service use, and can be used to target hard-to-reach groups or to explore barriers to care. The second approach, a more dynamic conceptualisation, focuses on how symptoms are interpreted and managed by individuals, as well as their social networks, over the course of time. In this approach, carers, referral networks or informal sources of help, all play a key role.

The research stemming from these two approaches are not necessarily contradictory, but address different questions. On the one hand, the angle of inquiry may be simply to investigate if help is being accessed, while on the other, the concept of ”where, when and how” help is accessed is prominent.

For this reason, some pathways to care researchers have called for increasing use of mixed methods, triangulating findings from different research streams, in an attempt to address these types of research questions more holistically [204, 220].

Chapter 2. Research Rationale, Approach, and Context

Research Rationale

As described previously, the majority of psychiatric conditions emerge before the age of 25, and mental illness is the largest contributor to burden of disease in young people. The current mental health system is failing to provide access to services that is easy, engaging, and timely. Instead, young people and their families consistently describe mental health help-seeking as a long, painful and complicated journey. These complex pathways to care delay treatment. For youth, who are at critical developmental junctures, longer durations of untreated illness can have grave impacts on the foundations of their adult lives and can be associated with worse clinical outcomes.

It is essential that appropriate mental health services be made accessible early and effectively in the development of such problems, to prevent their negative effects and reduce long term consequences. Yet, empirical knowledge on the pathways to mental health services for young people across the broad spectrum of mental health disorders is lacking. These gaps must be addressed if we are to truly improve youth mental health services and outcomes.

Objectives:

This dissertation aims to advance understanding of pathways to mental health services for young people in order to guide efforts to improve service delivery. The objectives of this dissertation are :

a. To describe and understand of pathways to care for youth populations, with the overarching goal of contextualizing the current state of knowledge, and to identify the gaps to be addressed.

b. To describe pathways to mental health services for young people in the specific context of child welfare services, and to identify specific predictors of such patterns of service use for young people in this context.

To address these objectives, the following research questions will be addressed.

a) What is the current state of knowledge on pathways to care for young people across contexts and for the broad range of mental health disorders?
b) How do youth and families describe their experiences of pathways to mental healthcare?
c) What are the pathways to mental health services for young people involved in child welfare services, including the primary stakeholders involved in initiating their care?

Research Significance:

This body of work directly addresses several knowledge gaps in the mental health service use of young people. While prior research has been conducted on pathways to care for institutionalized, adult patients as well as for youth experiencing a first episode of psychosis, there is limited research into pathways to care for youth across a broad range of mental health problems. This knowledge gap is problematic as current reforms in youth mental health service delivery across the world are based on increased accessibility and the early identification of youth, yet little is known about where and how youth are currently receiving care. Past research has demonstrated the importance of tailoring services to promote better and more equitable access to all youth seeking mental health care. These initiatives require the knowledge of barriers that young people face when seeking help for mental health issues in their context, and to identify disparities in the uptake of health services. Increasing access to services for youth has the potential to improve outcomes, prevent significant delays in achieving personal milestones, and to alleviate distress among youth and their families.

This work also addresses the needs of youth in child welfare services. While their heightened need for mental health services is well-acknowledged, few studies have investigated the patterns of mental health service use among youth in child welfare services, including the types of interventions and service settings commonly used. Understanding the components of the pathways to mental health care and their impact on treatment delays is essential for the better delivery of mental health services.

Overall, this work will examine how youth and families access mental healthcare in a novel and comprehensive fashion. The knowledge generated through these studies can help inform policy and service recommendations for the design of interventions that reduce treatment delay and facilitate direct, youth-friendly pathways to care. Decreasing delays to services for youth has the potential to improve outcomes, to prevent significant interruptions in achieving personal milestones, and to alleviate distress among youth and their families, and would globally reduce the societal burden imposed by mental health problems.

Research Approach

Cabral et al. [221] identified three main avenues of pathways to care research: the first, a systems approach, is focused on barriers, gaps and accessibility within health systems; the second, a patient-oriented approach, is focused on patient perceptions and experiences; and the third, the contextual approach, integrates service use as part of a cultural and social context. We have outlined this dissertation according to these approaches.

First, in Manuscript I, a systems approach will be utilized through the examination of pathways to care within different mental healthcare systems, through a systematic review of published quantitative literature from across the world.

Second, in Manuscript II, a patient viewpoint approach will be employed, through the meta-synthesis of youth and family experiences related to their own pathways to mental health care.

Finally, Manuscripts III and IV represent a contextualized approach, whereby service utilization and pathways to care are examined in the context of a specific setting. In this case, we focused on a previously understudied group, youth involved in child welfare settings, who, as described previously, often have high rates of mental health problems and specific needs for services given their context and environment. While the second part of this dissertation is based on data collected from services in Montreal, Canada, the insights generated from these studies will add to the growing body of literature addressing youth mental health service utilization around the world.

The following dissertation adopts the paradigm of pragmatism as a guiding orientation. Pragmatism is an approach based on the worldview that research should emerge from the desire to produce actionable knowledge and embraces a plurality of methods suitable to address identified research questions [222]. The focus of pragmatic research orientations is largely on the consequences or outcomes of the research questions, rather than primarily the methods employed [223]. This approach was adopted due to the overarching aim for the research production to focus on real-world problems and identify actionable, real-world solutions to these problems.

Preface

As outlined in Chapter 1, contemporary research examining pathways to care has mostly emerged out of the field of early intervention (EI) for psychosis. The examination of pathways to care in this field has allowed researchers and clinicians to flag any ‘missed opportunities’, e.g., nodes along the pathway to care where symptoms of psychosis could have been identified and links to EI services strengthened. Such efforts have been widespread; and systematic reviews on pathways to care in psychosis were published in 2006 [224], and in 2013 [179]. Given the potential benefits of analyzing pathways to care to improve service delivery, reduce treatment delays and provide young people “softer” landings into care, it is important that examinations of youths’ pathways to mental health care span the entire range of mental health problems. Recognizing this need, we undertook the first systematic review of studies investigating pathways to care, across the broad spectrum of youth mental health problems, in order to establish the state of the literature in this field.

The following manuscript was published in the journal Social Psychiatry and Psychiatric Epidemiology in 2018, as a peer-reviewed Invited Review.

Chapter 3

Manuscript I

Pathways to Mental Health Services for Young People : A Systematic Review

Kathleen MacDonald, Nina Fainman-Adelman, Kelly K. Anderson, and Srividya N. Iyer
Social Psychiatry and Psychiatric Epidemiology 53, no. 10 (2018): 1005-1038.
https://doi.org/10.1007/s00127-018-1578-y

Publisher : Springer Nature
Date : August 22nd, 2018

Abstract

Purpose : While early access to appropriate care can minimise the sequelae of mental illnesses, little is known about how youths come to access mental healthcare. We therefore conducted a systematic review to synthesise literature on the pathways to care of youths across a range of mental health problems.

Methods : Studies were identified through searches of electronic databases (MEDLINE, PsycINFO, Embase, HealthSTAR and CINAHL), supplemented by backward and forward mapping and hand searching. We included studies on the pathways to mental healthcare of individuals aged 11–30 years. Two reviewers independently screened articles and extracted data.

Results : Forty-five studies from 26 countries met eligibility criteria. The majority of these studies were from settings that offered services for the early stages of psychosis, and others included inpatient and outpatient settings targeting wide-ranging mental health problems. Generally, youths' pathways to mental healthcare were complex, involved diverse contacts, and, sometimes, undue treatment delays. Across contexts, family/carers, general practitioners and emergency rooms featured prominently in care pathways. There was little standardization in the measurement of pathways.

Conclusions : Except in psychosis, youths' pathways to mental healthcare remain understudied. Pathways to care research may need to be reconceptualised to account for the often transient and overlapping nature of youth mental health presentations, and the possibility that what constitutes optimal care may vary. Despite these complexities, additional research, using standardized methodology, can yield a greater understanding of the help-seeking behaviours of youths and those acting on their behalf; service responses to help-seeking; and the determinants of pathways. This understanding is critical to inform ongoing initatives to transform youth mental healthcare.

Keywords : youth mental health, mental health services, pathways to care, help-seeking behaviour, treatment delays

Introduction

Most psychiatric conditions emerge before the age of 25 [1]. Mental illness is the largest contributor to the burden of disability-adjusted life years (DALYs) among young people aged 0–24 in high-income countries and the seventh-highest contributor to DALYs in low- and middle-income countries. Globally, mental illnesses account for a quarter of all years lived with disability (YLDs) in children and youth aged 0–24 [2].Despite this heavy burden, many youths with mental health problems remain untreated or face delayed detection, long waitlists and multiple help-seeking contacts before obtaining appropriate care [1, 3].

Such complex ‘pathways to care’ delay treatment. For youths (typically understood as individuals who are within the critical development juncture between childhood and adulthood, i.e., aged between 11 and 25–30 years old [4, 5]), longer durations of untreated illness can have grave impacts on the foundations of their adult lives and can be associated with worse clinical outcomes [6, 7]. Pathways to care—defined as the “sequence of contacts with individuals and organizations prompted by the distressed person’s efforts, and those of his or her significant others to seek help, as well as the help that is supplied in response to such efforts” [8]—have been garnering research attention for several years.

In the early 1990s, a multinational study by the World Health Organization (WHO) [9] showed that pathways to mental healthcare varied substantially depending on context and resource availability. In regions with access to relatively well-developed mental health services, patients experienced more direct routes from the community to specialized care. However, in areas with few services, patients experienced a wide variety of pathways that often included traditional or faith healers. In the field of first-episode psychosis, concern with the adverse consequences of delayed treatment [10] has spurred numerous investigations of pathways to care and barriers to accessing specialized services [11]. In addition to primary care providers and mental health services, help-seeking pathways for psychotic disorders involve diverse contacts like emergency rooms (ERs), social services, the criminal justice system, school counsellors, and religious agencies. Pathways to psychosis services have been known to be influenced by several socio-demographic factors, including gender, age, ethnicity, and socioeconomic status [12]. However, these findings have been inconsistent and their implications for policy and service delivery difficult to assess.

Sequences of healthcare contacts do not occur randomly [8], but are influenced by multiple intersecting individual, social, cultural, and systemic factors. Studying pathways to care allows us to identify the loci of barriers and delays to treatment; and key agents in the help-seeking process, including individuals in distress, family/carers, informal contacts (e.g., teachers, employers, web resources, etc.), and formal health services. Such knowledge is crucial for providing timely access to services.

New youth mental health initiatives [13], particularly in Australia, Canada, Ireland and the United Kingdom, are striving to make appropriate services accessible early in the course of mental illnesses to mitigate their short- and long-term negative consequences. It has been argued that extant conventional mental health systems are neither youth friendly nor sufficiently accessible. Young people and their families have described mental health help-seeking as a long, painful, and complicated journey. Though they represent the peak incidence of mental health problems, youths are frequently the least likely to use mental health services [14] and often receive help only when their problems become crises. Their help-seeking efforts may also be impeded by repeated evaluations and difficult transitions, especially between child and adult services [15].

Although literature reviews on pathways to care have been conducted in the field of psychosis [11, 16] and across adult mental health disorders [17], evidence on the different trajectories youths follow to obtain mental healthcare has yet to be synthesized. Such a synthesis is essential if ongoing efforts to transform youth mental healthcare [13, 18] are to achieve their ends. Our objective was therefore to conduct a systematic review of literature on young people's pathways to care for a range of mental health problems.

Methodology

The protocol for this systematic review was developed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses [19] (PRISMA) and was registered at the PROSPERO Centre for Reviews and Dissemination (ID: 42016039208) in June 2016.

Search strategy

Search terms were generated by consulting 20 experts in youth mental health across disorders, and a university librarian. We included search terms related to pathways to care; service utilization; help-seeking; mental disorders; and delays to treatment (see online supplementary material for search strategy). Relevant studies were identified through searching five electronic databases: MEDLINE (1946 onward), Embase (1947 onward), PsycINFO (1967 onward), HealthSTAR (1966 onward) and CINAHL (1937 onward). Articles were further identified using backward and forward citation mapping of selected articles using Web of Science, and hand searches of journals that had previously published material on pathways (n = 4). The electronic search was conducted in July 2016 and updated in March 2018.

Selection of relevant studies

Two experts independently screened titles, abstracts, and keywords and resolved disagreements by consensus. Articles were included if they were peer-reviewed; were written in English or French; and reported quantitative findings. To be selected, studies had to focus on youths' individual trajectories to seeking or receiving treatment for mental health or substance use at any establishment, regardless of the presence or absence of a formal diagnosis. The mean age of study participants had to be between 11 and 30 years (so as to include the largest possible range of definitions of 'youth' used in pertinent literature). Alternatively, at least 50% of a study's sample had to be within that age range. We excluded studies of youths with chronic physical health conditions or a primary diagnosis of intellectual disability. Full texts were obtained for all potentially relevant studies. Two reviewers independently screened the full text of each article to check whether it met inclusion criteria. The authors of six studies were contacted for additional information to determine their eligibility. Of these, three authors responded and provided data that had not appeared in the original studies, which were then included in our review.

Data extraction

A data extraction sheet was created and refined following pilot testing on ten randomly selected included studies. Two reviewers independently extracted and compared data from all included studies and resolved disagreements by discussion. We extracted data on participant demographics, study design, instruments used, study setting, healthcare context, pathways to care, and measures of treatment delay. If needed, authors were contacted for clarifications or missing information. The two reviewers also independently ascertained the quality of each included study using a rating scale adapted from the Newcastle–Ottawa Quality Assessment tool [20], which had been used in a systematic review on pathways to care in first-episode psychosis (See Supplementary Material) [21].

Results

The electronic search yielded 17,381 publications, including 1454 from the March 2018 search update. Hand searching yielded another 45 articles. After duplicates were removed, 11,524 studies remained. Initial title and abstract screening identified 845 potentially relevant studies for full-text screening. Of these, 45 studies fulfilled the inclusion criteria (see Fig. 1). The main reasons for exclusion were misalignment of studies' objectives with those of this review, study methodology, language, and participants' age ranges. Five studies were excluded post hoc because their participants' age ranges could not be established (n = 3), or for involving the same participants as other included publications (n = 2).

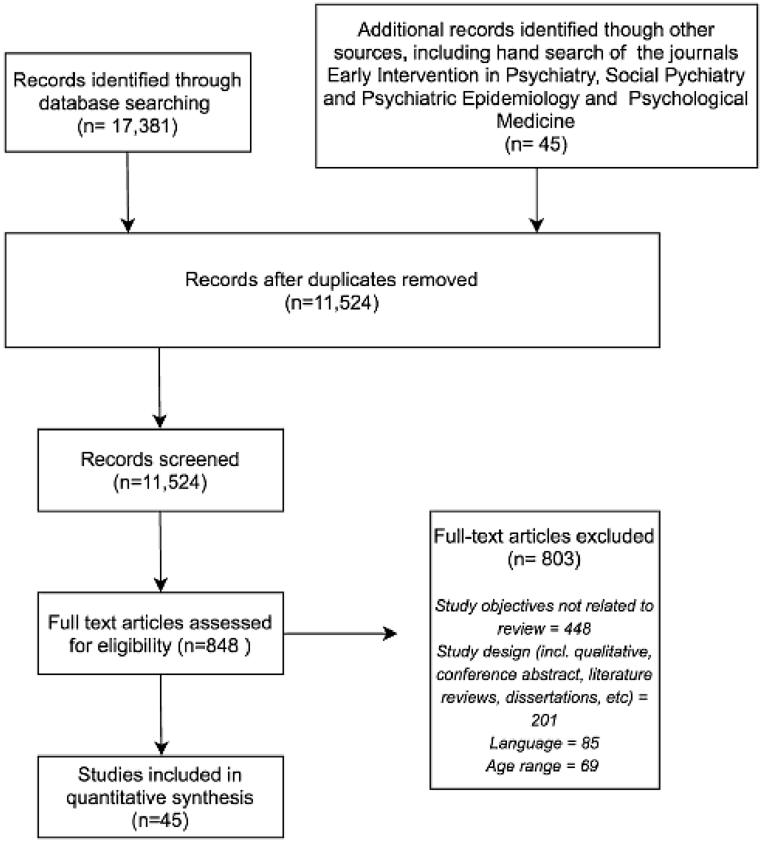

Figure 1. PRISMA Flow-Chart of Included Studies

Study characteristics and settings

The characteristics of included studies are summarized in Table 1. The studies were conducted across a wide range of countries (n = 26). Their sample sizes ranged from 15 to 1266 (mean = 203). Twenty-six studies were conducted in early intervention services for psychosis. Other study sites were general psychiatric inpatient (n = 3) and outpatient units (n = 9); and specialized services for youths with anorexia (n = 1) and those at risk for psychosis (n = 6)

Healthcare system and organizational contexts

We extracted information about the healthcare system in which each study was conducted (Table 2). Many studies described organizational features, including available healthcare tiers (e.g., public/private) and local practices (e.g., preference for traditional healers). Fourteen studies reported allowing open referrals, wherein direct referrals to the services were possible. Two studies described a gatekeeper system where referrals from primary care were required to access mental healthcare. All other studies did not specify their settings' referral systems.

Instruments and data sources

Studies differed in the instruments used to ascertain pathways to care. The majority had developed their own interview guide or questionnaire (n = 22) but provided limited to no information on the methodology used to develop the measures or their psychometrics. Semi-structured interview based instruments included the WHO Encounter Form [9] (n = 14); the Circumstances of Onset and Relapse Schedule [67] for early psychosis (n = 4); the Pathways to Care Schedule [68] (n = 3); and the Basel Screening Instrument for Psychosis [69] (n = 1). One study used the structured Referral Sequence and Problem Interview [49]. Irrespective of the instruments used, most studies collected and corroborated information from multiple sources (n = 27). In these cases, individual interviews were supplemented by family/carer interviews and/or chart review. Some studies relied on a single data source—patient interviews (n = 16) or chart information (n = 2). One study used national registry data, which included healthcare contacts and durations of untreated illness.

Timeframes

Timeframes for delimiting pathways to care, i.e., the start and endpoints of journey into care, differed widely across studies. Startpoints included the onset of symptoms or initial suspected illness (n = 22); 6 months preceding entry (n = 1); lifetime (n = 4); 28 days preceding prodromal symptom onset (n = 1); 48 h prior to admission (n = 1); and first contact with health services (n = 1). Endpoints included entry or referral to a specialized service (n = 13); admission to hospital (n = 8); initiation of care (n = 7); and entry to a general psychiatric service (n = 5). For studies that did not specify a timeframe but used the WHO Encounter Form (n = 5), we assumed that instrument's stated timeframe of 12 months preceding the interview (see Table 2). Other studies did not specify clear start (n

= 10) or endpoints (n = 7).

Pathways to care

The focus of this review was on articles that examined individuals' pathways to care (i.e., sequence or number of helpseeking contacts). Outcome measures included descriptions of full trajectories, or first and last contacts before a specific endpoint. Considered clinically relevant, first and last contacts are often described in pathways to care studies [16]. Thirty-five studies described full pathways to care sequences, including the total number and types of contacts in individual participants' pathways to care. Seven studies described the most common pathway contacts for their sample, in addition to common first and last contacts. Three studies described the most common overall and first contacts along participants' pathways to care (see Table 3).

Overall pathways

Twenty-eight studies reported the number of contacts before receiving specific services, which ranged from 0 to 15 contacts per participant (with a pooled mean across studies of 2.9 contacts). One study [43] dichotomized pathways into 'short' (three or fewer services before referral) and 'long' (four or more services). Its authors noted that the number of contacts did not always indicate pathway complexity or length of delay. For example, a pathway with many contacts could reflect appropriate referrals as mental health problems progressed, whereas shorter pathways could reflect repeated contacts with specific services or concurrent use of different services before an appropriate referral.

Key pathway agents

Contacts involved in young people's pathways to mental healthcare were varied and included medical professionals (general practitioners, psychiatrists); non-medical professionals (psychologists, social workers, counsellors, school teachers, rural healthcare workers); informal sources of help (family, friends, employers, colleagues); healthcare institutions (emergency services, inpatient units, walk-in clinics); criminal or justice system (police, prisons, lawyers, courts); traditional or faith-based healers (prayer houses, priests, herbalists, clergy); and technology-enabled contacts (websites, helplines, crisis lines) (Table 3).

First contact

Twenty-nine studies reported the first contact along the pathway to care. In order of frequency, young people's first help-seeking contacts were general practitioners (14/29); psychiatrists or specialized services (5/29); faith or traditional healers (4/29); ERs/inpatient units (3/29); family or friends (2/29) and social workers (1/29). General practitioners were among the top three most frequent first sources of help in 24 of 29 studies.

Referral sources

Studies of pathways to care often describe their referral source as the 'successful contact', i.e., the contact that resulted in an individual obtaining the service in question. Twenty-two studies examined referral sources. Of these, eight described the ER/inpatient unit as the most common 'successful' referral source. Self-referrals (i.e., referrals made by youths themselves, or by family/carers on their behalf) were the most frequent referral source in six studies. Other prominent referral sources included general practitioners, general hospitals, helplines, and outpatient units.

Treatment delays

Of the 39 studies that measured treatment delay, 23 were from first-episode psychosis settings, and 16 were from other mental health services (see Table 2).

Duration of untreated psychosis (DUP)

DUP is defined as the time between the onset of symptoms and the start of appropriate care (operationalized as the commencement of antipsychotic medication or admission to services). Across the 23 studies that reported DUP, mean DUP ranged from 1.5 to 102 weeks and median DUP ranged from 8 to 130 weeks. Of these 23 studies, 10 also assessed 'help-seeking delays' (time between the onset of initial symptoms and contact with the first pathway agent) and 'referral delays' (time between contact with the first pathway agent and the commencement of treatment at the study setting). Of these, three studies found that help-seeking delays exceeded referral delays [12, 34, 36]; six studies found referral delays to be longer, [35, 39, 40, 45, 48, 53]; and one study [54] found an even split between both delay components.

Duration of untreated illness (DUI)

Fifteen studies from a range of mental health settings described the length of treatment delays to their services. Although definitions of DUI varied, most studies conceptualized it as the time between the onset of symptoms and the commencement of treatment at their setting. DUI estimates ranged from 1 week to 45 years (Table 2). Despite our inclusion criteria focusing on young people between the ages of 11 and 30, the upper end of the range for DUI is 45 years. This is because we also included studies in which at least 50% of the included sample was in the age group of interest. Unfortunately, some of these studies did not break down their delay indices by age group (See Table 1 for participant characteristics for each included study.) At the very least, this wide range for DUI is indicative that there are often extremely lengthy delays before the receipt of appropriate treatment. Eight studies divided DUI into help-seeking and referral components. Of these, three studies reported lengthier help-seeking delays [28, 55, 56] and five reported lengthier referral delays [41, 43, 46, 51, 64]. Impact of pathways to care on treatment delays Seven studies found that encountering specific pathway agents affected treatment delay. One study [29] found that initial contacts with counsellors or courts led to longer DUPs. DUPs were shorter following any contact with general practitioners [56, 59], or following referrals from emergency services [42]. In settings other than psychosis services, contacts with traditional or faith healers [46] or private general practitioners/physicians [41] were notably associated with longer DUIs. Family involvement during help-seeking was associated with shorter help-seeking delays in one study [54].

Factors influencing pathways to care

Often, families/friends played a substantial role in the initiation of treatment. In two studies [26, 41], 70% of participants had sought mental healthcare on the advice of family. One of these studies [41] contrasted this with the much lower rate of individuals deciding on their own to seek services (16%). Families were found to be highly involved at various points along the pathway to care by recommending sources of help [28, 52], being the most common first source of help [36, 39, 62], directly initiating contact [31, 41, 54, 70] or being the most common contact [37, 60]. Studies' methodologies may have influenced their findings. For example, while 12 studies included families/relatives in their definitions of help-seeking contacts, 26 studies only considered professional contacts. Seven studies did not explicitly describe their inclusion criteria for pathway contacts.

Negative pathways to care

Negative pathways, generally defined as those involving contacts with the criminal justice system, emergency or inpatient units, are associated with poor patient experiences and disengagement [12]; and high costs, despite sometimes resulting in reduced treatment delays. A number of studies explored the involvement of police and emergency services along pathways to care. In a study whose entire sample was African–American [34], over a quarter of participants had at least one contact with police, and police accounted for a fifth of all contacts. In another US study [33], the pathways of over half the Black participants featured some police involvement, a rate significantly higher than that observed in other ethnicities. In a Canadian study [71], emergency rooms were four and three times more likely to be the first contact for Asians and other ethnicities, respectively, than for White and Black participants. Overall, emergency services figured prominently as pathway agents across studies and contexts (n = 15).

Costs

Two studies [30, 44] examined the costs associated with various pathways to care. In a Canadian study [30], pathways to care involving inpatient units were 18.5 times costlier than pathways with no inpatient unit involvement. This was attributable to the greater involvement of police and emergency services with participants who ended up being inpatients. An Indian study demonstrated that the median monetary cost of an individual's pathway to care was more than half the average family's monthly income [44].

Conceptual frameworks

The only three studies that explicitly described being guided by a framework [26, 41, 50] all used Goldberg and Huxley's conceptual framework [72]. This framework proposes that mental health problems manifest at five levels (from in the community to among those in specialized care), with individuals' advancement to subsequent levels being checked by selectively permeable filters that pertain to problem recognition (e.g., by general practitioners) and referral (e.g., to specialized care).

Quality appraisal

The methodological quality of the studies was mixed (see Table 4 for quality scores). Six studies met over 75% of the quality appraisal criteria; 34 studies met 50–75% of the criteria; and five studies met under 50% of the criteria. Key limitations were insufficient reporting on sample size determination; low participation rates or inadequate differentiation between participants and non-participants; and non-standardized ascertainment of pathways to care.

Discussion

Pathways to mental healthcare for youths tend to be complex, with multiple help-seeking contacts, and, sometimes, lengthy delays before appropriate care begins. Across many contexts, general practitioners played a prominent role in the help-seeking process. The role of primary care is notable given the international consensus that integrating mental health services within primary care is essential to address gaps in mental healthcare provision [73].

In our reviewed studies, primary care physicians were more frequently among the first help-seeking contacts than a ‘successful’ referral source. To be the first line of mental healthcare, primary care providers must be adequately trained to effectively detect problems, render support, initiate treatment, coordinate with all healthcare tiers, and refer appropriately. Across settings, families played an influential role along pathways to care. This highlights the need for including families as pathway agents, something only few studies did. It also indicates that families need to be targeted in outreach efforts to reduce treatment delays for youths. Thus, giving due regard to families is important because familial involvement is known to mitigate the negative effects of and facilitate recovery from many mental illnesses [74]. Given the increasing rates of hospitalization and emergency visits among youths with mental health problems [75], and the high rates of emergency services involvement noted in our review, it is necessary to improve our understanding of the determinants of and trajectories to these endpoints that are associated with high personal and societal costs. Notably, the reviewed studies offer limited insights into what determines which youths follow these negative pathways, barring examinations of ethnicity as a determinant in the case of psychosis [23, 33, 34, 71].

Many of the factors leading to fragmented or difficult access to mental health services occur across age ranges. Studies assessing pathways to care in young children [76] and older adults [77] have also reported complex trajectories prior to obtaining services. Notably, however, many mental health systems have attributes that are known to disrupt care specifically for youth; chief among these being the transitions from child–adolescent to adult services [15]. These transitions, often rigid and poorly executed, can lead to disengagement from services and poor clinical outcomes. As such, it may be important for future research to prospectively assess pathways into and through services, and to pay specific attention to how transitions across mental health systems contribute to treatment delays and complicated pathways.

Reconceptualising pathways to care beyond psychosis.

This review reveals that knowledge on pathways to care in youth mental health is largely driven by first-episode psychosis literature. This is likely due to the field's focus on reducing the DUP. Despite some disagreements on optimal treatment [78], there is enough consensus on care benchmarks for early psychosis researchers to clearly define 'appropriate care' and precisely delimit youths' pathways thereto. Also, early intervention programs for psychosis target age groups that match our review's age-based selection criterion. There is an evidence base for the adequacy of treatment for mental disorders other than psychosis [79]. Efforts to quantify treatment delays have also expanded to more disorders, with the adoption of DUI measures in bipolar [80], anxiety [81] and mood [82] disorders. Yet, specific inquiries into pathways to care across these disorders, at least with respect to youth-focused literature, remain limited, as does our understanding of the association between pathways to care and treatment delays.

The concept of appropriateness of pathway contacts warrants reflection. In early psychosis, contacts following the onset of frank psychotic symptoms that do not result in the commencement of psychosis-specific treatment can be viewed as missed opportunities for early intervention and prevention. More generally in youth, however, mental health symptom presentations are often transient and overlapping, and sometimes difficult to distinguish from developmentally normative behavioural or mood changes. It may therefore be difficult to establish an optimal 'pathway to care' in the broad field of youth mental health, and especially challenging to determine whether and when individuals reach an appropriate service. Two identical pathways may, in one case, reflect the appropriate use of a stepped-care model or, in another case, an inappropriately complex pathway. Moreover, even for similar problems, different individuals may have different optimal endpoints, based on available services, individual preferences, previous experiences, etc. Such complexities notwithstanding, studies on pathways to care can yield a greater understanding of how treatment gets delayed; and help identify the key agents involved in young peoples' help-seeking processes and targets for outreach.

It has been argued that 'one-stop' multidisciplinary integrated youth services [13] can improve pathways to mental healthcare for young people. A central tenet of these services is the concept that 'every door is the right door'. Such services aim to cater to youths with a range of needs (e.g., physical health, sexual health, mental health, housing, etc.) and types/severities of mental health problems. Examples of integrated youth services initiatives includes headspace in Australia [83], Jigsaw in Ireland [84], Youthspace in Birmingham, UK [85] and ACCESS Open Minds, Foundry and Youth Wellness Hubs Ontario in Canada [66, 86, 87]. Only one study in our review [43] focused on pathways to care at a cross-diagnostic service that addressed severe and complex mental health conditions. We strongly recommend that the transformation of youth mental healthcare, including the establishment of youth hubs within community settings, be accompanied by increasing study of pathways to this presumably desirable endpoint. Such research is pertinent given young people's preferences for community-based settings for mental healthcare [88].

Contextual sensitivity

Pathways to care are quite variable across geographies, reflecting differences in healthcare, social, and cultural contexts. Many studies reported the attributes of their healthcare systems that may have influenced pathways to care. Importantly, individuals contacted many providers before reaching even those services that had open referral systems. This is perhaps unsurprising, given that, at least in psychosis, service configuration alone does not appear to impact treatment delays [89]. This finding underscores the importance of early identification and outreach in reducing treatment delays [67] as rapid access to care depends not only on systemic factors, but also on such influencers of help-seeking such as stigma, mental health literacy, and awareness of available services [90, 91]. Notably too, some studies reported longer referral delays than help-seeking delays, suggesting that the delay in treatment was attributable more to the care system itself. One can therefore conclude that the effort to reduce treatment delays and simplify pathways has to be directed at both the help-seeking and the referral components of treatment delay.

The importance of primary care physicians prevailed in settings promoting ‘stepped care’ or general practitioner gatekeeper models (Canada, Australia and Western Europe). Some contexts that allowed direct access to specialized care were likely to report self- or family-initiated referrals. In general, the role of general practitioners seems to be influenced by features of the healthcare system such as the availability and affordability of private or public mental health professionals.

Our review included studies from both low- and middle- income countries (LMICs) and high-income countries. With more than 80% of the world’s population, LMICs deploy less than 20% of the world’s mental health resources [92]. Often in LMICs, specialized care is inaccessible to many. These differences were reflected in our review. Certain LMICbased studies described a difficulty in accessing formal mental healthcare, and cultural factors that influenced helpseeking (e.g., faith healers). More pathways to care research is needed in LMICs that have begun emphasising the integration of youth mental healthcare into existing community structures such as school, primary care, and community campaigns [93]. Such research can yield valuable insights on whether pathways to mental health care are simplified when addressed through larger public health promotion and development initiatives. Notably, only four studies were from the United States, a country that otherwise generates volumes of mental health research. This suggests that interest in pathways to care may itself be a feature of public healthcare systems. Studies on pathways to care need to better report on the organization of local mental health services/systems, and beliefs about illnesses and services. This would help contextualize the appropriateness of potential routes to care across contexts.

Measuring pathways to care

Many challenges remain in the assessment of pathways to care. The lack of standardization in the measurement of pathways to care is a major limitation that, in psychosis research, has been identified for over a decade [16]. Wide variance in the definitions of start- and endpoints of pathways; and what and who constitutes a help-seeking contact limits our ability to compare results across studies. In many cases, the instruments chosen to assess pathways to care had a major influence on findings.Studies varied in their inclusion of formal, informal and ‘novel’ (e.g., webbased) contacts. The only study that specifically probed it, found that the internet figured prominently in the help-seeking process.

Only three studies mentioned being guided by a theoretical framework, despite the frameworks for help-seeking behaviour and service use being available since the early 1990s [94,95] and having been modified for mental healthcare pathways research. Studies on pathways to care are often premised on assumptions about the desirability of fewer contacts and, less frequently, the undesirability of certain types of contacts. Most studies are descriptive and provide estimates of individual and aggregate numbers and types of contacts made before a defined endpoint. However, evidence is lacking for whether more contacts along the pathway necessarily translate into longer treatment delays. Factors other than simply the number and type of contacts (e.g., waitlists, multiple encounters with the same contact, multiple contacts ending in evaluation but no treatment, etc.) may have a greater impact on treatment delays. Furthermore, reports of the numbers and types of help-seeking contacts do not reveal whether different services were accessed concurrently; whether appropriate treatments or referrals were offered and declined; or whether contacts met the individual’s needs. Also, notably absent is any measurement of how youths themselves perceived various help-seeking contacts.

To advance research on pathways to youth mental healthcare and, thereby, youth mental health outcomes, we outline some key recommendations informed by our review. An important first step is standardization in the reporting of pathways to care. Specific recommendations in this regard are:

a. Making it a standard to use and report theoretical frameworks in pathways to care research would facilitate better comparability across studies, more meaningful syntheses of extant knowledge, and easier identification of gaps.

b. Studies on pathways to care should define pathways clearly, specifying start and endpoints.

c. Studies should describe their intended methods of assessing pathways to care, justifying the choice of methodology in relation to study aims and the chosen theoretical framework. Ideally, an instrument with established psychometric properties should be used. Where a novel instrument is used, its psychometric properties must be established and/or described.

d. The instruments should use a clearly specified timeframe, and techniques such as anchor dates should be employed to reduce the effects of telescoping bias, whereby events are recalled as occurring earlier or more recently than they actually did [96]. This will allow for the accurate estimation of treatment delay indices.

e. Studies should report on whether specific types of contacts were defined a priori or post hoc after collecting personal narratives, and whether specific types of contacts such as informal contacts (e.g., friends) and online resources were probed for in the interview.

f. Studies should describe key features of the healthcare context (e.g., universal healthcare, access based on insurance, etc.) and referral system (e.g., walk-in access; need for a referral from a general practitioner, etc.) of their study setting.

The emergence of integrated youth services that, across geographic contexts, strive to adhere to common principles [97] provides both a framework and an impetus for standardising the measurement of pathways to care. In addition to addressing the considerations for reporting of pathways to care outlined above, a standardized measure for pathways to care to be used across youth services should be relevant to and feasible for implementation in a range of contexts (urban, rural, Indigenous, high- or low-income, etc.). An ideal measure would capture pathways into the service (e.g., walk-in, referral, etc.); what was offered at the service (e.g., evaluation, short- or long-term treatment, crisis intervention, etc.); and pathways out of the service.

Integrated youth services aim to offer well-publicised, rapidly accessible entry into a range of services and supports (not only those pertaining to mental health). The implicit assumption that such broad-spectrum services translate into more direct pathways and shorter delays to appropriate mental healthcare need empirical testing. Some integrated youth services only offer interventions to those with mild to moderate mental and substance use concerns, referring more complex cases to external services. Future research therefore needs to examine whether such integrated youth services also succeed in simplifying pathways to care for youth with complex presentations. A foundational principle of current endeavours to transform youth mental healthcare has been a commitment to making services youth-oriented, and engaging youths in service design and evaluation. Consistent with this, the creation or deployment of any standardized measure of pathways to care should be conducted in partnership with youths and their families, and should pay due regard to youths' perceptions of their pathways into care. Future studies would also do well to enquire about e-pathways to care, as youths are known to turn to the internet and social media in seeking mental health help [98].

Limitations

Our potential for comparisons across contexts and populations was limited by the lack of a standard methodology for ascertaining and reporting pathways to care. Our review's scope was shaped by its inclusion of only quantitative studies that tend to focus on numbers and types of help-seeking contacts. Other significant aspects of the help-seeking process, such as beliefs about illnesses, and perceived barriers and facilitators to help-seeking, are largely found in qualitative analyses of pathways to care. Quantitative and qualitative approaches can have complementary potentialities in pathways to care research [99]. Our age-based criterion was deliberately broad to accommodate studies that may have included, but not solely focused on, youths. However, this impedes our confidence in the applicability of our findings to exclusively youth-focused settings.

Conclusion

Across contexts, young people's pathways to mental healthcare are often complex and involve various formal and informal agents. Further research is necessary to better understand, and ultimately, to simplify and streamline pathways to appropriate services. This is an essential step towards ensuring easier, timelier access to care and, thereby, shaping youth mental health outcomes. More research is needed to address critical gaps in our knowledge of young people's pathways to care for problems other than psychosis; the determinants of pathways; and the help-seeking behaviours of and service responses to underserved groups such as Indigenous youths, youth in protection/welfare systems, and homeless youths.

Acknowledgements

The authors wish to thank Gerald Jordan, Megan Pope, and Kevin MacDonald for inputs on drafts of this manuscript. The study was funded by a Canadian Institutes of Health Research (CIHR) Foundation Grant (Iyer). K. MacDonald is supported by a Fonds de Recherche du Québec-Santé (FRQS) Doctoral Scholarship in partnership with Quebec's Strategy for Patient-Oriented Research Support Unit, as well as an ACCESS Open Minds Doctoral Studentship. K. Anderson is supported by a New Investigator Fellowship from the Ontario Mental Health Foundation and an Early Researcher Award from the Ontario Ministry of Research, Innovation, and Science. S. Iyer is funded through the CIHR New Investigator Salary Award Program and has previously received salary support from FRQS.

Compliance with ethical standards

The authors declare that they have no conflict of interest.

Table 1 . Study Characteristics

Study	Study objectives	Country	Population	Setting	N	Mean age (range)	(% male)	Instrument	Source of data
Addington et al. [22]	To determine the number of attempts it took before patients with FEP received adequate help, the signs or symptoms that led them to seek help and the people from whom they attempted to seek help	Calgary, Canada	First-episode psychosis	Early intervention for psychosis program	86	24 (15–51)	66.3%	Interview developed for the study	II + FI
Anderson et al. [12]	To estimate the extent to which sociodemographic, clinical, and service-level factors were associated with negative pathways to care and referral delay	Montreal, Canada	First-episode psychosis	Early intervention for psychosis program	324	Median 22.6 (14–30)	69.8%	CORS	II + FI + CR
Anderson et al. [23]	To compare the pathways to care and duration of untreated psychosis for people of Black African, Black Caribbean, or White European origin with FEP	Toronto and Hamilton, Canada	First-episode psychosis	Early intervention for psychosis program	171	21 (19–27)	66.7%	WHO Encounter Form	II + FI + CR
Archie et al. [24]	To examine ethnic variations in the pathways to care for persons accessing early intervention services in Ontario	Ontario, Canada	First-episode psychosis	Early intervention for psychosis program	200	24.5 (16–50)	78%	CORS	II + FI + CR
Bakare [25]	To assess first points of contact and referral sources for a group of patients seen in a neuropsychiatric facility in South-Eastern Nigeria	Enugu, Nigeria	Any mental illness	Child and adolescent inpatient unit	393	15.7 (3–18)	55.7%	Interview developed for study	II + FI
Bekele et al. [26]	To describe the routes taken by patients to reach psychiatric care, evaluate the time delay before seeking psychiatric care, and investigate the relationship between delays in the pathway to care and sociodemographic and clinical factors	Addis Ababa, Ethiopia	Any mental illness	Mental health hospital (inpatient and outpatient)	1044	29 (2–85)	62.2%	WHO Encounter Form	II + CR
Bhui et al. [27]	To assess (1) which services or agencies are encountered by patients in their pathways to specialist psychiatric care; (2) which services or agencies and individual characteristics of patients were independently associated with the shortest DUP	East London, UK	First-episode psychosis	Specialist psychiatric service	480	67.7% under 30, (18–64)	61.3%	WHO Encounter Form	II
Chadda et al. [28]	To study the help-seeking behaviour of patients visiting a mental hospital	Delhi, India	Any mental illness	Outpatient clinic	78	50%+ under 30, (18–49)	61.5%	Questionnaire developed for study	II + FI + CR
Chesney et al. [29]	To describe the pathways to care for patients with FEP in Singapore	Singapore	First-episode psychosis	Early intervention for psychosis program	900	27.1, (16–40)	49.7%	Interview developed for study	II + CR
Cheung et al. [30]	To estimate the public health costs of specific help-seeking pathways into an early intervention psychosis clinic	Edmonton, Canada	First-episode psychosis	Early intervention for psychosis program	50	22.2	82.0%	Semi-structured interview (PCI)	II
Chiang et al. [31]	To review the help-seeking pathways and reasons for delay for patients with FEP	Hong Kong	First-episode psychosis	Early intervention for psychosis program	55	22.2 (16–30)	60.0%	Interview developed for study	II + FI
Chien and Compton [32]	To explore the possible effects of mode of onset on pathways to care	Atlanta, United States	First-episode psychosis	Hospital for FEP psychiatric units	76	Mean 23.2	77.6%	Interview developed for study	II

Table 1 . Study Characteristics

Study	Study objectives	Country	Population	Setting	*N*	Mean age (range)	(% male)	Instrument	Source of data
Commander et al. [33]	To compare the experiences of people with non-affective psychoses from three broad ethnic groups, with respect to (a) pathways to care (b) the treatment received while in hospital (c) the delivery of care post-discharge	Birmingham, UK	First-episode psychosis	4 hospital inpatient units	120	65% under 35 (16–60)	59.1%	WHO Encounter Form	II
Compton et al. [34]	To examine the pathways to care and number of help-seeking contacts prior to hospitalization in first-episode patients of African–American background, and to ascertain the frequency of contact with primary care providers and police	Atlanta, United States	First-episode psychosis	Public sector hospital or crisis centre (inpatient)	25	22.8 (18–32)	76.0%	Symptom onset in schizophrenia inventory, CORS	II
Cougnard et al. [35]	To describe the pathways to care between onset of psychosis and first admission	Bordeaux, France	First-episode psychosis	Acute wards of two psychiatric hospitals	85	27.8 (17–45)	63.9%	Questionnaire developed for study	II + FI + CR
Del Vecchio et al. [36]	To explore the role of relatives in pathways to care of patients with a recent onset of psychosis	Naples, Italy	First-episode psychosis	Outpatient unit	34	26 (18–35)	64.7%	Pathways to care Form	II
Ehmann et al. [37]	To examine the treatment delay associated with community and inpatient pathways into care for persons experiencing FEP	Vancouver, Canada	First-episode psychosis	Early intervention for psychosis service	104	20.9 (15–37)	67.3%	WHO Encounter Form	II + FI
Etheridge et al. [38]	To assess whether duration of untreated psychosis in Rotherham reflected that reported nationally and internationally, and to identify potential obstacles to early identification and treatment	Rotherham, UK	First-episode psychosis	Early intervention for psychosis services (inpatient and outpatient)	18	29.4 (15–50)	61.1%	Questionnaire developed for study	II + FI
Fridgen et al. [39]	To examine the help-seeking behaviour of individuals at risk for psychosis or with FEP in a low-threshold system with easy access to mental health care facilities, in which a specialized early detection clinic was newly established	Basel, Switzerland	First-episode psychosis	Early intervention for psychosis outpatient clinic	61 UHR + 37 FEP	28.4 (18+)	59.0%	Basel interview for psychosis	II
Fuchs and Steinert [40]	To examine patients' help-seeking contacts and the delays on their pathways to psychiatric care in Germany	Ravensburg, Germany	First-episode psychosis	Admission in hospital for first-episode psychosis	66	Median 26 (14–51)	59.0%	IRAOS + interview, adapted	II
Giasuddin et al. [41]	To find out the referral patterns, delays to reach mental health professionals, and diagnoses and treatment received before reaching psychiatric care	Dhaka, Bangladesh	Any mental illness	Outpatient clinic	50	25.8 (12–45)	58.0%	WHO Encounter Form	II
Hastrup et al. [42]	To document DUPs in Denmark and investigate associations of DUP with demographic characteristics, premorbid and illness-related factors and health-service factors	Denmark	First-episode psychosis	General population with FEP diagnosis	1266	21 (15–25)	55.5%	Danish Psychiatric Register	CR
Hodgekins et al. [43]	To examine care pathways experienced by young people accessing a pilot specialist youth mental health service for those with non-psychotic, severe, and complex mental health conditions	Norfolk, UK	Any mental illness	Specialist mental health service	94	18.3 (14–25)	28.7%	Interview developed for study	II or FI + CR
Jain et al. [44]	To evaluate the pathway to care of mentally ill patients attending a tertiary mental health facility in Jaipur, to highlight the difficulties of the mentally ill and their relatives in accessing appropriate care	Jaipur, India	Any mental illness	Tertiary mental health facility	76	59% under 30	71.5%	WHO Encounter Form	II + FI

Table 1 . Study Characteristics

Study	Study objectives	Country	Population	Setting	*N*	Mean age (range)	(% male)	Instrument	Source of data
Judge et al. [45]	To examine the duration of untreated psychosis in an FEP population, to describe precipitants of help-seeking attempts, and to identify barriers to obtaining appropriate treatment	North Carolina, USA	First-episode psychosis	Early intervention for psychosis clinic	20	19.8	75.0%	Pathways to care interview (Perkins)	II
Kurihara et al. [46]	To trace the help-seeking pathway of mental patients and to elucidate the role of traditional healing	Bali, Indonesia	Any mental illness	Admission to Mental Hospital	54	30.6	48.0%	Interview developed for study	II + FI + CR
Lahariya et al. [47]	To study the sociodemographic profile of psychiatric patients; to understand the pathways to care of the patients attending the facility, and to explore the interrelationships between pathways to care and sociodemographic variables	Gwalior, India	Any mental illness	Outpatient department of a psychiatric hospital	295	16–45	68.8%	WHO Encounter Form + interview	II
Lincoln et al. [48]	To gain an understanding of treatment delays in light of an initial episode of psychosis through examination of pathways to care	Melbourne, Australia	First-episode psychosis	Early intervention for psychosis program	62	22.8 (16–30)	64.5%	WHO Encounter Form	II
McMiller and Weisz [49]	To determine whether African–American and Latino families were less likely than Caucasian families to seek help from agencies and professionals prior to contacting clinics for their child	California, USA	Any mental illness	Community mental health clinic	192	11.4 (7–17)	64.0%	Referral sequence and problems interview	II + FI
Mkize and Uys [50]	To determine the pathways of care that clients with mental illness take, the effects of socio-cultural and economic factors on the pathways to mental health care and the satisfaction with different service providers consulted	Natal, South Africa	Any mental illness	Admission to a mental health institution	15	67% below 29 (15–59)	46.7%	Interview developed for study	II
Naqvi et al. [51]	To systematically study the care and referral pathways taken by patients before they present to a psychiatrist at a university teaching hospital	Karachi, Pakistan	Any mental illness	Outpatient psychiatry clinic	94	53% under age 30	55.3%	Interview developed for the study	II
Neubauer et al. [52]	To investigate the duration of untreated illness and paths to first treatment in early vs intermediate vs late age of onset anorexia nervosa	Varied institutions, Germany	Anorexia	Specialized services for anorexia (inpatient and outpatient)	140	22.3	All female	Multiple choice questionnaire developed for study	II
Norman et al. [53]	To examine and compare the extent of delay in individuals contacting health professionals and the delay in receiving treatment once such contact is made	London, Canada	First-episode psychosis	Early intervention for psychosis program	110	26.2 (16–51)	80.0%	CORS	II + CR + FI
O’Callaghan et al. [54]	To establish if, when and where people seek help in the early phase of psychosis in a representative sample	Dublin, Ireland	First-episode psychosis	Community-based psychiatric services	142	30.5 (16–64)	62.0%	Beiser scale for DUP; interview for pathways	II
Phillips et al. [55]	To summarize patterns of referral to one service providing clinical care for young people known to be at high risk of developing a psychotic illness	Melbourne, Australia	Ultra-high risk for psychosis	Specialized clinical service	162	18.8 (14–30)	61.0%	Interview developed for study	II + FI
Platz et al. [56]	To obtain information about type of health professionals contacted by patients on their help-seeking pathways; number of contacts; type of symptoms leading to contacts; interval between initial contact and referral to a specialized service	Switzerland	First-episode psychosis, ultra-high risk for psychosis, help-seeking but	Specialized outpatient service for UHR	104	22 (14–40)	73.0%	Interview developed for the study	II

Table 1 . Study Characteristics

Study	Study objectives	Country	Population	Setting	*N*	Mean age (range)	(% male)	Instrument	Source of data
			not UHR or FEP						
Reeler [57]	To investigate pathways to care	Harare, Zimbabwe	Any mental illness	Psychiatric inpatient unit	48	28.2	31.1%	WHO Encounter Form	II
Reynolds et al. [58]	To explore the impact of a general practitioner training programme on referrals and pathways to care for people at high clinical risk of psychosis or with a first-episode psychosis	Southwark, UK	First-episode psychosis	Early intervention for psychosis program	102	21.9(UHR) 24 (FEP)	59%, (UHR), 75% (FEP)	Chart review methodology	CR
Sharifi et al. [59]	To conduct a first study on the duration of untreated psychosis and pathways to care among patients with first-episode psychosis in Iran as a developing country	Tehran, Iran	First-episode psychosis	Admission to psychiatric hospital	91	27.4	58.2%	Interview developed for the study	II + FRI + CR
Shin et al. [60]	To examine patients' help-seeking contacts in a context (Korea) where pathways to care had not been examined before	South Korea	Ultra-high risk for psychosis	Early intervention for psychosis programs	18	15.8 (15–18)	72.2%	Interview developed for the study	II + FI
Stowkowy et al. [61]	To prospectively investigate the pathways to care of those at clinical high risk of developing psychosis	Toronto, Canada	Ultra-high risk for psychosis	Clinic for ultra-high risk of psychosis	35	21 (14–30)	71.4%	Pathways to care interview (Perkins)	II + FI
Subramaniam et al. [62]	To create a typology of patients with first-episode psychosis based on sociodemographic and clinical characteristics, service use and outcomes using cluster analysis	Singapore	First-episode psychosis	Early intervention for psychosis program	900	27.1 (15–41)	49.6%	Chart review	CR
Turner et al. [63]	To present the clinical and sociodemographic characteristics of patients referred to an early intervention for psychosis service and to describe their pathways to care	Christchurch, New Zealand	First-episode psychosis	Early intervention for psychosis program	182	22.4 (16–30)	72.5%	Interview developed for the study	II
Graf von Reventlow et al. [64]	To acquire accurate knowledge about pathways to care and delay in obtaining specialized high risk care	Finland, Germany, Netherlands, UK	Ultra-high risk for psychosis	Early intervention for psychosis program	233	23	54.9%	WHO Encounter Form, EPOS Form	II
Wiltink et al. [65]	To investigate if the drop in rates of transition from ultra-high risk to FEP may be due to potential changes in patterns of referral to a large ultra-high risk clinic	Melbourne, Australia	Ultra-high risk for psychosis	Early intervention for psychosis program	150	18.3	44.0%	Interview developed for the study	II + CR

DUP, duration of untreated psychosis; CORS, Circumstance of Onset and Relapse Schedule; CR, chart review; FEP, first-episode psychosis; FI, family interviews; II, individual interviews; IRAOS, Instrument for the Retrospective Assessment of the Onset of Schizophrenia; PCI, Pathways to Care Interview; UHR, ultra-high risk

Table 2. Study outcomes I—Pathways to care, treatment delays and health system contexts across studies

Study	Pathway to care definition	Pathway to care timeframe	Pathways to care (number of help-seeking contacts)	Treatment delays, in weeks	Notes on health system context
Addington et al. [22]	The number of individuals who were sought out for assistance with mental health concerns	From onset of psychosis to EI service	Pre-onset: mean 1.7, range 1–4 After onset: mean 2.3, range 1–6	DUP mean 102, median 27, range 0–780	Comprehensive program for individuals experiencing their first episode of psychosis. It is predicted that 80–90% of all new cases in Calgary are being referred to this specialized program
Anderson et al. [12]	Type and sequence of contacts that the patient or family member sought help from	Lifetime until entry to EI service	Median 3	DUI median 194.4, DUP median 16.4 Referral delay median 1	Only specialized service for treatment of FEP within catchment area. Patients referred from any source
Anderson et al. [23]	Series of help-seeking contacts made by patients and their family members in response to the symptoms of a mental illness	Onset of psychotic symptoms to contact with EI service	Median 6 (White Europeans); Median 4 (Black African and Black Caribbean)	Black Caribbean DUP median 69.5, White European DUP median 30.4, Black African DUP median 39.1	Hospital and community-based early intervention services for FEP in two cities
Archie et al. [24]	Sequence of all formal and informal supports contacted by participants seeking help	Onset of psychosis—entry to service	Mean 2.9 (SD = 2), median 3	DUP mean 60.6, median 22.1, SD 11.2	Specialized services within catchment area Referrals accepted from all sources (including self-referrals)
Bakare [25]	Places where help was sought	Prior to presenting to hospital	NS	NS	Healthcare system is divided between primary, secondary, and tertiary care. Patients are free to access any tier of healthcare without referral
Bekele et al. [26]	The routes taken by patients to reach psychiatric care	NS—(WHO Encounter Form uses previous 12-month timeframe)[a]	Range 0–4 contacts	Median 38, range: less than 1–45 years	Only mental hospital that provides outpatient and inpatient services for the full range of psychiatric disorders in the entire country. Patients can refer themselves directly to services
Bhui et al. [27]	The services/agencies encountered by patients in their pathways to specialist psychiatric care	NS—(WHO Encounter Form uses previous 12-month timeframe)[a]	Range 0–3. 13% were in contact with psychiatric services at first contact; 73.33% at second contact, and 97.71% at third contact	Median 12, IQR 1–9.5	The East London First Episode Psychosis Study was a large, population-based incidence study in three neighbouring boroughs
Chadda et al. [28]	The various treatment services utilized by a group of psychiatric patients visiting a mental hospital	From onset of illness to mental health hospital	Range 0–3	Median 78. Help-seeking median 52, range 4 days–20 years	Catchment area serving 30–40 million population. Facilities for psychiatric treatment are generally available in general hospital psychiatric units, mental hospitals and office-based practice. In India, mental hospitals remain one of the major service providers to the mentally ill
Chesney et al. [29]	The individuals and organizations who are contacted by patients and their carers in order to seek help and receive treatment	Sources of help until referral to EI service	Mean 2.7 (SD, 0.9), median 3, range, 1–7	Mean 53.6, median 20, range 0–204, SD 24.3	The only state mental hospital in Singapore, single largest tertiary care facility in Singapore
Cheung et al. [30]	Sequence of contacts with individuals and organizations in seeking help	Post-onset and up to 1 year prior to admission/intake at the early psychosis clinic	Mean 4.48 (inpatient pathways), mean 2.68 (outpatient pathways)	NS	Specialized FEP clinic within a public health service responsible for a region of approx. 1 million people
Chiang et al. [31]	Help-seeking contacts before treatment in the EASY programme, a service for early psychosis	NS	Mean 1.06	DUP mean 23.5 for GP first contact; mean 60 for private psychiatrist; mean 36.2 for helpline; mean 1.49 for ER	The programme accepts referrals of patients with FEP aged between 15 and 25 years, with an open referral system
Chien and Compton [32]	The various help-seeking contacts made between the onset of illness and engagement in treatment	Onset of illness to engagement in treatment	Mean 2.2 (SD 1.5), range 1–8	Mean 27.7	Urban, public sector psychiatric units
Commander et al. [33]	Past history of involvement with forensic and psychiatric services	48 h prior to admission	30% of Asian group, 45% of Black group, 10% of White, and 10% of White group had over 3 contacts	NS	Four hospitals providing most inpatient care in Birmingham

Table 2. Study outcomes I—Pathways to care, treatment delays and health system contexts across studies

Study	Pathway to care definition	Pathway to care timeframe	Pathways to care (number of help-seeking contacts)	Treatment delays, in weeks	Notes on health system context
Compton et al. [34]	Any help-seeking attempt initiated for the purpose of evaluating or treating either prodromal or psychotic symptoms	From the onset of prodromal symptoms until first hospital admission	Mean 3.3 (SD 2.0), range 1–8	DUI mean 146.4, median 128, SD 151.3, range: 0.6–476.9. DUP mean 65.3, median 32.9, SD 89.1, range 0.4–337.7. Help-seeking delay mean 88.6 median 48.7, SD 48.7, range: 0.6–394.9	Public sector outpatient services are available, though this sample focused on patients requiring hospital admission
Cougnard et al. [35]	Number and profession of successive helping contacts, and the treatment and referral proposed by each contact	Between onset of psychosis and first admission	Median 2, range 1–7	Help-seeking delay median 9. Median delay to first treatment 28. Median delay to admission 52	Universal access to care with free access to private or public mental health professionals
Del Vecchio et al. [36]	Pathways to psychiatric care	NS	Mean 0.8 (SD 0.8)	DUP mean 33.3 SD 54, DUI mean 145.4 SD 141.9. Help-seeking delay mean 17.6 SD 45. Referral delay mean 15.6 SD 29.9	NS
Ehmann et al. [37]	Help-seeking efforts leading up to referral to program'	Onset of psychosis to referral to program	Mean 3.02 (SD 1.31), range 1–7	Mean 92, median 30.5, SD 131, range 1–691	Single EI program for psychosis within a defined catchment area; accepts referrals from any source
Etheridge et al. [38]	Experiences of obtaining care when they first developed symptoms of psychosis	From when the illness started to referral	NS (service users), mean 3 (carers, on behalf of service users)	67% had DUI less than 52, 22% between 52 and 156, 11% more than 1	Swallownest Court Services, including the rehabilitation ward, assertive outreach service and day hospital
Fridgen et al. [39]	Person contacted first along the help-seeking pathway and which persons or institutions were contacted subsequently	Any help-seeking attempt before coming to the early detection clinic	Mean 1.5, median 1, range 0–6	DUI median 177, DUP median 52. Referral delay mean 165, median 39	Psychiatrists in private practice and general practitioners, both with the possibility of referring to the university outpatient clinic
Fuchs and Steinert [40]	Professional contacts	Before admission	42% had more than 1 contact, range 1–5	Mean 71; median 8 Help-seeking delay mean 5	Sole psychiatric hospital in catchment area. Patients can consult outpatient psychiatric care without a referral
Giasuddin et al. [41]	Initial and intermediate carers, and number of steps needed to reach mental health personnel	From symptom onset to arrival at a psychiatric service	Mean 2.7	DUI mean 48, Median 25; Range 1–156. Help-seeking mean 13.8	Direct access to specialized care is permitted
Hastrup et al. [42]	Referral source was defined as general practitioner, emergency wards or other hospital services Contact leading to FEP diagnosis was reported as either with an inpatient or an outpatient unit	Interval from onset of psychotic symptoms to initiation of appropriate treatment (antipsychotic medication)	NS	32.7% had a DUP below 26, 17.7% had DUP between 26 and 52. 32.8% had a DUP longer than 52	Danish National Indicator Project (DNIP). In Denmark, it is mandatory for all psychiatric hospital units and relevant clinical departments to report data on all patients with schizophrenia to the registry
Hodgekins et al. [43]	Sequence of help-seeking contacts with individuals and organizations	From date of onset	Mean 5.53	Mean delay 195; Mean help-seeking delay 70.9; Mean referral delay 118.4	Pilot specialist youth mental health service for young people aged 14 to 25 years with non-psychotic, severe and complex mental health conditions
Jain et al. [44]	Sources of care used by patients before seeking help from mental health professionals and also the factors that modify it	From onset to visit with mental health professionals and to tertiary care centre	Total mean 5.3 (SD 10.7), median 2, range 0–67 Mean before reaching any mental health professional: 3.9 (SD 6.7), median 2, range 1–51	Mean DUI 212, Median 56, Range 1–1042	Patients allowed to seek help from any source of their choice and this includes faith healers. Government-run tertiary care centre providing free treatment to catchment area

Table 2. Study outcomes I—Pathways to care, treatment delays and health system contexts across studies

Study	Pathway to care definition	Pathway to care timeframe	Pathways to care (number of help-seeking contacts)	Treatment delays, in weeks	Notes on health system context
Judge et al. [45]	Each help-seeking attempt to whom participants turned for help	Onset of psychosis and administration of antipsychotic medication[a]	Mean 5.1, range 1–15	DUP mean 83.4, range 8–312 From onset to recognition = 33.8, from recognition to treatment = 63	The only specialized psychotic disorders clinic in a catchment area, which ranges from suburban to rural
Kurihara et al. [46]	All sources of care sought	Prior to visiting mental hospital	NS	DUI to hospital admission median 26 Help-seeking delay median 6 Referral delay to hospital median 12	Access to both general practitioners and community health centres is readily available. In Bali, mental disorders are commonly considered 'non- medical diseases' thought to be the domain not of doctors, but of traditional healers
Lahariya et al. [47]	A pathway a patient adopts to reach the appropriate treatment centre	NS (WHO Encounter Form uses previous 12-month timeframe)[a]	NS	DUI 45.6	Outpatient department of a specialty psychiatric hospital affiliated with medical college in the city
Lincoln et al. [48]	Range of people to whom individuals turn to for help	NS (WHO Encounter Form uses previous 12-month timeframe)[a]	Mean 4.9 SD 2.8, median 4.5, range 1–17	DUP mean 38.8, median 17.2. Help-seeking delay mean 16, median 4.4	Comprehensive and integrated community-based service for young people with FEP
McMiller and Weisz [49]	Sequence of consultations and referrals preceding child clinic intake	Prior to contact with mental health clinic	NS	NS	NS
Mkize and Uys [50]	Actions taken by individuals towards the early detection of mental illness. Specifically, steps or consultations taken by the client before being admitted to a mental health institution	Time of the onset of mental illness to the time of their admission to a mental health institution	NS	Range 26–130	NS
Naqvi et al. [51]	Care and referral pathway before presenting to a psychiatrist, including all professional and non-professional avenues	Since the onset of symptoms to appropriate care	Median 2	Help-seeking delay mean 146, range 1–6 years Delay from first contact to psychiatrist mean 198	Most mental health facilities are in urban areas, but are under-resourced. No referral system in operation
Neubauer et al. [52]	Previous treatment facilities and paths to first treatment	Between onset and initiation of treatment	NS	Mean DUI = 109, SD, 160, range 0–843	German healthcare system, details not specified
Norman et al. [53]	All formal services, organizations or professional services consulted regarding any mental health/psychiatric problems experienced by the patient	Lifetime until entry to EI service	NS	Mean DUP 61.1, median 21, SD 100.8. Help-seeking delay mean 25.1, SD 58.5. Referral delay mean 44.6, SD 88.5	EI service with open referral system within a public healthcare system[a]
O'Callaghan et al. [54]	All previous contacts with health services, the police and the judiciary, and any treatment received	From 28 days prior to onset of prodrome to entry to EI service	Median 2, range 0–8	Mean DUP 82; DUI 180. Delays evenly split between help-seeking and referral delays	Catchment area-based psychiatric services receiving referrals from general practitioners and emergency departments
Phllips et al. [55]	Previous contacts made with health and allied services	Prior to referral	Mean 2.36, SD 1.32, range 1–7	Total delay mean 127. Help-seeking delay mean 85.8, SD 132.71. First contact to treatment delay mean 41.4, SD 91.4	Specialized clinical/research service for young people thought to be at high risk of developing a psychotic episode

Table 2. Study outcomes I—Pathways to care, treatment delays and health system contexts across studies

Study	Pathway to care definition	Pathway to care timeframe	Pathways to care (number of help-seeking contacts)	Treatment delays, in weeks	Notes on health system context
Platz et al. [56]	Professional groups that individuals had previously contacted for similar problems	Previous contacts	Mean 2.38, SD 1.4, median 3, range 1–8; no difference between UHR, FEP and help-seeking others	First contact to referral for UHR: mean 124, median 36, SD 217.1, range 1 day–7.6 years Referral delay median for UHR, FEP and help-seeking others = 28 Median help-seeking delay lower for FEP than for UHR and help-seeking others	Semi-urban catchment area of part of the only general psychiatric outpatient clinic. Patients can refer themselves directly to any public or private psychiatric facility and do not require referrals
Reeler [57]	Various carers, kinds of treatment offered, and the times of various events	NS (WHO Encounter form 12 months)	NS	Help-seeking delay range 1–56.4; referral delay range 4.4–50.5	Filter model of service, with stress on a primary care base
Reynolds et al. [58]	Referrals and pathways to care to specialized early intervention service following trainings to general practitioners	NS	Range 1–5	NS	Community-based team accepts referrals from any source
Sharifi et al. [59]	Pathways that patients take to reach psychiatric care (admission to psychiatric hospital)	Any previous helping contacts and referrals	NS	Mean 52.3, median 11	Care to patients with mental illnesses is delivered by public and private sectors. Patients and their families select their own care provider
Shin et al. [60]	The contact process from when the illness is suspected until the first psychiatric treatment	From the initial suspected psychiatric illness until the first psychiatric help was noted	Median 0.7, range 0–4	Mean 53.24, SD 50.28 DUI mean 56.49, range: 2 –156	The Korean public health system does not provide a GP and therefore seeking psychiatric help is initiated by patients themselves. Each centre is main provider of psychiatric services in their area
Stowkowy et al. [61]	All help-seeking activities collected in chronological order from onset of prodromal symptoms	For the period from the onset of prodromal symptoms to referral to clinic	Mean 1.7, range 1–4	NS	UHR clinic accepting referrals from all sources
Subramaniam et al. [62]	The sources of help sought in chronological order till the patients were referred	First contact to admission	Mean 3.2, range 1–7	DUI mean 26, DUP mean 21.7	Comprehensive, integrated, multidisciplinary and patient-centred program
Turner et al. [63]	Patients' contact with social agencies prior to entering EI service	6 months prior	Mean 3.87 (SD 6.31), range 0–42	DUP mean 17.14 for schizophrenia; DUP mean 4.14 for affective and other psychosis	The service available to all those with first-episode psychosis referred into the only early intervention for psychosis service in the Christchurch catchment area
Graf von Reventlow et al. [64]	Number of help-seeking events from onset of at-risk criteria to receiving appropriate treatment	The period between the onset of frank psychosis and receiving an adequate treatment	Mean 2.9	DUI mean 182.5, help-seeking delay mean 72.6. Referral delay mean 110.9	Public sector mental health care (Finland, the UK) and private mental healthcare sector providing beds in psychiatric hospitals (Germany, the Netherlands)
Wiltink et al. [65]	When a (health) service was first contacted, how many and which other services were contacted after that, and who made the referral	From onset to referral to clinic	Mean 1.93	Total delay 46.5. Referral delay 6.5	The catchment area-based program with open referral system

DUP, duration of untreated psychosis; EI, early intervention; ER, emergency room; FEP, first-episode psychosis; IQR, inter-quartile range; NS, not specified; SD, standard deviation; UHR, ultra-high risk

[a] Inferred from text, not explicitly stated

Table 3. Study outcomes II—Help-seeking contacts across studies

Authors	Key pathway agents	Common first help-seeking contacts	Common referral sources
Addington et al. [22]	Most common: emergency services (33%), family physicians (23%) Other: psychologists, teachers/counsellors, psychiatrists, family, emergency services, police, clergy, social workers, and friends		Emergency services (52%), family physicians (18%), psychiatrists (18%)
Anderson et al. [12]	Over 45% of patients had contact with police or ambulance	Emergency services (62%)	Emergency services (74%)
Anderson et al. [23]	Primary care physicians are most commonly used overall	Most common: primary care physicians	Most common: inpatient units
Archie et al. [24]	Most common: emergency services and primary care physicians, family, doctors/walk-in clinics, clergy/homeopath/other non-medical contacts, psychologists, psychiatrists, school counsellors, psychiatric admissions	Family doctor/walk-in clinic (31%), emergency services (24%), clergy/homeopath (12%)	Psychiatric admissions (40.2%), family doctor/walk-in clinic (14.8%), emergency services (13.8%)
Bakare [25]	Neuropsychiatric hospitals, prayer houses, other hospitals, traditional healers, patent medicine stores, roadside medical labs, specialized school for children	Psychiatric hospitals (48%), prayer houses (22%), other hospitals (21%)	Relatives, family, or friends. (92%), other hospitals (7%), prayer houses/faith healing centres (1%)
Bekele et al. [26]	Priests, herbalists, nurses, doctors	Priests/holy water (31%), doctors (21.5%), herbalists (4.5%)	Self-referrals (41%)
Bhui et al. [27]	Primary care physicians, emergency services, police, community-based health and social care agencies, prisons, psychiatric services, native or religious healers	Primary care physicians, emergency services, and criminal justice agencies	
Chadda et al. [28]	Traditional healers, psychiatrists, non-psychiatric doctors, Ayurveda (Indian system of herbal medicine)	Psychiatrists (58%), religious faith healers (30%), physicians (12%)	
Chesney et al. [29]	Medical specialists, psychiatrists, private psychiatrists, direct referrals, at-risk clinic, primary care physicians, health professionals, counsellors community health assessment team, police, employers and teachers, other, traditional or religious healers, courts, lawyers	Specialist care (59%), primary care (27%), police (12%)	Thirty patients (3%) were self-referred
Cheung et al. [30]	Teachers, counsellors, police, psychologists, psychiatrists, family physicians, emergency services, public health, outpatient psychiatry, other		
Chiang et al. [31]	Self-referral, medical, non-medical and religious, alternative help	Social workers, primary care physicians	Telephone helpline, emergency services, primary care
Chien and Compton [32]	Hospital/emergency services, police, outpatient service, family physicians	Psychiatric hospital and emergency (32%), psychiatrists, counsellors, or outpatient mental health clinics (26%), police (20%)	Psychiatric hospitals, psychiatric or general emergency services, police (25%), psychiatrists, counsellors, or outpatient mental health clinics (13.2%), emergency services (7.4%)
Commander et al. [33]	Psychiatrists, social workers, police, emergency services, primary care physicians, community psychiatric nurses, other, self		
Compton et al. [34]	Most common: mental health professionals and psychiatric emergency services, general emergency department, primary care physicians, police, other	Mental health professionals (32%), psychiatric emergency services (24%), general emergency departments (20%)	Psychiatric emergency services (36%), mental health professionals (20%), general emergency departments (20%), police (20%)
Cougnard et al. [35]	Primary care physicians (32%)	Primary care physicians (37%), psychiatrists	
Del Vecchio et al. [36]	Primary care physicians, psychiatrists, neurologists, psychologists, relatives	Primary care physicians (28%), psychiatrists (30%), neurologists (21%)	
Ehmann et al. [37]	Relatives/friends, schools, counsellors or crisis line, mental health teams, general physicians, private psychiatrists, hospitals, direct entry		Relatives/friends (52%), primary care physicians (16%), self-referrals (9%), counsellor or crisis line (8%), mental health teams (6%), psychologists (5%)
Etheridge et al. [38]	Primary care physicians, relatives, psychiatrists, teachers, hospitals	Most common by service users: relatives, primary care physicians, psychiatrists, teachers and hospitals Most common by family/carers on behalf of a service user: primary care physicians, school staff, police and emergency services	
Fridgen et al. [39]	Friends, family, psychiatrists, primary care physicians, colleagues, partners, other physicians, psychologists, priests, alternative medicine	Family or friends (46%), private psychiatrists (14%), or primary care physicians (12%)	Outpatient departments, private psychiatrists, other physicians, self-referrals, family
Fuchs and Steinert [40]	Most common: mental health professionals (46%), primary care physicians (20%), hospitals (18%), and psychosocial contacts (16%)	Primary care physicians (18%)	
Giasuddin et al. [41]	Private practitioners, native or religious healers, other medical facilities, general hospitals	Private practitioner (44%), native or religious healer (22%), direct pathway (16%)	

Table 3. Study outcomes II—Help-seeking contacts across studies

Authors	Key pathway agents	Common first help-seeking contacts	Common referral sources
Hastrup et al. [42]	Primary care physicians, inpatient units, outpatient units, and emergency services, other medical specialists	Outpatient services (59%), hospital services (41%)	Emergency services (26%), primary care physicians (22%), hospitals (46%)
Hodgekins et al. [43]	Primary care physicians, education services, emergency services, social care, other	Primary care physicians, educational settings	
Jain et al. [44]	Faith healers, non-psychiatric allopath care providers, alternative medicine, direct entry, mental health professionals	Faith healers (40%), non-psychiatrist allopath care provider (29%), other psychiatrist (15%)	
Judge et al. [45]	Relatives, emergency services		
Kurihara et al. [46]	Most common: traditional healers. Others: primary care physcians, hospital doctors, community health centres	Traditional healers (43%), primary care physicians (7%), direct entry (4%)	Traditional healers (67%), community health centres (17%), and primary care physicians (13%)
Lahariya et al. [47]	Faith healers, psychiatrists, allopathic practitioners, traditional healers, other (friends and family)	Faith healers (69%), psychiatrists (9%)	Others (including previous patients), allopathic practitioners
Lincoln et al. [48]	Mental health professionals (50%), primary care physicians (17%)	Primary care physicians (36%), psychiatric services (16%), police (12%)	
McMiller and Weisz [49]	52% of all contacts were 'professional' (56% for Caucasians, 47% for African–Americans and 42% for Latino)	45% of first contacts were Healthcare professionals (53% for Caucasians, 32% African American, 30% Latino)	
Mkize and Uys [50]	Traditional healers, faith healers, hospitals, police, mental health institutions, primary health care clinics	Primary care physicians (33%), faith healers (20%), traditional healers (20%)	
Naqvi et al. [51]	Religious healers, primary care providers, specialists, hospitals doctors, psychiatric services		Self-referrals (49%), hospital or other specialists (20%), Primary care (2.9%)
Neubauer et al. [52]	Physicians, health professionals, mental health professionals, social networks, eating disorder clinics, day clinics	Inpatient treatment (55%), outpatient facility (39%), eating disorder-specific centre (4%)	
Norman et al. [53]	Primary care physicians, community or school counsellors, psychologists, social workers, psychiatrists, hospitals, emergency services	Before psychosis: primary care physicians (40%), community or school counsellors (30%), psychologists or social workers (20%) After psychosis, hospital or emergency services (43%), primary care physicians (39%), community (13%)	Emergency services (49%), private psychiatrists or non-emergency hospital (26%), primary care physicians (15%)
O'Callaghan et al. [54]	Primary care physicians, emergency services, counselling services, police, religious organizations, complementary and alternative medical services, and clinic website	Primary care physicians (59%), other, including emergency services (41%)	
Phillips et al. [55]	Primary care physicians, private psychiatrists/psychologists, outpatient services, inpatient services, other		Youth access team, generic and mental health services, school and university counsellors and youth housing and employment workers
Platz et al. [56]	In-patient services, primary care physicians, alternative medical practitioners, non-medical counselling services, non-specified professionals	Primary care physicians (34.6%)	General practitioners, private psychiatrists/psychologists, psychiatric outpatient services
Reeler [57]	Hospital doctors, traditional healers	Hospital doctors	Hospital doctors
Reynolds et al. [58]	Primary care physicians, community-based teams, out of area teams, emergency services, police, prison, child and adolescent mental health teams, specialized services	Primary care physician (43%), emergency services (24%), police (11%)	Post training, 46% were referred by primary care physicians
Sharifi et al. [59]	Psychiatrists, primary care physicians, other health professionals, traditional healers, other professional	Psychiatrist (25%), traditional healer (23%) or a primary care physician (18%)	Family (33%), health professionals (32%) and the legal system (17%)
Shin et al. [60]	Most common: internet and family members (57%) Other: patients, teachers, physicians, specialized clinic, shelters		
Stowkowy et al. [61]	Primary care physicians, mental health clinics, psychiatrists and other individuals		Primary care physicians (29%), psychiatrists, mental health clinics and social workers, (14% each), Self-referral (11%)
Subramaniam et al. [62]	Primary care physicians, polyclinics, other primary care, hospitals, traditional or religious healers, direct entry, counsellors, police, courts, family, relatives, friends, other	Family, primary care physicians	Family

Table 3. Study outcomes II—Help-seeking contacts across studies

Authors	Key pathway agents	Common first help-seeking contacts	Common referral sources
Turner et al. [63]	Primary care physicians, school counsellors, religious ministers, psychiatric outpatient clinics, private psychiatrists, other, mental health services, other health services		Inpatient services (64%), emergency services (16%), general practitioners (7.7%)
Graf von Reventlow et al. [64]	Physicians, psychiatrists, psychologists, nurses, social workers, treatment teams, other counsellors, other healthcare professionals, other professionals		
Wiltink et al. [65]	Primary care physicians, teachers, counsellors, drug and alcohol services, accommodation services, youth health services, emergency services, public hospital, other		

Table 4. Quality appraisal scores

Study	Research question	Representativeness of participants	Non-participation rate	Adequacy of sample size	Adjustment for confounding factors	Definition of pathways to care	Ascertainment of pathways to care	Measurement of pathways to care	Method of ascertainment
Addington et al. [22]	+	·	+	−	−	+	+	+	+
Anderson et al. [12]	+	+	+	−	+	+	+	+	+
Anderson et al. [23]	+	·	+	−	+	+	+	+	+
Archie et al. [24]	+	+	·	−	+	+	+	+	+
Bakare [25]	+	·	−	−	·	+	+	−	+
Bekele et al. [26]	+	−	−	−	+	+	·	+	+
Bhui et al. [27]	+	·	−	−	+	−	−	+	+
Chadda et al. [28]	+	·	−	−	+	−	−	+	+
Chesney et al. [29]	+	·	−	−	·	+	+	−	+
Cheung et al. [30]	+	+	−	−	·	+	+	+	+
Chiang et al. [31]	+	·	·	−	−	−	+	−	+
Chien and Compton [32]	+	+	−	−	+	+	+	−	+
Commander et al. [33]	+	+	+	−	·	+	·	−	+
Compton et al. [34]	+	−	−	−	+	+	+	+	+
Cougnard et al. [35]	+	·	+	−	+	+	+	−	+
Del Vecchio et al. [36]	+	·	−	−	+	+	+	+	+
Ehmann et al. [37]	+	·	−	−	·	+	+	+	+
Etheridge et al. [38]	+	−	·	−	·	−	·	−	+
Fridgen al [39]	+	+	−	−	·	+	−	·	+
Fuchs and Steinert [40]	+	·	+	−	·	−	·	−	+
Giasuddin et al. [41]	+	+	+	+	+	+	·	+	+
Hastrup et al. [42]	+	+	+	−	+	−	−	−	+
Hodgekins et al. [43]	+	·	−	−	·	+	+	+	+
Jain et al. [44]	+	·	+	−	·	+	+	+	+
Judge et al. [45]	+	·	−	−	·	+	+	−	+
Kurihara et al. [46]	+	·	+	−	·	+	+	+	+
Lahariya et al. [47]	+	·	+	−	·	−	+	+	+
Lincoln et al. [48]	+	·	+	−	+	−	·	+	+
McMiller and Weisz [49]	+	·	·	−	−	+	·	−	+
Mkize and Uys [50]	+	−	−	+	+	+	·	+	+
Naqvi et al. [51]	+	+	−	−	−	−	·	−	+
Neubauer et al. [52]	+	·	+	−	+	+	+	−	+
Norman et al. [53]	+	·	−	−	·	+	+	+	+
O'Callaghan et al. [54]	+	·	+	−	+	+	·	−	+
Phillips et al. [55]	+	·	·	−	−	−	+	−	+
Platz et al. [56]	+	+	−	−	−	−	+	−	+
Reeler [57]	+	·	−	−	−	+	·	+	+
Reynolds et al. [58]	+	·	·	−	+	+	−	−	+
Sharifi et al. [59]	+	+	+	−	·	+	+	−	+
Shin et al. [60]	+	·	−	−	·	+	·	−	+
Stowkowy et al. [61]	+	·	−	−	+	+	+	+	+
Subramaniam et al. [62]	+	·	−	−	+	+	·	−	+
Turner et al. [63]	+	·	+	−	·	+	·	−	+
Graf von Reventlow et al. [64]	+	+	+	−	+	−	+	+	+
Wiltink et al. [65]	+	·	·	−	−	+	·	−	+

−, Criterion not met; •, Criterion partially met; +, Criterion satisfied

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Bridge

Findings from Manuscript I revealed that youths' pathways to mental health services are generally complex and involve diverse and often numerous informal and formal contacts and lengthy delays. We noted that for many youth, these pathways include family and friends, general practitioners, and often also Emergency Rooms. This review yielded insights into the number and types of pathways to care for young people, but not a cohesive, holistic understanding of youths' and families' experiences of seeking mental health care. This gap was significant as most quantitative studies on pathways to care are premised on assumptions such as those that a pathway with few contacts is most desirable; or that the endpoint of a pathway to care is merely the initiation of contact with an "appropriate" mental health care system/provider. Youth and families' viewpoints on these matters are crucial.

An exploration of individual experiences of pathways to care was thus an evident next step. We undertook a meta-synthesis of qualitative studies of the mental health care pathway experiences of young people and their carers. Qualitative meta-synthesis methodology, which aims to integrate and interpret results from a number of qualitative studies rather than simply aggregate results, fit our objective of arriving at a comprehensive understanding of youths' pathways to care. This understanding went beyond the depth and breadth of the original individual qualitative studies and complemented our systematic review of quantitative studies of pathways to care (Manuscript I) by providing nuances that are otherwise missed by quantitative studies. For example, we were able to establish the particular roles of key actors, such as family and friends, in aiding young people's access to mental health services.

We were also able to gain valuable insights on the experience of having police or ER contacts, long viewed as simply 'negative encounters' in one's trajectory to mental health services. Such insights are essential in developing new mental health services that are specifically tailored to the youth population, and informed by the voice of youth and families, in addition to evidence on numbers and types of pathways to care.

The following manuscript was published in the journal Social Psychiatry and Psychiatric Epidemiology in 2020.

Chapter 4

Manuscript II

Experiences of Pathways to Mental Health Services for Young People and their Carers: a Qualitative Meta-Synthesis Review.

Kathleen MacDonald, Manuela Ferrari, Nina Fainman-Adelman,and Srividya N. Iyer
Social Psychiatry and Psychiatric Epidemiology (2021) 56(3), 339-361..

Publisher : Springer Nature
Date : November 2020

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Abstract

Worldwide, growing concern with young people's mental health is spurring service reform efforts. Such reform requires a full understanding of the experiences of young people and their carers when seeking mental health help.

To generate such an understanding, we conducted a meta-synthesis of qualitative literature on the perspectives of youths and their carers on navigating mental health systems. Five electronic databases were searched (Medline, PsycINFO, EMBASE, CINAHL, HealthSTAR). Studies were included if they explored the experiences of pathways to mental health services of persons aged 11 to 30 years and/or their carers; were published in English or French; and used qualitative methodology. Quality appraisal was conducted using the CASP tool.

The synthesis of 31 included studies yielded three themes —initiating contact with mental health services; characteristics of services' response; and youths' and carers' appraisal of services. Themes about initiating contact included mental health literacy, structural barriers, and social support. Service response-related themes included complex pathways, waitlists, eligibility, and fragmented care. In terms of service appraisal, positive encounters featured providers who were accessible and perceived as caring. Negative appraisals resulted from feeling misunderstood and excluded and being ill-informed about treatment.

Across diagnoses and settings, youths and carers had difficult experiences accessing mental healthcare. While individual, social, and healthcare factors shaping pathways to care varied, systemic complexities were a common inhibitor. This synthesis informs recommendations for improving mental health services and youths' pathways to them. It underlines the need for grounding reform in youths' and carers' perspectives and needs.

Keywords : Pathways to Care; meta-synthesis; youth mental health; Qualitative; lived experiences

Introduction

Most mental health problems have their peak incidence in adolescence and young adulthood [1]. Delayed treatment of these problems can lead to poorer treatment outcomes, including lower remission rates and higher relapse rates [2,3,4]; and increased risk of complex symptomatology and/or comorbidity, which early treatment seeks to prevent [3, 5].

Despite growing recognition of the high prevalence of mental disorders in youth and the importance of early treatment, youths' service utilization rates remain low. Prior research has explored barriers along the pathway from symptom onset to treatment commencement [6]. Among youths, most such research has focused on help-seeking delays, i.e., delays between the emergence of a mental health problem and seeking help. A systematic review of youths' help-seeking delays identified low mental health literacy and stigma as major barriers [7].

Effectively addressing mental health problems depends not only on timely help-seeking, but also on a rapid and appropriate response by the mental health system. The observation that substantial delays occur after individuals contact mental health services has spurred interest in youths' modes and routes of accessing help. These "pathways to care" have been defined to include the attempts that distressed individuals and/or their carers make to seek help, and care providers' and organizations' responses to that help-seeking [8]. Pathways to care intersect with social, cultural and systemic factors that shape their direction and duration [8]. Our recent systematic review of quantitative literature (45 studies) revealed that youths' pathways to mental health services are generally complex, and involve diverse and often numerous informal and formal contacts and lengthy delays [9].

While quantitative indices yield an overview of pathways to care, a cohesive understanding of how youths and their families/carers experience them is largely missing. A recent focus on lived experience has infused emerging healthcare research and reform strategies with patient-orientation. Still, 'visible, constructive and generally efficacious gateways and pathways to mental health services' [10] are unlikely to develop if young people's views and those of their carers, particularly on the accessibility and acceptability of care, go unheeded. We, therefore, undertook a systematic review and meta-synthesis of qualitative studies of pathways to mental health services, from the perspectives of young people and their carers.

Methodology

Meta-synthesis

The review protocol was developed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) [11] and registered at the PROSPERO Centre for Reviews and Dissemination (ID: CRD42016039208) in June 2016.The use of qualitative meta-synthesis is growing in the literature on youth mental health [12, 13]. Qualitative meta-synthesis is a technique for reviewing, translating, and integrating findings from qualitative studies to form novel, powerful interpretations [14, 15]. To achieve this, authors' original findings, using their terms, were listed for each included paper. From these summaries, key concepts were identified, and relationships between concepts were compared. This juxtaposition helped identify points of convergence and divergence between concepts. This allowed us to elicit links between studies and map how each study contributed to the understanding of the topic. Further readings elicited patterns across studies that we juxtaposed and integrated to identify key concepts.

Search methods

Consulting researchers with expertise in youth mental health and a university librarian, we generated search terms that were related to pathways, service use, help-seeking, and mental disorders (see Supplementary Material 1). Pertinent studies were identified on the electronic databases MEDLINE (1946 onwards), Embase (1947 onwards), PsycINFO (1967 onwards), HealthSTAR (1966 onwards), and CINAHL (1937 onwards). Additional articles were identified by backward and forward citation mapping using Web of Science, as well as hand searching. The search was conducted in July 2016 and again in April 2020.

Screening

Two authors [KM; NFA] independently screened titles, abstracts, and full texts for inclusion and resolved disagreements by consensus. Articles were included if they were peer-reviewed; written in English or French; and reported on qualitative studies of experiences of pathways to mental health services, regardless of the presence or absence of formal diagnoses. Further, at least 50% of study participants had to be 11–30 years old. We excluded studies of youths with chronic physical ailments or a primary diagnosis of intellectual disability.

Quality appraisal

Quality appraisal was implemented with the Critical Appraisal Skills Programme (CASP) Qualitative Checklist [16]. First, two authors [KM; NFA] independently assessed the included studies' quality, and resolved disagreements through discussion and re-rating, reaching consensus for all studies. A third researcher [MF] with substantial expertise in qualitative methodologies reviewed the final ratings. Quality ratings are presented in Supplementary Material 2.We did not exclude any studies based on quality assessment, as recommended by experts like Sandelowski et al. [14, 17] and Atkins et al. [18].

Results

Study selection and characteristics

12,081 studies were reviewed at the title and abstract stage. 896 full texts were screened, including 17 found by hand search. Of these, 31 studies met our inclusion criteria (see Fig. 1).

Geographic and healthcare systems

Except for one study from India and one from Bangladesh, all studies were conducted in high-income, mostly Western countries. With few exceptions, all countries where the re-

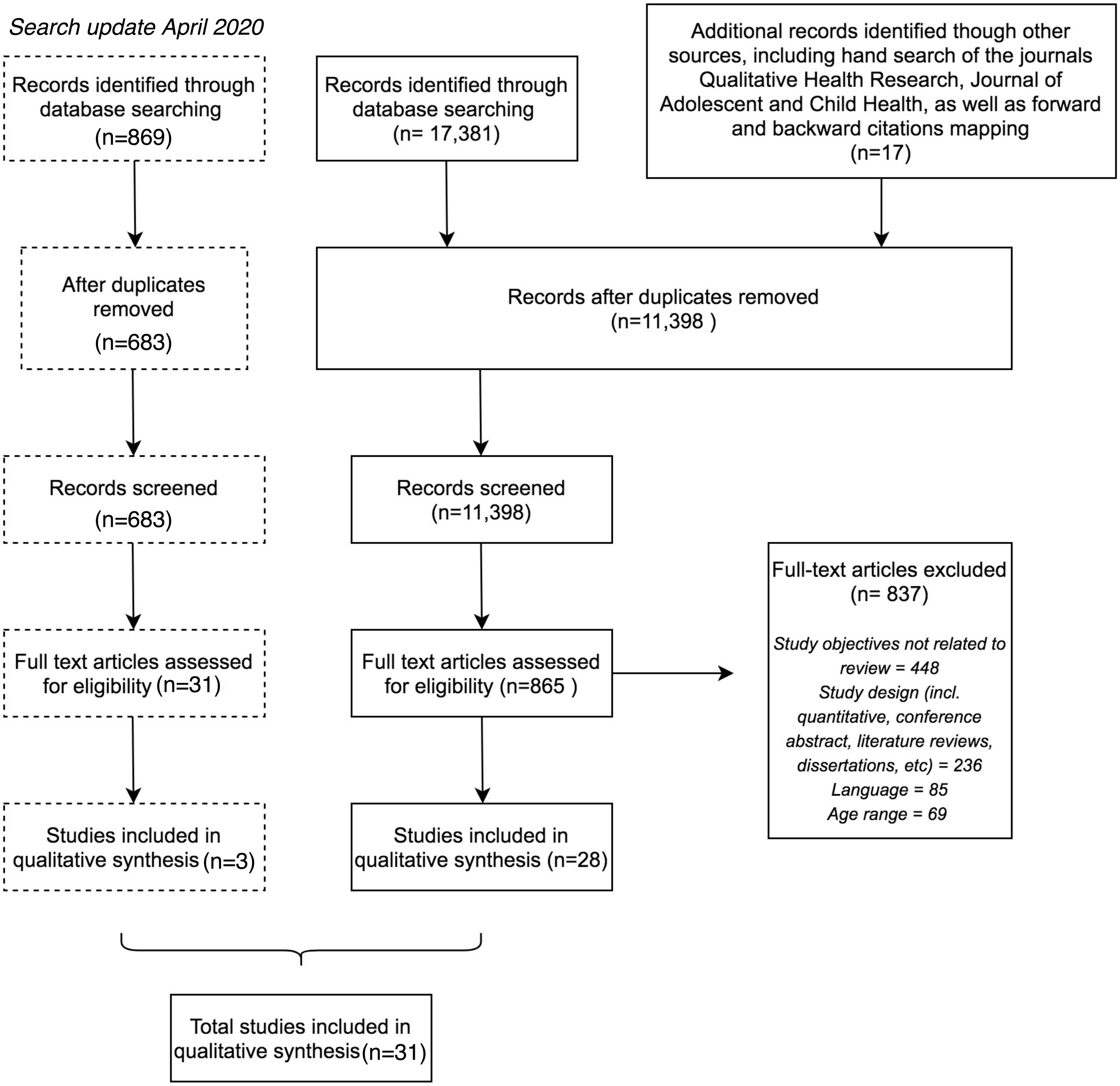

Figure 1. PRISMA Flow-Chart of Included Studies

viewed studies were conducted have universal, primarily publicly funded healthcare systems (see Table 1). Most studies were conducted in urban settings, though three studies specifically focused on experiences of youths growing up in rural communities [19,20,21].

Study service settings

Fourteen studies were conducted in specialized psychosis services (including two inpatient units); eleven in general mental health services; two in ultra-high risk for psychosis programs; and one each in a substance use treatment facility; a crisis inpatient unit; an integrated youth service; and with youths with ADHD.

Participants

Thirteen studies focused solely on youth perspectives, while seven explored carer experiences. Nine studies combined both. One study was conducted with service providers. One was conducted with youths, families, and their service providers. Notably, although we used the term 'carer' to encompass all caregiver roles (parents, siblings, friends, etc.), the carer perspectives in most studies were those of mothers.

Many studies reported on the ethnic backgrounds of their participants, though very few explored the impact of ethnicity in their analysis. While the gender composition of participants varied greatly between studies, most studies did not discuss gender in their results (see Table 1). Only one study specifically focused on the role of gender in pathways to care experiences [22]. Many studies reported participant characteristics, such as income or deprivation indices, though these factors were not commented on further in the studies' analyses. Two studies specifically focused on low-income [23] and uninsured [24] youths.

Synthesis

The synthesis of key concepts yielded three core themes describing participants' pathways to mental health services: initiating contact with mental health services, response from services, and appraisal of services. For each of these themes, subthemes relating to youth and carer perspectives were identified (see Fig. 2).

The importance in our synthesis of these three core themes is in line with prior work on dynamic models of adolescent help-seeking. More specifically, the themes that we developed align significantly with the 'action' stage described in Rickwood et al.'s help seeking model

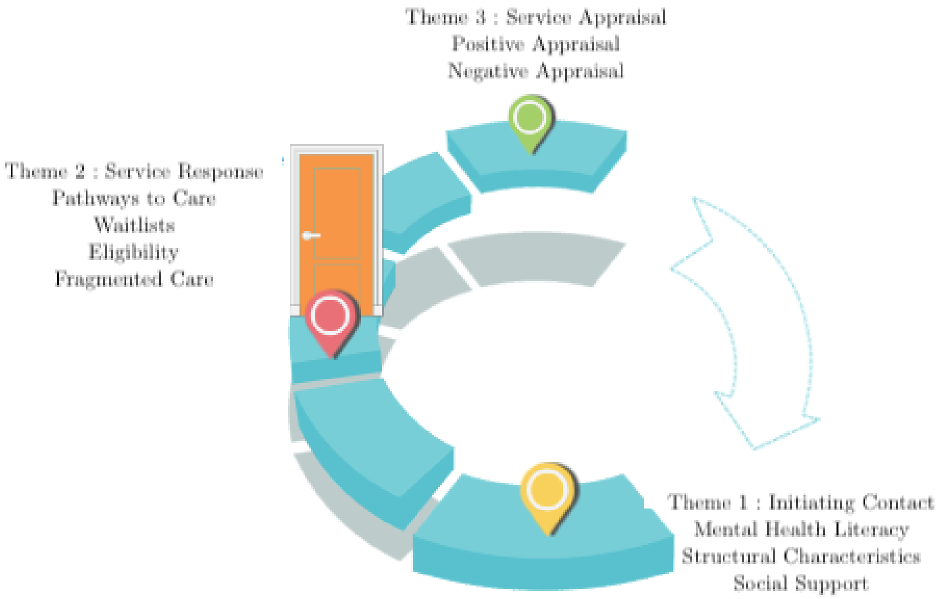

Figure 2. Study Themes. *The three core themes and related subthemes illustrate key components along individual's pathways to mental health services. These experiences do not necessarily occur in a sequential fashion; instead, an individual's pathway is dynamic and infuenced by a variety of personal, social and systemic factors*

[25]. This action stage has been further elaborated upon by others [26, 27] to incorporate stages including intention formation, i.e., deciding to seek services; contacting services; and service appraisal. Our synthesis adds to the evidence that such stages do not occur in a linear fashion but are dynamic in nature, and are based on the complex interaction between individuals, their support circle, and the healthcare system.

Theme 1: Initiating contact with the mental health system

This theme represents the efforts made by youths and their carers as they initiate contact with the mental healthcare system.

1.1 Mental health literacy

“I didn’t know this was a condition that you could seek medical treatment for.”[28]

Youth, First-episode psychosis service, Montreal, Canada (Urban)

Mental health literacy, defined as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention,” [29, 30] was a prominent theme across the reviewed studies. Youths and carers often reported not realizing that services existed for the problem they faced or where to find appropriate services [20, 21, 26, 28, 31, 32, 33, 34, 35, 36, 37, 38, 39, 41]. Especially when help-seeking was initiated by carers, many young people reported being unaware of their problems until after their first contact with mental healthcare or after treatment began [31, 38, 40]. Both, youths and carers, described dismissing distress as ‘teenage angst’ or attributing atypical behaviours to the developmental stage [31, 32, 37, 38, 41, 42, 43, 44].

”Cos like you see like on that, movies and people went to therapy... I thought I was going kinda cuckoo.... I thought they [friends] would have called me crazy.” [45]

Female youth, Youths at risk for psychosis, Greater London, UK (Urban))

Expectations about mental health services influenced whether youths or carers contacted services. Negative attitudes and stigma about mental illness and help-seeking prevailed among young people [19, 20, 26, 28, 32, 38, 41, 42, 43, 44, 45, 46] and carers, who sometimes denied that their families were affected [21, 32, 36, 44]. Across contexts, such attitudes reduced the likelihood of symptom disclosure and help-seeking.

Concerns about privacy were common [19, 20, 33, 45]. Knowing that formal healthcare providers were bound by confidentiality facilitated disclosure for some [45]. Service providers described the struggle to balance confidentiality and safety, suggesting that legal constraints like mandatory reporting hindered the disclosure of behaviours like self-harm [23].

Mental health literacy was affected by past experiences with the healthcare system [24, 26, 32, 36, 41, 47]. Positive past experiences helped people recognize signs and symptoms [32, 36] and identify whom to reach [24, 26]; or increased the likelihood of help-seeking [41, 47]. Conversely, negative previous experiences, such as perceived lack of improvement [32], or a negative first encounter at a hospital [39] delayed future help-seeking as youths were less willing to contact these services when care was needed again.

1.2 Structural and systemic characteristics

A prominent theme in initiating contact with the mental health system pertained to its structural characteristics, which often contributed to delays.

> *"It's hard to get around if you don't have a car... if I lived just out of town, that would be hard if I had to go to an appointment every week cause my mom works... "[19]*
>
> (Female youth, Child and Adolescent Mental Health Services, Australia (Rural)

Transportation was a commonly cited issue [19, 21, 23, 26, 33], especially where public transit was scarce [19, 39], and youths lived far from services [33] and in rural areas [19, 21]. Further, for some participants, the decision about where to first seek help was based on distance to the provider [39].

Cost was cited as a prominent barrier [21, 33, 35, 36, 39], especially by accompanying carers who described having to take time off work and pay for gas, parking, and accommodations. Some carers described considering private treatment, but lacking the requisite financial resources [21]. Other parents, in studies based in the United States, spoke of lacking insurance coverage [24, 26, 48].

1.3 Social support

Youths' sources of social support were critical in initiating contact with the mental health system.

> *"I told her [mother] all about it; I explained her everything ... and then the day after she called my GP and we went over and saw him." [46]*
>
> (Youth, Specialized first-episode psychosis service, Region Zealand, Denmark)

Overwhelmingly, parents' involvement in youths' pathways to services was seen as crucial. Parents' roles were wide-ranging — from being the first ones to whom youths disclosed symptoms [26, 31, 40, 43] to suggesting, initiating and pushing for care [23, 24, 26, 28, 31, 32, 39,40,41, 43, 46, 49, 50].

> *"Services... are extremely fractured and extremely hard to access, and I am a forceful, pretty highly educated, middle-class person with some resources and the ability to be an advocate and push against the system for my family members.... It's this thick, impenetrable soup of inaccessibility and... you have to invest an incredible amount of time in educating yourself and finding out what your resources are." [35]*
>
> (Carer, Carers of youths receiving mental health services [not specified], Indianapolis, USA (Urban))

Among carers, the theme of negotiating/advocating for access to services was prominent [21, 34, 35, 41, 47]. First-time carers described difficulties in negotiating admission to services and educating themselves about resources. Some carers felt that they had not been able to access services because they had not pushed hard enough [21]. They reported that their own social circle (friends, neighbours, colleagues) helped them advocate for their child [21, 26, 37, 39, 49, 51]. Their difficulties with such advocacy were exacerbated by cultural and language barriers [28, 34, 50].

Further, some carers reported that advocating for involuntary hospitalization had been "traumatic yet necessary"[48].

> *"My putting him in the hospital was my cry for help too. I just felt I couldn't handle it anymore, and I saw that instead of getting better, he was just getting worse. So I said that's it." [48]*
>
> (Carer, First-episode psychosis service, New York metropolitan area, USA (Urban))

Theme 2: Response from services

The mental healthcare system's responses to help-seeking were identified as among important factors that influence help-seeking, engagement with care, and outcomes.

2.1 Complex pathways

> *"We'd get stuff piecemeal here and there... but didn't really know what resources were available in this community... it was like everybody had their own little niche, but nobody had the overall perspective." [37]*
>
> (Carer, First-episode psychosis service, Ohio, USA)

Youths and carers described the complexity of navigating mental health services after establishing first contact. Many young people reported contacting multiple mental health services before obtaining care [23, 24, 28, 31, 33, 34, 36, 38, 41, 42, 44, 46, 47, 49, 51, 52]. These pathways were described as confusing, unsatisfactory, and frustrating [31, 42]. Youths and carers also resented having to "tell their story multiple times" [31, 52]. Carers described interacting with the system under a "cloud of uncertainty," not knowing what high-quality care should look like or how treatment should progress [42]. Others described navigating the healthcare system as time-consuming and difficult, a characterization that service providers and government officials have echoed.

> *"... a bit of an unfortunate characteristic of the mental health system... a lot of time it is about keeping clients out, and when they do get in, get rid of them as quickly as you can and you refer on to other agencies." [23]*
>
> (Non-government mental health service provider, Services in low-to-middle socio-economic areas, Perth, Australia)

Informal support contacts (e.g., family, friends, support groups, self-help) were described as helpful throughout youths' pathways to care [37, 47, 52]. In some studies [26, 35, 36, 44, 46, 47] youths and carers reported using the Internet to research symptoms and services before seeking formal help.

Some participants attributed the complexity of their pathways to misdiagnoses or dismissals by general practitioners [26]. Others criticized the poor connections and "territorial squabbles" between different services whose clinicians had difficulty cooperating to help youths [21]. Others described service providers' inability to connect with appropriate resources when problems escalated [37].

Numerous studies, including the three studies based in inpatient units, described police encounters along their pathway to services [24, 26, 31, 32, 40, 48, 53]. For some, this contact was deemed "helpful" and precipitated entry to services [24, 32, 40]. For others, this represented a coercive or traumatic experience along the journey to care [44, 48].

2.2 Eligibility

> *"They [county mental health services] denied me, like three times... then they diagnosed me with depression, and that was like my ticket in the door." [24]*
>
> (Female youth, Short-term inpatient crisis stabilization unit [following a visit to a crisis emergency centre], USA (Urban))

In some studies, services only admitted cases meeting specific eligibility criteria. Some participants described being ineligible for age-restricted [21] or diagnosis-specific services (e.g. only for depression or psychosis) [24, 34]. Others reported not qualifying for certain services because their symptoms were not severe enough [21, 33, 34, 37, 39, 47]. Participants described being turned away because they were deemed 'too functional' [22, 48], an issue which, in one study, was reported solely among female participants and identified as a key aspect in understanding gender differences in pathways to care [22]. In some cases, services only became available when crises emerged [19, 21, 24, 33, 49], leaving some carers relieved when youths' behaviours escalated enough to warrant emergency care [35].

2.3 Waitlists

> *"I sort of felt that you... had to overdose or do something to harm yourself to get in here fairly quick cos there's such a demand for these services... But I did it the hard way [attempting suicide]... six months waiting list otherwise." [19]*
>
> (Youth, Child and Adolescent Mental Health Services, Australia (Rural))

Frequently, even when services were identified and available, long waitlists delayed the commencement of treatment [19, 21, 24, 34, 52]. This was especially so in rural communities [19, 21], where recruiting and retaining mental health professionals was difficult. Interestingly, participants in several studies [19, 24, 33,34,35] opined that accessing mental healthcare through emergency or crisis services could result in a substantial reduction in waiting times.

> *"It's the fastest way in to the [outpatient clinic] eligibility, because eligibility takes up to a year. But if you go to the hospital, you get a therapist and a psychiatrist right away." [24]*
>
> (26-year-old female youth, crisis service, Texas, USA)

2.4 Lack of continuity of care

> *"Once she hit the magic age of 16, there's nothing... too young for adult services, too old for kids' services." [21]*
>
> (Carer, Children's community mental health agency, Ontario, Canada (Rural)

Fragmented care was prominent across studies, especially with age-based transitions [21, 31, 34, 41]. Other difficulties included lack of planned discharge from hospital services [26, 42, 48] and transitions between services or from inpatient to outpatient or emergency to hospital settings [26, 41, 42, 48]. Some decried discontinuity between providers, even within the same setting [31]. In one study, both youths and parents had difficulty describing the different roles of and relationships between clinicians providing their care [50].

> *"We kept getting sick of telling our same story to different people. We probably saw three different psychiatrists in the time that we were there [inpatient unit]." [31]*
>
> (Carer, Child and adolescent mental health services, Auckland, New Zealand (Urban)

Theme 3: Appraisal of services

A key component in the process from help-seeking to eventual engagement with care is youths' and carers' appraisal of that care. Both positive and negative encounters were discussed.

3.1 Positive appraisal

> *"[the service] was helpful because one of their comments was, if she won't come to see us, she obviously needs help and we'll come out to see her"*
>
> (Parent of youth with unspecified mental health problem, Australia)

Commonly appreciated aspects of service encounters included providers who were perceived as resourceful, knowledgeable, providing useful information [20, 37, 47, 48], caring, supportive, non-judgmental or trustworthy [20, 31, 42, 47]. Youths described positive relationships with providers who related to their problems [45] by drawing on their own experiences or being close in age. For youths, learning of health professionals' confidentiality obligations was reassuring [20, 23, 45].

Families greatly appreciated being informed about youths' treatment and progress, and being included in decision-making [31, 42, 47]. Families also appreciated culturally appropriate care, including by providers or interpreters [50] who shared their language or culture [21].

Youths and carers highlighted the importance of services being available and rapidly accessible [20, 31, 37, 47]. Many described flexible services positively, noting instances where service providers offered transportation, made home or community visits, and remained available by means like text messaging and email [21, 23, 31, 50].

Both, youths and carers described the experience of receiving a diagnosis as difficult but "helpful", a "relief" or 'essential' [37, 43, 47, 52].

Contrasting their frustrations at being stymied by professional squabbles, many spoke positively of instances in which services had collaborated effectively [23, 51] or professionals like general practitioners or school counsellors had referred to appropriate services promptly [34].

3.2 Negative appraisal

> *"I think they treat you more like a number. And I think, being treated like a person instead of a number or a case, because, if you're a case, you're like 'I'm schizophrenic', you're not a person anymore." [32]*
>
> European-origin youth, First-episode psychosis services, Ontario, Canada

Across contexts, young people shared experiences of frustration when they felt misunderstood, dismissed, or underestimated by service providers [26, 28, 32, 48, 52]. Other negative experiences included hospitalization or coercion [31, 44]; exposure to unwell peers [31]; and encountering staff who seemed insensitive or negative [26, 31, 32, 44, 48]. Others bemoaned feeling "disrespected," "labelled," left in the dark [32] or unable to trust providers, especially when appointments were cancelled or rescheduled [21]. Carers perceived services most negatively when they felt excluded or insufficiently informed [21, 37, 42, 47, 48]. They also criticized difficulties in scheduling appointments or contacting providers [48, 54]; absence of diagnoses [37, 47, 52]; providers not appreciating their knowledge or not seeing them as partners [21, 35, 52]; and uninformed or insensitive providers [34, 38]. They expressed frustration with receiving "brief encounters" (e.g., one-three sessions) for problems that they felt warranted more care [21]. Emergency or inpatient entry points were often described as traumatic [48, 54].

> *"I don't remember them being very forthcoming at the hospital.... In fact, every piece of information that we found out there was almost [a] tooth and nail pull...." [37]*
>
> Carer, First-episode psychosis service, Ohio, USA

Stigma exacerbated youths' frustrations with treatment [28, 45], led to refusal of care [42] and contributed to families' difficulty in accepting services [48]. Perceived stigma was aggravated when service providers' attitudes seemed stigmatizing [48], with carers and youths describing feeling "blamed" for the illness [35].

Participants in six studies described concerns with school-based mental health services. Privacy and confidentiality were the main concerns for youth [44, 45, 50] while carers were concerned about the lack of mental health training and support from staff [20, 35, 52].

Discussion

Across clinical diagnoses and study settings, young people from various backgrounds and their carers reported a range of similar experiences when seeking and obtaining help for mental health problems.

The findings of our meta-synthesis align with models of help-seeking like the Revised Network Episode Model [55], which conceptualizes health service use as a product of interactions between individuals, social networks, and the healthcare system. This synthesis broadens our understanding of youths' pathways to care beyond their quantitative features, the focus of our previous systematic review [9], which described pathways as complex, instead of simple, linear progressions. The current qualitative synthesis broadens our understanding of the drivers of this complexity. Specifically, we found that the most prevalent structural barriers to care were waitlists, strict eligibility criteria, and fragmented, inaccessible care. These factors, compounded with known help-seeking barriers, such as mental health literacy, stigma, and self-reliance [7, 25], contribute to significant delays prior to youth engaging with appropriate services. These delays to treatment are known impact clinical recovery [56, 57] and can impede the attainment of personal, educational, and vocational milestones [58, 59]. On the other hand, strong social supports, flexible services, and positive perceptions of care were key factors in accepting treatment.

A finding common across many reviewed studies was the identification of mental health literacy as a prerequisite to initial contact with health services. Improving literacy involves enhancing youths' and families' ability to recognize mental health issues, to cultivate attitudes that facilitate help-seeking, and to navigate the healthcare system.

Across contexts and settings, the role of caregivers in facilitating pathways to mental health services was evident in both youth and carer perspectives. Carers often sought help from varied sources and spoke of the inhibitory role of stigma in judging the need for treatment. Thus, a greater recognition of caregivers' roles and needs is crucial. Our work and that of others [60, 61] has consistently shown that carers (predominantly parents), despite often initiating help-seeking, lack support in obtaining help.

It should be noted that the included studies reflect the perspectives of youths and families who attend mental health services, and therefore represent a minority [62] of youth with mental health problems who are engaged with care. Importantly, even amongst this group, the reviewed literature reflected largely negative experiences of accessing care, and of the services received. Complex pathways to care, undue treatment delays and other negative experiences of care have also been previously reported in youth mental health-focused literature reviews [9, 63] and cannot be discounted. Still, it is also noteworthy that some young people in our reviewed studies reported quick, easy access to services and many had positive impressions of providers and of the care they received.

Given that negative experiences have higher emotional potency than positive ones [64], these experiences may be more likely to be reported and published than positive stories, especially in healthcare settings where investigating adverse events is the norm [65]. As such, further research specifically aimed at exploring positive mental healthcare experiences of youth is warranted. Studies using a strength-based lens, focusing on the resources of individuals and their communities [66], have explored positive healthcare experiences, such as among transgender populations [67]. By specifically investigating the factors which lead to positive encounters, this type of research may elicit high-quality practices on which to model improved services [63].

As with our quantitative systematic review [9], a large proportion of studies were conducted in early intervention services for psychosis. We investigated the differences between studies conducted in these settings [22, 26, 28, 31, 32, 34, 36,37,38, 42, 43, 46, 48, 49] compared to studies with youths presenting all other mental health conditions [19,20,21, 23, 24, 33, 35, 39,40,41, 44, 45, 47, 50,51,52,53]. Our first finding was that the systemic characteristics of waitlists, eligibility, and fragmented services were less often cited by studies set in early intervention for psychosis settings. (Supplementary Material 3). This may be due in part to the emphasis of the early psychosis field to standardize certain aspects of care, including establishing benchmarks [68] for wait-times to reduce treatment delays and advocating for consistent case management for two years after illness onset. Further, mental health literacy, while an important theme across all reviewed studies, was especially noted within the context of early psychosis. This may be because while psychotic symptoms are well-defined, they remain relatively unknown within the general population, pointing to the need for increased early identification efforts within community settings.

Service and policy implications

Our synthesis revealed that, across contexts, young people and carers call for service delivery improvements to simplify pathways, assure confidentiality, clarify provider roles, and reduce repeated evaluations. If bureaucratic complexities cannot be dismantled, service providers should, at least, improve communication with youths and caregivers to dispel perceptions of being left in the dark. Inter-service transitions should be minimized or, at least, follow clear protocols for coordinating care and sharing information about diagnoses and treatment between youths, families, service providers, and agencies [69].

Familial alienation from services often prolongs pathways by contributing to disengagement and negative appraisals of services. Family engagement can be improved by acknowledging carer perspectives; clear protocols for information sharing, shared decision-making and confidentiality; and family-focused interventions.

The consistent identification of mental health literacy and self- and social stigma as key factors in care pathway experiences indicates a need for youth-focused mental health awareness and stigma reduction efforts. Too often, access to services was contingent on having an assertive, knowledgeable advocate to negotiate entry into complex healthcare systems. This additionally disadvantages already-vulnerable groups like immigrant, uninsured, homeless and culturally and linguistically diverse youths. Equity necessitates making services accessible without requiring persistence or advocacy. Policies on the training of general practitioners, police officers, teachers, emergency room and other frontline workers should include mental health literacy and capacity-building.

Youths' and carers' eligibility-related concerns warrant reflection. Many specialized services are organized around tightly defined acceptable 'cases'. Because youth mental health problems are often transient and protean, overly restrictive eligibility criteria can impede access to early intervention. However, new transdiagnostic approaches based on pluripotent trajectories of youth mental health presentations may need to consider that many youths and their families considered receiving a 'label' or diagnosis a helpful component of their care.

Youth and carers described positive experiences when services were flexible, for example, by providing multiple communication options or home-based visits. Further, our findings point to the need for such services to be easily accessible by public transport. Given that the cost of care was often identified as a barrier to access, youth services should operate on the principle of universal coverage [70]. The difficulty in providing and accessing mental healthcare in rural and remote areas that we found can be mitigated through technology-enabled solutions, to which young people are known to be amenable [71].

Youth and carers' positive impression of services were largely influenced by providers' personal characteristics (being caring, trustworthy, honest, etc.) These qualities should be emphasized during clinical training and considered during the hiring process.

Finally, investments in youth-centered care should be grounded in the perspectives and needs of young people and carers. Across many reviewed studies, youths were asked to identify what could ease pathways to mental health services. Their responses included:

1. Confidentiality and relatability : Youths' perceived alliance improved when providers emphasized confidentiality and were relatable. One participant described how a counselor disclosing her own experience of similar problems facilitated disclosure [45].

2. Integrated services : Integrating mental health services with general healthcare could alleviate stigma-related concerns by making the nature of help-seeking youths' problems less obvious. Further, youths who have availed any kind of care from an integrated youth service may be likelier to seek help for a mental health problem in a timelier manner or to have such a problem noticed early on by a service provider.

3. Sensitivity training: General practitioners, emergency room staff, police, detention center staff, and other frontline workers should be trained about mental health, available resources, biases, and stigma [32].

4. Service improvements : Services should be enhanced by de-crowding waiting rooms to make them less intimidating to youths with paranoia or social anxiety; providing peer support; improving communication between providers to reduce the need for repeating stories; shortening inpatient stays; limiting the use of coercion; and providing leisure activities during hospitalizations. Youths described the importance of stability of "people and places"

(e.g., not switching rooms), and a personalized, warm welcome upon entry [28, 31, 50].

Limitations and future research directions

Despite providing rich data on participants' ethnicity, gender, sexual orientation, etc. and contextual information on rurality, healthcare system characteristics, etc., most studies, barring few exceptions [19, 20, 21, 24, 32], did not explore the role of these factors. This despite such factors being known to shape access to care [72, 73]. As such, our ability to meaningfully comment on how social, structural and contextual realities impact upon the equitability of access to and experiences of seeking mental healthcare was limited. This limitation was perhaps exacerbated by the meta-synthesis method, which, in including studies from different contexts, runs the risk of overlooking important explanatory context information within each study [74]. To mitigate this risk, we gleaned as much contextual information as possible from the studies. Ultimately, design and methodological decisions made by authors of the included studies would also be reflected in this synthesis.

Assessing the quality of qualitative research is critical in meta-synthesis reviews but can be problematic due to the limitations of quality appraisal tools. The CASP [15] tool we used offers a simple and flexible method to assess qualitative studies but does not capture nuances related to different qualitative research traditions and practices [75]. Overall, the quality of the included studies is cause for optimism about the value of qualitative methodologies in the pathways to care field.

To advance research on youths' and families' experiences of pathways to mental healthcare, we outline some key recommendations informed by our meta-synthesis:

1. The perspectives of youths experiencing a wide range of mental health problems is needed. Further, integrated, transdiagnostic youth mental health services, with shared core service design principles, including well-publicized, easily accessible portals of entry, are rapidly be-

ing developed around the world [76]. Our synthesis included only one study from such a hub [33]. The promise of this model in simplifying youths' pathways to care—in terms of both initial contact and subsequent connections to needed services—needs further empirical investigation.

2. Future research should focus on youths less likely to access care, such as gender minorities; homeless youths; youths not engaged in employment, education, or training [77], etc., as well as the perspectives of the many youths who do not reach formal services or seek mental health supports elsewhere. For population-scale insights, qualitative approaches should be integrated into examinations of pathways to care in community samples, thus increasing the sample size for studies of this nature.

3. Questions remain about how positive and negative encounters along the pathway to care may shape whether and how individuals engage with services. Longitudinal studies starting at the onset of help-seeking may allow a more thorough unpacking of the dynamic and non-linear nature of steps from help-seeking to appraisal to engagement with care.

4. Currently, few studies explicitly enquire about and report young people's positive experiences of accessing and receiving mental health services. There is thus a need for research that focuses on eliciting and supporting best practices in youth-friendly services. Some examples include co-design focusing on youth and carer participation in services design and research [78]; purposive sampling methods to capture positive episodes of care [67]; and using positive deviance approaches [79] to identify successful cases and generate recommendations for clinical improvements in other settings.

5. Most of the world's young people live in low- and middle-income countries. Some studies from these countries may have been excluded from our synthesis based on language of publication. Still, there is an urgent need to address the striking knowledge gap around how

young people and their families in these countries access and navigate mental healthcare.

6. Most of the included studies used an inductive approach, which allows themes and theoretical understanding to emerge from the data. The use of a deductive approach [55, 78, 80] could advance existing theoretical frameworks of help-seeking and pertinent social theories (e.g., stigma theories).

Compliance with ethical standards

The authors declare that they have no conflict of interest.

Table 1. Study Characteristics

Study	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Anderson et al. [28]	Montreal, Canada	FEP clients at an early intervention program	To describe the experiences of patients with FEP on their pathway to care and to identify factors that help or hinder help-seeking efforts	16 service users (75% male)	5/16 visible minority; 11/16 non-visible minority	NS	Median 22.5	Structured and semi-structured interviews	Specialized service using open referral system with
Aisbett et al. [19]	Victoria, Australia	Rural child and adolescent mental health service users	To explore Australian rural adolescents' experiences of accessing help for a mental health problem in the context of their rural communities	3 service users (all female)	NS	2/3 participants in school, 1/3 employed	Range: 15–17	Semi-structured interviews	Horsham and Ararat are rural cities with some restriction in the availability of goods and services
Boulter and Rickwood [47]	Canberra, Australia	Parents of children with any mental health concern in local care services	To gain an insight into parents' experiences of seeking help for their children with mental health problems	15 carers, (6.7% male)	NS	Family income:1/15 = < 50,000; 7/15 = 50,000–100,000;7/15 = > 100,000	Under 18	Semi-structured interviews	NS
Boyd et al. [20]	Victoria, Australia	University students from rural background with any mental health concern	To explore Australian rural adolescents' experiences of accessing help for a mental health problem in the context of their rural communities	6 service users (16.7% male)	NS	NS	Mean 20, range 17–21	Semi-structured interviews	Rural communities in Australia
Boydell et al. [21]	Rural Ontario, Canada	Children and youth with a diagnosis of emotional and/or behavioural disorder in local mental health agencies	To examine issues of access to mental health care for children and youth in rural Canadian communities from the family perspective	30 carers representing 35 service users (20% male)	NS	18/30 carers employed	Mean 11.6, range 3–17	In-depth semi-structured interview with parents	Publicly funded health system with provision of medical and hospital services to all citizens
Boydell et al. [41]	Urban Canadian city	Ultra-high risk for psychosis clinic	To identify the ways in which youth at ultra-high risk for psychosis access mental health services and the factors that advance or delay help seeking	10 service users (2 male) and 30 significant contacts	3/10 Chinese; 6/10 European; 1/10 Interracial	Family income:2/10 = 40000-60000;3/10 = > 60,000; 4/10 = NA	Mean 17, range 14–20	In-depth qualitative interviews	The clinic receives weekly referrals of individuals who may be at risk for psychosis and allows direct referral
Cabassa et al. [42]	NYC, USA	FEP clients at an early intervention clinic	To understand the pathways to care from the onset of a first episode of psychosis to entry into a specialized early intervention service	20 service users (55% male) and 10 carers	11/20 Hispanic; 5/20 African-American; 2/20 Non-Hispanic; White; 2/20 Asian	NS	Mean 23.7 SD 4.4	Semi-structured interviews	NS

Table 1. Study Characteristics

References	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Cadario et al. [31]	Auckland, NZ	FEP clients at child and adolescent mental health services	To examine by qualitative means the experience of first-episode psychosis and the experience of accessing effective treatment, from two perspectives—that of the adolescents and that of their primary caregivers	12 service users (58.3% male) and 12 carers	7/12 NZ European; 4/12 NZ Māori; 1/12 NZ *Māori*/Cook Island *Māori*	NS	Range 15–18	Unstructured and semi-structured interviews	An in-patient unit for children and adolescents and three community-based child and adolescent mental health services. One of the services included a team that ran an early intervention service for psychosis in adolescents
Carr-Fanning et al. [52]	Republic of Ireland	Young people with ADHD and their parents	To explore stress and coping in pathways through care for young people and their parents	15 service users (60% male) and their parents (total 32)	NS	Range of socio-economic backgrounds	Mean 12.8, SD 3.09, range 7–17	Semi-structured interviews triangulated with other sources	NS[a]
Chen et al. [26]	NYC USA	FEP clients in a psychiatric hospital adolescent inpatient service	To develop a pathway model of parental help seeking for adolescents experiencing FEP and identify crucial time points for intervention	12 service users (62.8% male) and 16 carers (19% male)	9/12 Caucasian; 1/12 African American; 4/12 Hispanic. 2/12 Asian	Income: 12.5% = 0–20,000; 6.3% = 20000–40000; 18.6% = 40000–60000; 28% = 60,000–80000; 37.5% => 100000	Mean 18.8, SD 2.3	Semi-structured interviews	NS
Ferrari et al. [32]	Ontario, Canada	FEP clients at an early intervention program	To explore young peoples’ and their family members’ journeys of seeking help for psychosis	25 service users (52% male) and 9 carers	16/25 European; 5/25 African;4/25 Caribbean	NS	Not described	Focus groups, interviews, chart review	NS[a]
Ferrari et al. [22, 32]	Ontario, Canada	FEP clients at an early intervention program	To investigate the role of gender in pathways to early intervention programs	25 service users (52% male)	16/25 European; 5/25 African; 4/25 Caribbean	NS	Mean 26	Focus groups and individual interviews, chart review	NS[a]
Gerson et al. [48]	New York metropolitan area, USA	Young people with recent-onset, non-affective psychosis, from inpatient or outpatient	To understand the experiences of families seeking treatment for young people with recent-on- set psychosis	13 families (77% male)	5/13 Caucasian; 4/13 Hispanic, 3/13 African American; 1/3 Asian	NS	Mean 20.7 SD 3, range 16–24	Open-ended interviews	NS

Table 1. Study Characteristics

References	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Gronholm et al. [45]	Greater London, UK	Young people at ultra-high risk for psychosis in primary schools	To explore stigma in relation to pathways to care among young people putatively in an early stage of increased risk of developing psychotic disorders	29 service users (34.5% male)	19/29 White; 9/29 Black; 1/29 Asian	NS	Mean 15.7	Semi-structured interviews	NS[a]
Jansen et al. [46]	Denmark	FEP clients at an early intervention program	To explore service users' experience of an early detection service and transition to specialized treatment service, including pathway to care	10 service users (50% male)	All participants of ethnic Danish background	2/10 in school; 2/10 in part-time employment; 2/10 unemployed; 4/10 not in school or work due to illness	Median 21, range 18–27	Semi-structured interviews	NS[a]
Jansen et al. [43]	Denmark	FEP clients at an early intervention program	To describe service-users' experiences with and understanding of their illness and pathway to care	11 service users (54.5% male)	All participants of ethnic Danish background	NS	Median 20, range 15–24	Semi-structured interviews	NS[a]
McCann et al. [34]	Melbourne, Australia	Caregivers of FEP clients at an early intervention program	To describe the lived experience of first- time primary caregivers of young adults with FEP, with a focus on how they access specialist FEP services	20 carers, (15% male)	NS	NS	FEP clinic range 14–30	Semi-structured interviews	NS[a]
McCann and Lubman [33]	Melbourne, Australia	Youth with depression at an integrated youth service (headspace)	To examine the experience of young people with depression accessing one of these services, with a focus on understanding how they access the service and the difficulties they encounter	26 service users (38.5% male)	NS	7/26 paid employment; 19/26 no paid employment	Mean 18, range 16–22	Semi-structured interviews	Integrated youth service providing physical health assessment and treatment; evidence-based interventions; and improving service integration through co-location with other services[a]
Nadeau et al. [50]	Montréal, Canada	Migrant youth accessing care at a community health clinic	To better understand quality of care, including factors improving access to care and collaborative services use, efficacy and satisfaction	5 service users (80% male), 5 carers and 5 service providers	3/5 South Asian,1/5 South east Asian. 1/5 Canadian/European	4/5 with low socioeconomic status 1/5 with medium socioeconomic status	Mean 14, range 12–17	Semi-structured interviews	Primary-care, community based health and social service center offering YMH services as part of a collaborative care model involving multi-disciplinary teams and on-site child psychiatrists

Table 1. Study Characteristics

References	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Narendorf et al. [24]	Texas, USA	Young adults admitted to a short-term crisis inpatient unit	To examine psychiatric crisis care with a group of young adults who all lack insurance	55 service users (54.5% male)	15/55 White;15/55 African American;11/ 55 Hispanic; 11/55 multi-racial; 3/55 Asian/American-Indian	NS	Range 18–25	Semi-structured interviews	The psychiatric emergency center is the only public facility designated exclusively for psychiatric crisis in a large urban county in Texas. The unit was exclusively for those without insurance, and all admissions were voluntary
Novins et al. [53]	Southern United States	Adolescents at a residential substance abuse treatment center	To explore how Aboriginal Indian adolescents entering/receiving treatment described their pathways to care	89 service users (60.6% male)	All participants of American Indian background	NS	Range 16–18	Surveys, interviews, and chart reviews	The program, operated by a Southern AI tribe and funded by the Indian Health Service (IHS), is designed to provide specialized treatment of patients with substance use disorders, including those with comorbid psychiatric disorders
Nuri et al. [39]	Dhaka, Bangladesh	Patients at the NIMH institute (variety of diagnoses)	To understand the care pathways of patients with mental illness	40 service users (57.5% male)	NS	16/23 of adults unemployed	Mean 25.5	Semi-structured in-depth interview guide and a structured questionnaire (WHO encounter form)	Based at the NIMH, the only mental health institute of Bangladesh, which caters to whole country. Mental health patients have direct access to psychiatric services in Bangladesh hence general practitioners and hospitals are not gatekeepers
Oruche et al. [35]	Indianapolis, USA	Caregivers of children having received any mental health services in the past year	To identify what caregivers of children with diverse mental health needs say they need to help them improve their personal well-being	20 carers, (50% male)	16/20 Caucasian; 2/20 African American; 1/20 Asian; 1/20 Pacific islander	Median household income 50,000	Mean 12	Semi-structured focus group	NS
Pescodolio et al. [40]	Indiana, USA	Young people with any mental health concern at a public, voluntary facility	To systematically consider the different social processes through which people come to enter psychiatric treatment	109 service users (32.1% male)	82/109 White; 27/109 African American	NS	Mean 30.5	Semi-structured interviews	Public hospital

Table 1. Study Characteristics

References	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Platell et al. [23]	Perth, Australia	Disadvantaged youth with any mental health concern	To identify barriers and enablers to professional mental health service utilization for disadvantaged	8 service providers	NS	Service providers of adolescents of lower socio-economic background	Adolescents, age not specified	Semi-structured interviews	NS[a]
Sadath et al. [36]	Bangalore, India	FEP clients from inpatient and outpatient units	To explore the experiences in caring and help-seeking in carers of patients with first episode psychosis	11 carers, (72.7% male)	NS	2/11 working; 4/11 irregular work; 5/11 not working	Mean 22.3 SD 3.6, range 18–30	Semi-structured interviews	Tertiary public mental health care centre located in Bangalore, India
Schnitzer et al. [51]	Antwerp, Belgium	Parents who consulted any mental health services for their child	To explore how ultra-Orthodox Jewish parents make the decision to consult regular services for their child	21 carers	All participants of Orthodox Jewish background	NS	Under 19	Semi-structured interviews	Flemish statutory services, Flemish centres for school counselling co-operating with Jewish schools, Jewish services within the mental health and educational sector (i.e. support teams in schools)[a]
Skubby et al. [37]	Ohio, USA	FEP clients at an early intervention program	To understand the experiences of parents as they sought psychological and specialized medical services for a loved one with psychosis	11 carers	7/11 White; 4/11 Black	NS	14–30	Semi-structured interviews	Provides comprehensive, individualized, and appropriate interventions for individuals experiencing a first episode of a schizophrenia disorder. NS if public, private
Tanskanen et al. [38]	North London, UK	FEP clients at an early intervention program	To investigate service users and carers experiences of the onset of psychosis and help-seeking	21 service users (71.4% male),9 carers	7/21 White 8/21 Black 4/21Asian, 2/21 Mixed	NS	Mean 26.5, range 18–35	Semi-structured interviews	NS[a]
Webster et al. [44]	Sydney, Australia	Young people with any mental health concern in two community agencies	To explain how young people experience the onset of mental illness and manage their initial interactions health system	20 service users (40% male)	NS	NS	Mean 21, range 18–25	Semi-structured interview	NS[a]
Wong [49]	Hong Kong	FEP clients at an early intervention program	To identify the roles and functions played by the key individuals in the help-seeking pathway of Chinese caregivers with relatives suffering from psychosis	Service users (34.5% male) and carers	NS	NS	19	Semi-structured interviews	Clinics provide inpatient and com- munity mental health services for young people between the ages of 15 and 25[b]

ADHD attention deficit hyperactivity disorder, FEP first-episode psychosis, NS not specified, SD standard deviation, UHR ultra-high risk [a] Services come from countries with universal, primarily publicly funded healthcare systems [b] Another paper (Tang et al. [81]) outlining this service describes the program as part of the public healthcare system

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Bridge

As noted in Chapter 1, and subsequently established in Manuscripts I and II, there is a paucity of research on the mental health service use and pathways to care of youth in marginalizing contexts. This is despite youth in such contexts often facing a higher risk of mental illness, along with context-driven barriers to accessing timely, appropriate mental health services. As evidenced across both our reviews, limited research on pathways to care has been conducted with populations such as youth in child welfare; homeless youth; or youth not in education, training, or employment. Most pathways to care research is designed from the perspective of specific mental health services. In other words, the focus is often on describing the pathways to a specified "appropriate" service (e.g., number of contacts made or delay experienced before accessing an early intervention service for psychosis; source who referred to a particular treatment). This dissertation argues that it may be very important to also do pathways to care research from the perspective of youth populations, particularly youth who have been traditionally underserved by mental health services.

Youth in child welfare services are a particularly marginalized group. Youth involved with child welfare have high rates of adverse childhood events [226, 227], and often have high levels of social/material deprivation, both known risk factors for a variety of negative physical and mental health outcomes [228-230]. Often, their needs extend beyond what is currently offered by the child welfare system, and youth in care are known to receive a "patchwork of services" including physical health services, rehabilitation or addiction treatment, medication, psycho-social services, mental health care, etc. Multiple actors and systems– child welfare services, police, schools, parents, police, court, foster care placement contexts – are often involved in the lives of young people in whose cases child welfare is involved.

The issue of accessibility of mental health services is a priority for child welfare services in Quebec. A recent Special Commission on the Rights of the Child and Youth Protection [231] called for adopting a broad and collaborative vision to support the development of optimal service trajectories for youth in child welfare services. As a first step towards optimising service delivery for young people in child welfare, understanding the current pathways travelled by youth between and through services in their efforts to obtain mental health supports is needed. We aimed to address this knowledge gap by investigating the patterns of mental health service use and pathways to care for youth aged 11-18 involved with child welfare services in Montreal, Canada.

The following manuscript has been prepared for submission.

Chapter 5

Manuscript III

Patterns of Mental Health Service Utilization and Pathways to Care for Youth Involved in Child Welfare Services in Quebec, Canada

Kathleen MacDonald, Lise Laporte, Lyne Desrosiers, and Srividya N. Iyer
Prepared for submission.

Abstract

Introduction : Young people involved in child welfare services have high rates of mental health problems and are known to receive mental health services from a range of settings, including schools, hospitals, community-based primary health centres, and within child welfare agencies. Important gaps remain in our understanding of the patterns of service use across settings over the entire course of young people's involvement with child welfare services.

Methods: Data on mental health service contacts, including initiators, settings and reasons for contact, were retrospectively collected from medical charts for youth aged 11-18 (n=226) during their involvement with child welfare services in Montreal, Quebec. Logistic regression analysis was conducted to determine predictors of multi-setting use (defined as using mental health services in 3 or more settings), compared to the use of a fewer number of settings (one or two settings). Predictors examined were socio-demographic and childhood adversity variables, total duration of child welfare involvement, and number of placements.

Results: 83% of youth had at least one contact with mental health services over the course of their follow-up by child welfare services. 45% youth had contacts with three or more different service settings. Emergency Rooms were the top setting for mental health services. Number of placements (OR = 1.26, <0.001) and level of social and material deprivation (OR=2.86, <0.01) significantly predicted the use of $\geq$3 mental health service settings versus 2 or fewer mental health service settings. Youth with a higher number of placements and coming from neighborhoods with greater levels of social and material deprivation were more likely to use a higher number of mental health service settings over the course of their follow-up by child welfare services.

Discussion: These findings suggest a need for enhanced collaboration between youth-serving agencies to ensure that continuous and appropriate mental health care is being offered to vulnerable young people followed by child welfare systems. The relationship between placement instability and multi-setting mental health service use is disconcerting, and specific policies

may be needed to ensure that some young people do not experience multiple discontinuities of care.

Introduction

Youth involved in child welfare services (CWS) are known to have high rates of mental health problems, with estimates ranging from 25-50% [1]. A 2016 meta-analysis of epidemiological surveys reported a pooled prevalence of 49% for mental disorders among youth in welfare services, which is nearly four times greater than the prevalence among youth in the general population, which is estimated at 13% [2]. Youth in child welfare services have rates of suicide attempts that are four times higher than youth in the general population [3], and rates of substance use that are five times higher than their peers. Such high rates of mental health problems have been reported whether the youth were placed outside of their home [1, 3, 4] or remained in their family with active child welfare involvement [1, 5, 6].

Given the magnitude of their need for mental health services, efforts have focused on characterizing mental health service utilization in this population. Broadly, youth within child welfare systems utilize services at a higher rate than their peers. Research using administrative data from the United States demonstrated that, despite representing 4% percent of the eligible youth population in California, youth in welfare services accounted for 41% of mental healthcare visits [7]. Still, despite these reports of high rates of service use, numerous studies have also shown that many young people within child welfare systems do not receive services when needed, and that in fact, these youth commonly experience barriers in accessing appropriate, continuous, quality mental health care [8-10]. A survey of a nationally representative sample of children followed by child welfare agencies in the United States studied 3,000 families and found that only 44% of children in need of mental health services received care [1]. Among child welfare involved youth, factors related to the receipt of mental health services include non-kin placements [1, 11], parental risk factors [1, 11], immigration status [12], gender [11], childhood adversity [1, 11, 13, 14], and social/material deprivation [15].

Prior research on service use in the context of child welfare systems has commonly been based on nationally representative surveys or administrative datasets using a binary indicator of mental health service use (e.g., categorized as yes/no within a delineated timeframe, often the 12 months preceding the data collection)[1, 16-18]. Greater attention has also been paid to youth placed into foster care, despite the fact that youth who remain with their families while being followed by child welfare systems have been shown to have needs for mental health services that are equal to or greater than those in foster care [6, 14, 19]. Youth in child welfare services often receive mental health services from different settings, including schools, hospitals, and community-based primary health centres. This is at least partly attributable to youth in foster care being at high risk for falling through gaps in service delivery [20].

A two-timepoint investigation of mental health utilization across various settings in the U.S. noted that up to a third of child welfare youth had received mental health services from three or more distinct settings [11]. Commonly, studies looking at multi-setting or multi-sectoral service use in child welfare services have used either cross-sectional data or data for a specific time period (e.g., previous 12 months). Little is therefore known about the use of mental health services over the entire period of youths' follow-up by child welfare services. One difficulty in mapping such mental health service usage is the lack of administrative databases covering multiple service settings.

In three U.S.-based studies, involvement with welfare agencies appeared to trigger or arguably facilitate entry to mental health services, with studies showing a significant increase in the use of mental health services immediately after initial contact with child welfare services [1, 18, 21]. The immediate impact on mental health service use upon the involvement of child welfare has thus far not been examined in the Canadian context.

The specific aim of this study was to address this gap by examining mental health service use by youth throughout the entire period of their follow-up by child welfare services, including a fuller examination of the various stakeholders involved in initiating mental health contacts and the settings within which these occur. Understanding the patterns of mental health service use across the period of child welfare involvement is a crucial step in identifying gaps in the current provision of care and in effectively planning and delivering treatment options to these young people.

Methods

Healthcare Context

Canada benefits from a publicly funded universal healthcare system with provinces having jurisdiction for healthcare provision and delivery. In the province of Quebec, healthcare organizations (including community-based primary health centres, rehabilitation and youth centres, residential centers, and specialized and general hospitals) are organized geographically, with services planned and delivered to address the needs of a population within a defined catchment area. Despite the publicly funded nature of the system, a for-profit private healthcare sector also exists in Canada, and individuals or agencies acting in their interest can pay for these services out-of-pocket or via private insurance. Mental health services are offered in primary care settings (i.e., local, community-based primary health centres); secondary care settings (i.e., specialized services, hospital-based inpatient or outpatient centres); and tertiary care settings (i.e., residential programs). Private-sector mental health services are also available, predominantly through private psychologists and psychotherapists.

Child Welfare Services

Child welfare agencies provide an array of services, including psychosocial, rehabilitation and social integration services, family support and supervision, adoption, court reports, care placements, etc., for youth who have been found to be abused (physically, psychologically, sexually), neglected, or exhibiting behavioural problems. Care placements refer to the placements of children outside of their family home, often with kin, with foster parents, or in group home settings, on a temporary or permanent basis. Child welfare services can offer certain mental health interventions (e.g., risk assessment, psychotherapy). However, most often, youth in child welfare services end up using regular-stream mental health services when needed.

Ethics

This study was approved by the *Centre Jeunesse de Montréal-Institut Universitaire Institutional Ethics Committee.*

Sample

Our sample included 226 youth who received child welfare services from the two agencies in Montreal (*Centre jeunesse de Montréal*, n=142; and *Batshaw Youth and Family Centers*, n=84) between 2010 and 2019. Charts were selected based on parents' postal codes being located within two distinct catchment areas (Dorval-Lachine-Lasalle and Parc-Extension), in which a larger youth mental health project led by the author's supervisor was underway. The goal was to use the findings from this paper to inform service transformation efforts. Each youth's chart was reviewed yearly, and data were collected until they turned 18, or earlier if they were no longer followed by child welfare.

Parc-Extension is an urban neighborhood home to one of the provinces' most ethnically diverse populations, with just over 60% of the population being a visible minority. In Dorval-Lachine-Lasalle, one quarter of the population is a visible minority, and its population is spread between urban and suburban environments.

Data collection

Medical and psychosocial records held by child welfare agencies are extensive. On intake, child welfare workers collect a full history pertaining to physical and mental health, parental histories, etc., dating from the child's birth. Whenever available, police, medical and school records are included in the child's file. Four trained research assistants systematically collected information from charts, using a data collection template created for the study. The template was then pilot tested by the research team and refined. Ten percent of all charts were independently reviewed by a different rater to ensure accuracy. Inter-rater reliability was calculated and found to be acceptably high (κ= .71). Weekly team meetings with authors LL and LD were conducted where missing or incorrect data was reviewed and revised through consensus.

Data extracted from these charts include demographic information, diagnosed mental disorders, and all mental health symptoms reported in files including all related contacts' dates and professionals involved in diagnosing or reporting symptoms. Information relevant to family history and background was also retrieved, including living situation, parental history of mental illness and parental history of child welfare involvement. Social and material deprivation indices were derived by matching the participants' postal codes with the indices from the *Institut National de Santé Publique.* These neighborhood-level indices are calculated from census data using six indicators that predict health outcomes: the proportion of the population that has not completed secondary education; that is not employed; that lives alone; that is separated, divorced, or widowed; that has a low income; and that resides in single-parent family units. In our analysis, social and material deprivation indices were combined and divided into quintiles, with the most severe deprivation indicated as quintiles 4 and 5.

To document service utilization and pathways to care, all mental health contacts (defined as contacts involving a mental health professional and/or for a mental health problem) were noted and categorized as evaluations, treatment, or crisis interventions (defined as an ER visit or an intervention provided by a crisis support team). To distinguish between episodes of care, multiple appointments with one service provider (e.g., treatment occurring over a defined period) was counted as one contact. For each different mental health contact, a number of variables were extracted. These included the primary reason for seeking services; the stakeholder involved in initiating care (e.g., youth, family member, child welfare worker, school personnel, police, judge, and others); the duration of the episode; reason for episode termination of services; etc. (For full extraction template, see Supplementary Material).

Statistical Analysis

Descriptives were calculated for socio-demographic, child adversity, placement, and parental history variables. Pathways to services were examined, beginning with the type of mental health problem requiring care, the stakeholder who initiated care, and the setting within which care was received. Analyses of the Means (ANOM) of Proportions were conducted to compare the proportions of the types of stakeholders initiating care for each of the five most frequently cited mental health problems. The same analysis was conducted to compare proportions of the types of settings used by each category of stakeholder. An alluvial diagram was used to depict these pathways. The diagram was built using RawGraphs 2.0.

A logistic regression model was used to study if factors associated with mental health service use in this population, as described above, predicted the use of multiple mental health service settings over the course of young people's follow-up by child welfare services. These factors included gender, placement history, parental risk factors, immigration status, childhood adversity, and social/material deprivation. Multi-setting use was operationalized based on the frequency distribution of number of settings in this sample and informed by previous literature, particularly the Farmer (2010) paper that had previously investigated multi-setting use for mental health problems. Analyses were performed using JMP 15 Pro.

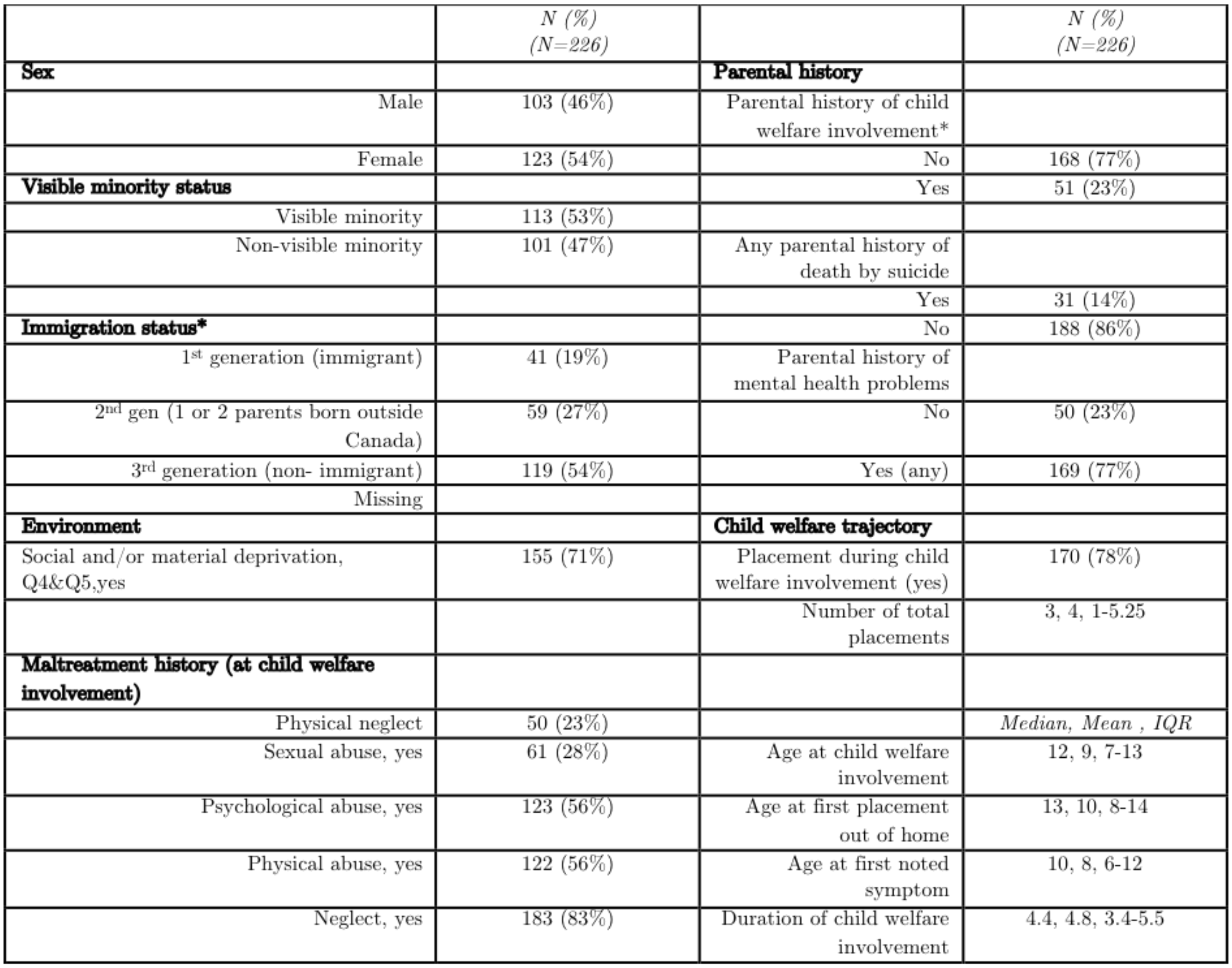
Finally, we examined the timing of changes in the frequency of mental health contacts using change-point analysis. This type of analysis allows for the detection of abrupt changes in data when a property of the time-series changes, in this case, the involvement of child welfare services. We established the number of mental health service contacts per month for the entire sample, in the six months prior to child welfare services involvement and in the first six months of child welfare services involvement. We then used the changepoint package in R to detect the change in variance of the data. The cpt.meanvar function with binary segmentation (BinSeg) method was employed to determine the number of changes in the mean and/or variance of the data. This analysis allows us to find the sequence of observations where a change in mean is detected and the percentage of this mean difference.

Results

1. Socio-demographic characteristics

As outlined in Table 1, the median age for youth at their first involvement with child welfare services was 12 years old (IQR 7-13). Our sample had slightly more females than males (54% vs 46%). 53% of the total sample belonged to a visible minority group, and 46% of the sample were either born outside of Canada or had at least one parent born outside of Canada. 71% of the sample lived in areas with high or very high levels of social and material deprivation.

Table 1. Sample Characteristics



	N (%) *(N=226)*		*N (%)* *(N=226)*
Sex		**Parental history**	
Male	103 (46%)	Parental history of child welfare involvement*	
Female	123 (54%)	No	168 (77%)
Visible minority status		Yes	51 (23%)
Visible minority	113 (53%)		
Non-visible minority	101 (47%)	Any parental history of death by suicide	
		Yes	31 (14%)
Immigration status*		No	188 (86%)
1st generation (immigrant)	41 (19%)	Parental history of mental health problems	
2nd gen (1 or 2 parents born outside Canada)	59 (27%)	No	50 (23%)
3rd generation (non- immigrant)	119 (54%)	Yes (any)	169 (77%)
Missing			
Environment		**Child welfare trajectory**	
Social and/or material deprivation, Q4&Q5,yes	155 (71%)	Placement during child welfare involvement (yes)	170 (78%)
		Number of total placements	3, 4, 1-5.25
Maltreatment history (at child welfare involvement)			
Physical neglect	50 (23%)		*Median, Mean , IQR*
Sexual abuse, yes	61 (28%)	Age at child welfare involvement	12, 9, 7-13
Psychological abuse, yes	123 (56%)	Age at first placement out of home	13, 10, 8-14
Physical abuse, yes	122 (56%)	Age at first noted symptom	10, 8, 6-12
Neglect, yes	183 (83%)	Duration of child welfare involvement	4.4, 4.8, 3.4-5.5

2. Mental Health Service Contacts

188 youth (83.19% of our total sample) had at least one contact with mental health services over the course of their follow-up by child welfare (median 4.4 years, range 3.4-5.5 years). Over a given 12-month period, the proportion of youth with mental health contacts was in the range of 36-41% of the sample. Of these 188 youth, 49% had some form of contact with mental health services prior to their involvement with child welfare services.

A. Reasons for Contact (see Table 2)

The most common reason for contact with mental health services was suicidal ideation (17% of all contacts); followed by externalized symptoms (15%) and substance use (11%). One-third of youth service users had at least one episode of care that followed them expressing suicidal ideation. 10% of youth had contact with mental health services following a suicide attempt.

B. Stakeholder involved in Initiating Care (see Table 2)

We examined the key stakeholders involved in initiating contact with mental health services. Child welfare services were the most common initiators of mental health contacts, followed by schools and youth themselves. Almost one-quarter of all youth had at least one contact with mental health services that they had initiated themselves, and one-fifth had at least one contact initiated by a judge.

C. Setting of mental health service (see Table 2)

ERs were the leading setting for mental health services, with almost 20% of all mental health contacts occurring at the ER, followed closely by hospital outpatient clinics and services within the child welfare agency. Nearly 40% of youth who had received mental health services had had at least one contact with an ER over the course of their follow-up by child welfare services. Notably, 8% of all contacts were with the private sector, with 28% of youth who had sought mental health services having accessed private services.

Table 2. Use of Mental Health Services During Child Welfare Involvement

Reason for Contact	n (%) of all contacts (N=861)	n (%) of all service users (N=188)
Suicidal ideation	141 (17%)	61 (32%)
Externalized symptoms	132 (15%)	73 (39%)
Substance Use	87 (11%)	39 (21%)
Internalized	57 (7%)	40 (21%)
Decline in functioning	66 (8%)	47 (25%)
Post-traumatic stress disorder	38 (4%)	26 (14%)
Emotional dysregulation	35 (4%)	27 (14%)
Medication related follow-up	32 (4%)	25 (13%)
Self-harm	29 (3%)	16 (9%)
Eating disorder	15 (2%)	7 (4%)
Suicide attempt	38 (4%)	19 (10%)
Borderline personality traits	11 (1%)	6 (3%)
Hallucinations	9 (1%)	7 (4%)
Somatic symptoms	8 (1%)	5 (3%)
Grief	5 (0.5%)	4 (2%)
Other	122 (14%)	-
Missing	36 (4%)	--
Stakeholder initiating care		
Child welfare worker	292 (36%)	120 (64%)
School staff	119 (15%)	77 (41%)
Youth	87 (11%)	46 (24%)
Family	62 7%)	44 (23%)
Judge	64 (8%)	41 (22%)
Police	49 (6%)	34 (18%)
Hospital staff	59 (7%)	30 (16%)
ER staff	25 (4%)	25 (13%)
Community-based primary healthcare staff	33 (5%)	21 (11%)
Medical clinic staff	14 (2%)	12 (6%)
Private sector professional	2 (0.2%)	2 (1%)
Substance use facility staff	2 (0.2%)	2 (1%)
Setting of mental health contact		
ER	157 (19%)	74 (39%)
Hospital outpatient clinic	154 (18%)	81 (43%)
Child welfare agency	135 (16%)	68 (36%)
School	111 (13%)	81 (43%)
Community-based primary healthcare centre	112 (13%)	70 (37%)
Private sector	71 (8%)	53 (28%)
Substance use clinic	54 (6%)	30 (16%)
Inpatient unit	27 (3%)	15 (8%)
Medical other	30 (3%)	24 (13%)
Missing	10 (1%)	NA

D. Pathways to Services

We examined pathways leading from mental health symptoms to contact with services (See Figure 1). We conducted an Analysis of Means for Proportions to determine whether group proportions differed significantly from the overall sample proportions. From these analyses (see Supplementary Material 2), we found that youth were significantly more likely to initiate care for substance use problems, and to seek help from substance use clinics. Schools were more likely to initiate mental health help-seeking on behalf of young people for externalized symptoms, and to seek help within school-based settings. Finally, both parents and police were more likely to seek mental health help at an ER.

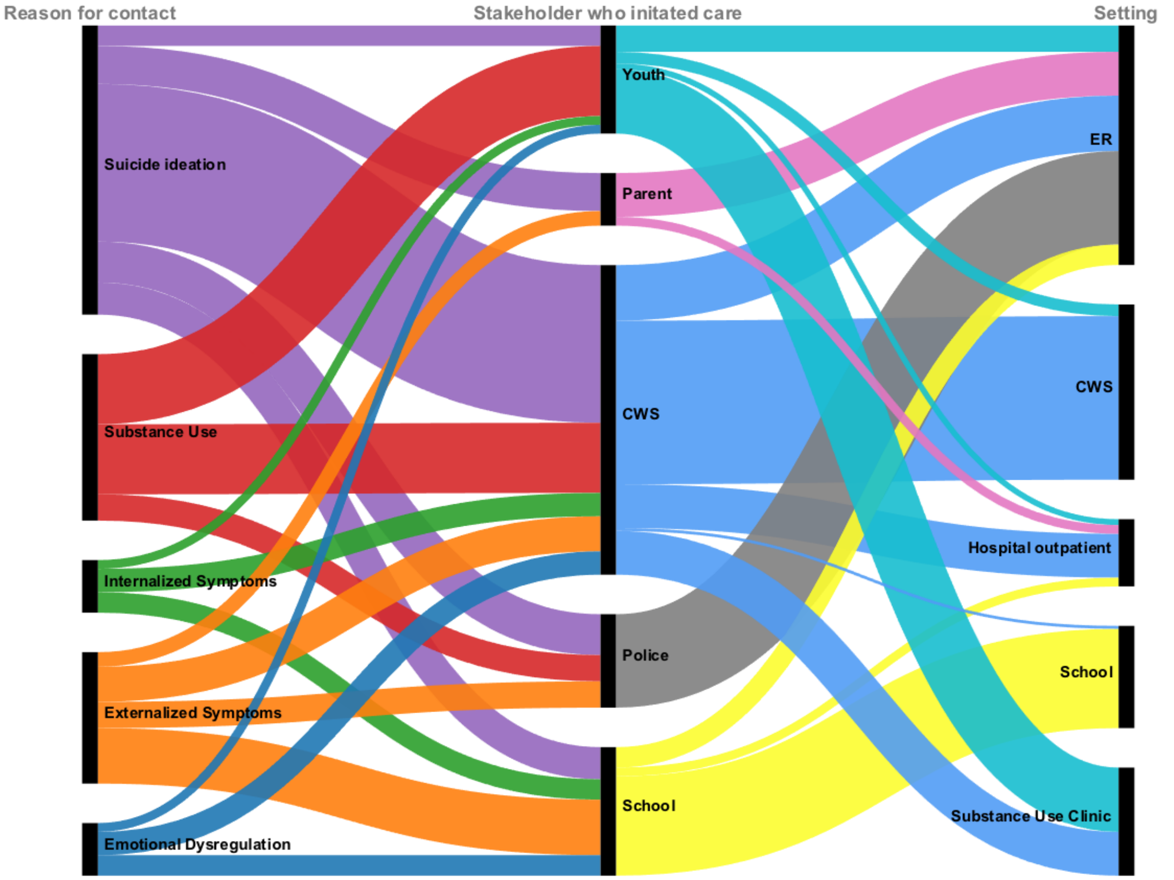
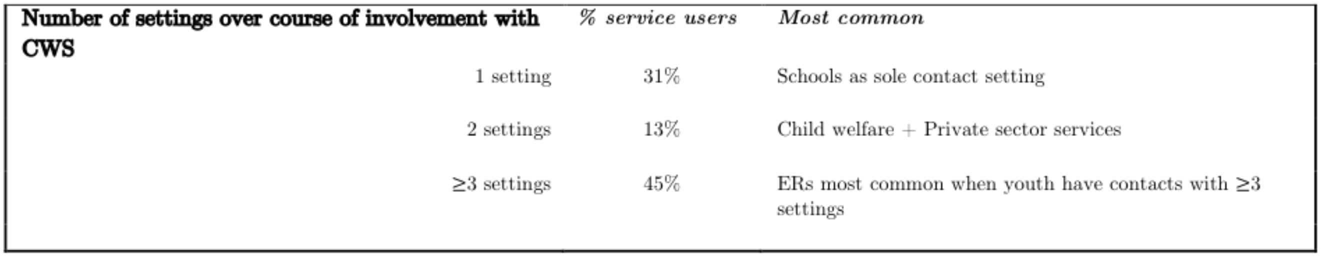


Figure 1. Pathways from mental health symptoms to contact with services

3. Patterns of service use

We investigated the use of multiple settings over the course of young people's follow-up by child welfare services. Many youth (45%) had accessed mental health services in at least three distinct setting types , e.g., school, private sector, ER. (see Table 3). The median number of settings for this group was 4.4 settings, with a range from 3-8 settings. When young people had accessed mental health services in only one setting, this tended to be their school.

Table 3. Patterns of service use



Number of settings over course of involvement with CWS	*% service users*	*Most common*
1 setting	31%	Schools as sole contact setting
2 settings	13%	Child welfare + Private sector services
≥3 settings	45%	ERs most common when youth have contacts with ≥3 settings

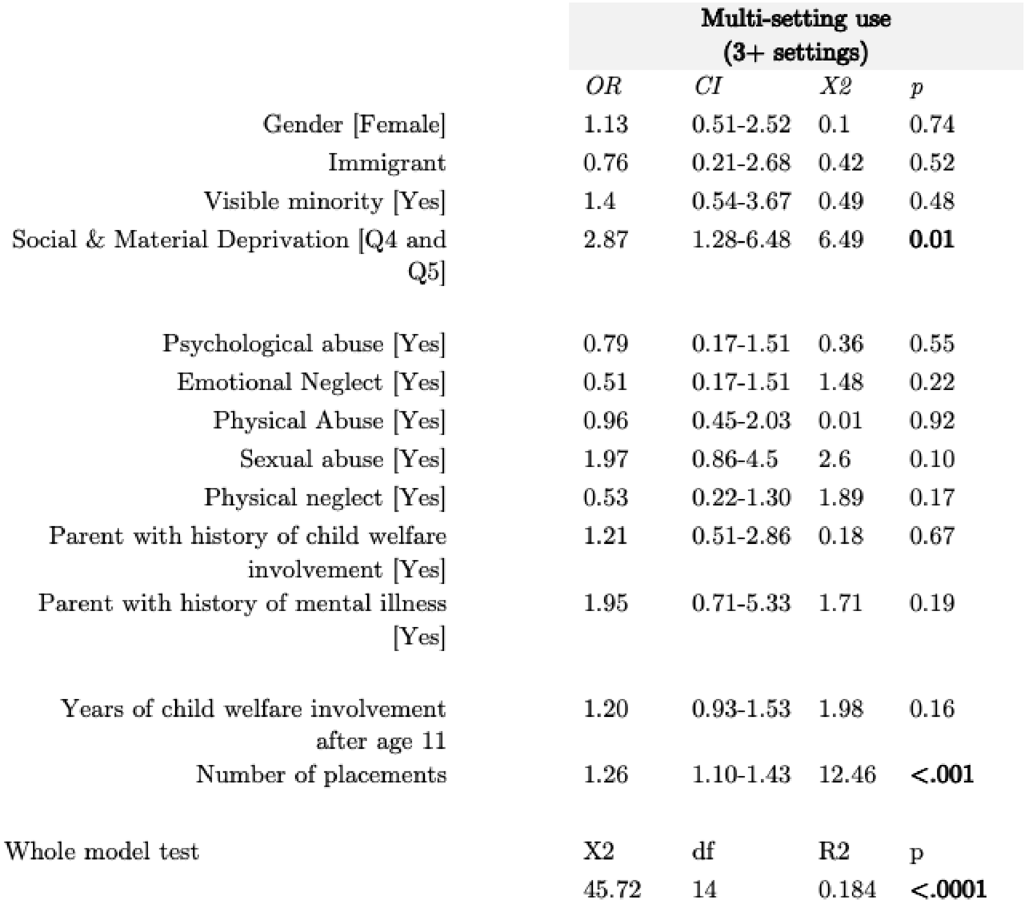
Logistic Regression

We conducted a logistic regression to examine multi-setting use for mental health problems in relation to the following variables — gender, visible minority status, immigration status, social and material deprivation; childhood adversity measures including physical neglect, emotional neglect, physical abuse, emotional abuse, and sexual abuse; parental history variables including parental history of child welfare involvement and mental illness; and child welfare services follow-up characteristics including number of placements and duration of follow-up by child welfare services. Tests to ensure that our data met the assumption of collinearity were conducted, using variance inflation factors. These tests indicated that multicollinearity was not a concern (VIF range = 1.21-2.31).

We defined multi-setting use as having accessed mental health services at three or more settings over the course of follow-up by child welfare services. Roughly half (45%) of the youth sample using three or more settings. Earlier, Farmer (2010) classified use of three or more settings for mental health problems as multi-setting use.

The logistic regression model was significant, (χ2 (14) = 45.72, p¡0.0001). It explained 18% (Nagelkerke R2) of the variance and accurately classified 79% of the cases as having used 3 settings versus one or two settings. The model (Table 4) revealed that higher numbers of placements and higher levels of social-material deprivation were associated with the use of $\geq$3 settings. Adjusted odds ratios are shown in Table 4.

Table 4. Logistic regression comparing patterns of service use



	Multi-setting use (3+ settings)			
	OR	*CI*	*X2*	*p*
Gender [Female]	1.13	0.51-2.52	0.1	0.74
Immigrant	0.76	0.21-2.68	0.42	0.52
Visible minority [Yes]	1.4	0.54-3.67	0.49	0.48
Social & Material Deprivation [Q4 and Q5]	2.87	1.28-6.48	6.49	**0.01**
Psychological abuse [Yes]	0.79	0.17-1.51	0.36	0.55
Emotional Neglect [Yes]	0.51	0.17-1.51	1.48	0.22
Physical Abuse [Yes]	0.96	0.45-2.03	0.01	0.92
Sexual abuse [Yes]	1.97	0.86-4.5	2.6	0.10
Physical neglect [Yes]	0.53	0.22-1.30	1.89	0.17
Parent with history of child welfare involvement [Yes]	1.21	0.51-2.86	0.18	0.67
Parent with history of mental illness [Yes]	1.95	0.71-5.33	1.71	0.19
Years of child welfare involvement after age 11	1.20	0.93-1.53	1.98	0.16
Number of placements	1.26	1.10-1.43	12.46	**<.001**
Whole model test	X2	df	R2	p
	45.72	14	0.184	**<.0001**

4. Timing of service use in relation to child welfare involvement

Change point detection analysis was conducted to examine whether there were significant changes in the frequency of mental health service contacts in the six months before and the six months after involvement with the child welfare system (See Figure 2).

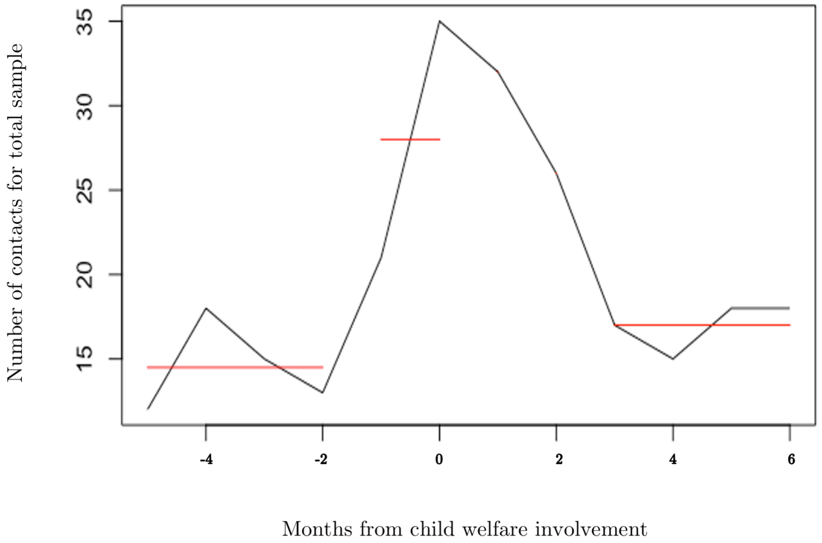


Figure 2. Timing of service use in relation to child welfare involvement

Two change points were detected which resulted in three distinct time-series segments. At six months prior to the involvement of child welfare services, the mean number of contacts for the entire sample was 14.5 contacts/month. At the first change point, which occurred two months before the involvement of child welfare services, the number of contacts began increasing significantly until child welfare services got involved (i.e., at time 0, the mean number of contacts rose to 32 contacts/month, an increase of 228%). The second change point, which occurred at two months after child welfare services got involved, represented a decrease in contacts (mean 17 contacts/month).

Given the high number of contacts occurring at the start of involvement of child welfare services, further analyses were conducted to investigate the types of mental health contacts occurring in these first weeks. Of the 35 mental health contacts that occurred within the first month following the start of child welfare involvement, 15 occurred on the same day that a youth was flagged to child welfare. These contacts were primarily crisis interventions (ER visits) initiated by entities other than child welfare services. Further, we found that the rates of both treatment and crisis interventions reach a peak just prior to child welfare involvement, while the rates of evaluations peak in the month after child welfare involvement begins (See Supplementary File 1).

Discussion

This study examined the patterns of mental health service use by youth in child welfare services, and the pathways involved in obtaining such services. Overall, a large majority of youth (83%) had contact with mental health services over the course of their involvement with child welfare services. In any given year, between 36-45% of the sample had at least one contact with mental health services, which is about double that of the estimate for the general Canadian youth population according to the 2018 CCHS (17%) [22].

Use of specific settings

ERs were the leading point of service receipt. High rates of ER use for mental health problems have been noted in the general youth populations, with some reports estimating a 75% increase in ER visits for mental health reasons for youth under the age of 24 in the last decade [23]. Our study sheds light on the fact that rates of ER use for mental health problems are particularly high for youth during their involvement with child welfare services. This is consistent with a previous literature review that reported that many youth (between 22%-43%) presenting at the ER for mental health problems had current or prior experiences of child welfare involvement [24, 25]. Given these high rates of ER use, their associated costs, and the fact that ERs are not designed to offer youth a soft landing into care, special attention must be paid to ensure that youth involved in child welfare services can access appropriate services prior to the emergence of a mental health crisis.

We also noted the relatively high use of mental health contacts being made in private settings for youth during their involvement with child welfare. These services were most often initiated by judges involved in the youth's case. Judge-initiated care is commonly mandated to occur within a certain time frame, and public services often fail to provide services within these timelines. As such, private sector services are utilized by child welfare services to ensure that treatment or evaluations are provided within court-mandated timeframes. This represents a failure of the public health system, which results in government-funded child welfare services having to resort to expensive private services.

Use of multiple settings

Many youth had contacts with mental health services across multiple settings over the course of their involvement with the child welfare system. This is consistent with studies from youth in the general population, who often present to a multitude of medical and social service sectors for mental health problems [26, 27]. The use of mental health services from different settings may reflect the natural course of mental health problems and the changing needs or desires of youth. On the other hand, it may also reflect a poor response to treatment, disengagement with care, a failure to appropriately assess and respond to a young person's needs or poor coordination between settings. In all cases, the combination of services from different settings provides an impetus for increased collaboration between the settings that interact and serve youth involved with child welfare agencies.

Emergency Rooms, schools, and hospital outpatient settings were the most common points of service receipt for youth in child welfare services, reinforcing the importance of strengthening the collaboration between each of these settings and child welfare agencies. Schools, for example, may be well-equipped to support early identification efforts and entry into services. Strengthened linkages between Emergency Room personnel and child welfare agencies could facilitate coordinated discharge planning and increase the likelihood of recommended outpatient follow-up. Such measures, characterized by better communication, shared policy development, formalized collaborative agreements, and cohesive treatment philosophies and goals, have been linked to greater service use and better mental health outcomes for young people in child welfare [28].

In our sample, higher numbers of placements were linked to an increased likelihood of multi-setting contacts for mental health problems. Placements changes have previously been linked to greater rates of outpatient service use [29] and higher rates of Emergency Room visits [30]. It has been suggested that higher rates of mental health issues are a predictor of placement instability [31, 32] while others have noted that disruptive placement changes can themselves negatively impact a young person's emotional and mental health [31-34]. Notwithstanding our inability to tease these two possibilities apart, our findings point to the reality that many youth in child welfare services experience a multitude of disruptions, in both home and healthcare environments. This is particularly critical as strong evidence exists for the importance of continuity of attachment ties for youth in welfare services [35], including continuity in healthcare [36]. Evidence also suggests that preventing placement instability can improve mental health outcomes for youth and their need for emergency mental health care [30]. Interestingly, one successful pilot project effectively reduced placements within child welfare by making a mental health clinician available on site at two foster care agencies [37].

Higher social and material deprivation was also associated with mental health contacts in multiple settings. Prior studies have found an association between social and material deprivation and increased mental health service use in the general population [38] as well as an association between deprivation and high rates of ER use in adults [39]. However, this association has rarely being examined in the context of child welfare services.

Timing of contacts

Our study replicated the findings from Leslie et al. [18] which revealed an increase in mental health service use around the commencement of the involvement of child welfare services. Our findings expanded on this research by showing that mental health service use increases steadily in the two months prior to the beginning of child welfare involvement, then reaches a peak during the first month of child welfare involvement, and decreases thereafter, with rates of mental service use after 3 months of child welfare involvement being only slightly higher than pre- child welfare rates.

The rise in mental health contacts prior to child welfare involvement may be explained by a pre-existing need for mental health services among these youth. Previous research demonstrated that existing psychological problems may increase youths' involvement with child welfare. Another study noted that the need for mental health services was the strongest predictor of youths' eventual placement in the foster care system [40]. The peak in contacts just following the commencement of child welfare involvement may be related to early scrutiny of youths' well-being as part of the initial investigation by child welfare workers. One survey from the USA revealed that many youth were placed in the custody of child welfare services by their parents specifically in order to receive mental health services [41]. Our analysis also revealed that the initial referral to child welfare was made on the same day as many mental health contacts, notably at the ER, suggesting that healthcare services may have played a role in reporting youth to child welfare, demonstrating the multifaceted relationship between health and social services.

Stakeholders involved in initiating care

Our study provided a novel examination of who initiates mental health services for this population. Notably, a wide range of actors were involved in initiating contact, including schools, judges, police, parents and others. This is particularly significant because child welfare workers are often viewed as "brokers" for services needed by youth in child welfare services [42], and youth involved with child welfare services have been considered 'help-receivers', whose decisions regarding healthcare are made for them by others [43]. However, the help-seeking ability of these youth is of particular importance, given that help-seeking skills can be vital once their involvement with child welfare ceases at age 18 [44], especially considering the high mental health needs of youth as they exit child welfare services [45], and the fact that mental health service use drops by as much as 60% once youth age out of care[46].

Our results showed that at least in our sample, youth (24%) themselves initiated contact with mental health services. The top reason for which youth themselves initiated contact was for substance use problems. This finding is salient given prior evidence that youth are reluctant to seek help for substance use disorders, with youth help-seeking rates for substance use being lower than those for other psychiatric conditions [47-49]. Our finding may be explained by the fact that in Quebec, substance use clinics specifically target outreach activities at child welfare systems so that youth in need are identified earlier. These outreach may address many of the barriers that have been noted in the literature as contributing to youth not seeking treatment for substance use. These include a lack of knowledge about treatment options, long waitlists, lack of youth-specific programs, and stigma [50, 51]. Altogether, this suggests that broader-spectrum early identification interventions should specifically target youth in child welfare services.

Social determinants

The rate of visible minority youth in our sample (53%) far exceeds the expected rate of 28%, based on census data from our two catchment-area based populations. Racial disproportionality within child welfare systems has been the subject of recent studies emerging out of Canada [52-56].There is a pressing need to identify and acknowledge that the historical legacies of social policies and institutional practices within Canada have placed a disproportionate burden on specific visible minority and immigrant communities, and that these legacies continue to affect youth and families in Canada today. While further examination of this matter is crucial, it should also be noted that many of these issues, including specifically anti-Black and anti-Indigenous racism within child welfare services in Canada, have been decried for over two decades [52, 57-59].

Limitations

Limitations of this study include the lack of information on clinical severity, precluding any examination of whether youth with greater clinical needs were seen more frequently, or in greater numbers of settings. We were also unable to gather information on all possible organizations providing care for young people, including, for example, the voluntary sector. Further, we were unable to record all reasons for service discontinuation, thus limiting our ability to contextualise youths' trajectories from one setting to another, and from describing whether their mental health needs were met by each episode of care. Our sample size also limited our power to test other variables which may be associated with patterns of service use, such as stakeholders involved in initiating care, and reasons for needing mental health services.

Overall, our findings suggest that the organization of health and social services along geographical catchment areas in Quebec (the context of this study) does not necessarily translate into service users having coordinated, integrated services with strong continuity of care. Many factors are known to prevent the coordination of services, including the reluctance to share resources, defending professional territoriality through specialization and the designation of professional acts, and the scarcity of financial resources and their inefficient use [60]. Youth face the prospect of repeating their story or having duplicated assessments due to lack of interprofessional collaboration. These factors are intrinsically linked to a need to strengthen integrated youth mental health services globally. Integrated services, which are gaining traction across different healthcare jurisdictions across the world, aim to address the broader issues of service gaps, lack of inter-sectorial collaboration, and concomitant service use by providing one-stop mental health services for youth with varying needs. These types of integrated services may greatly benefit youth involved with child welfare services, who have diverse needs and already present to multiple different settings. By integrating services at a systemic level, the broad range of needs that many youths in child welfare services have can be addressed more cohesively. This will however require the commitment of key stakeholders, such as, for example, through specific partnerships between integrated youth services and child welfare agencies and continuous evaluation of the effectiveness of such partnerships in terms of improved pathways and outcomes.

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Bridge

The previous manuscript was among the first to provide an in-depth portrait of the settings and key actors involved in youths' pathways to care over the course of their follow-up by child welfare services. One of the main findings from Manuscript III is the use of the Emergency Room (ER) as the leading mental health care contact for these youth.

In fact, the prominent role of Emergency Rooms in youths' pathways to care is a recurring theme across each of the three previous manuscripts. In our systematic review of quantitative studies on young people's pathways to mental health care, ERs were found to be a common first contact with the mental health care system (Manuscript I). In our qualitative meta-synthesis, we reported that families often described ERs as the quickest way to reach services, leading some to feel relief when a crisis requiring an ER visit emerged. Others described their ER contact as traumatic, or stigmatizing. (Manuscript II). In Manuscript III, ERs were found to be the most often accessed setting for mental health problems, and their use a a common experience, with over 40% of youth experiencing an ER visit over the course of their follow-up by child welfare services.

Youth in the general population are increasingly presenting themselves at ERs for mental health problems, and ERs are emerging as a key entry point into the mental health system. This issue raises multiple concerns including whether ERs are adequately equipped to respond to youth mental health needs. Despite these high rates of their use, little is known about the factors leading to ER use for youth experiencing mental health problems. This is especially true of youth in child welfare services. Therefore, we were interested in exploring the issue further, and examining how and why youth in the care of child welfare services present to Emergency Rooms for issues related to their mental health. In addition to determining the reasons for ER visits, we wanted to establish how these ER contacts intersected with the patterns of service use depicted in Manuscript III, for example, whether ER use occurred concomitant to other treatments or occurred during a gap in care.

The following manuscript has been prepared for submission.

Chapter 6

Manuscript IV

Emergency Room Use for Mental Health Problems Among Youth Involved in Child Welfare Services

Kathleen MacDonald, Lise Laporte, Lyne Desrosiers , and Srividya N. Iyer
Prepared for submission.

Abstract

Objective : In Canada, little research has focused on Emergency Room (ER) use by youth involved with child welfare services, who are a vulnerable population. Our aims were therefore to examine the characteristics of ER use in child welfare-involved youth; and to establish their trajectories to ERs.

Methods: Data on the use of mental health services, including ERs, were collected from charts for 226 youth during their involvement with child welfare in Montreal. Logistic regression was conducted to determine the predictors of ER use. Latent class analysis was used to distinguish trajectories to the ER based on reason for visit, initiator, previous mental health contacts, and placement history. Kaplan-Meier time-to-event analysis established whether trajectories were differentially associated with recurrent ER use.

Results: Over one-third of youth visited the ER at least once for mental health problems. Youth with a history of sexual abuse, parental mental illness, and placement outside home were likelier to have had ER contact. 44% of youth accessing ERs were already availing mental health services. 76% of ER visits did not precipitate mental healthcare in <30 days. 53% contacts resulted in another ER visit within one year. Three trajectories were found: ER contact initiated by child welfare workers for suicidal ideation/attempts for youth with at least one placement outside home; ER contact initiated by police for substance use and externalized behaviours; and ER contact initiated by parents for suicidal ideation/attempts for youth never placed outside home. Trajectories with police as main initiators were least likely to result in a recurrent ER visit.

Discussion: Despite all youth being followed by child welfare and many already receiving mental health services, youth had high, often recurrent ER use. This, along with treatment not commencing rapidly after ER visits, highlights the need for stronger coordination between child welfare, youth mental health and ER services.

Introduction

In recent years, the use of hospital Emergency Rooms (ERs) for mental health problems has been escalating. This is particularly true for young people [1-5], with reports estimating a 45-50% increase in ER visits for mental health reasons by youth under the age of 24 in the past decade [6, 7]. In many cases, Emergency Rooms have become the primary portal of access to the mental health system for young people [8-10], and mental health concerns make up about a quarter of all ER visits for children and youth in Canada and the USA [11-13].

The rise in ER use for mental health problems by youth is likely due to several complex and interrelated factors, including a high prevalence of mental health problems, coupled with gaps in access in primary care, long wait lists, and a desire for rapidly accessible care without appointments or referrals [10, 13-15]. In some cases, youth presenting to ERs for mental health problems are not experiencing an urgent need for care, but access ERs due to a lack of other options [1, 16]. Youth presenting at the ER for mental health problems are often older adolescents [17], females [18-21], racial or ethnic minorities [22, 23] and have experiences of childhood adversity, parental history of mental illness, and socio-economic deprivation [19, 24]. One study from Canada showed a disproportionate use of ER as a first mental healthcare contact among youth from immigrant compared to non-immigrant backgrounds [24]. Common reasons for youths' ER presentations include aggressive behaviours, mood disorders, suicidality, anxiety, and substance use [13, 25, 26].

Despite the predominance of ERs in responding to youth mental health crises, it has also been noted that ERs are not well equipped to address the needs of young people and their families [4, 5]. ERs often lack the required resources to provide needed mental healthcare. As such, youth often face difficulty in receiving the right mental health assessments or treatment at the ER [4], and few are referred to appropriate, continuous care following their ER visit [12, 27, 28]. Unsurprisingly, repeated ER visits are a common occurrence among youth, with up to 45% of all ER visits being made by recurrent users [12, 25, 29]. A Canadian study showed that almost 40% of youth who visit an ER for a mental health problem make three or more such visits for the same concern [30]. Such use of emergency services comes at a high expense to the healthcare system [31], and some youth have described their experience as traumatic [32] and shameful [33]. Understandably, a recent Canadian report included repeat emergency department visits within 365 days as a metric of the quality of the mental healthcare system [34].

Among youth, those involved with child welfare services are known to be particularly high users of ERs for mental health concerns [35]. A review from France demonstrated that 22-43% of all youth presenting to the ER for mental health problems had a history of child welfare involvement [26]. One factor linked to the use of ERs by child welfare-involved youth is their history of placements outside of the family home, with those with a placement history being more likely to use Emergency Rooms for mental health problems [36]. Increased numbers of placements were also linked to higher rates of ER use [37]. Certainly, the rates of mental health problems among youth in child welfare services [38-40] may place them at heightened risk for the types of psychiatric crises that warrant emergency care. Still, the high use of ERs by youth involved in child welfare services is concerning. Given these youth's links with health and social services, their mental health problems ought to have been identified and responded to early.

While many studies have examined ER use for mental health problems in children and adolescents [10, 41, 42], very few have investigated this issue within child welfare populations. Additional research is thus needed to examine the profiles of youth who use the ER for mental health problems during their involvement with child welfare services, particularly in the Canadian context where this issue has not been systematically addressed. This would allow us to identify young people at high risk of using ER services, as well as to identify organizational gaps that can be addressed to better respond to the mental health needs of youth in child welfare services. Accordingly, this study's objectives were 1) to examine the characteristics of ER use in our sample, including the predictors of being an ER user and the timing of ER encounters and 2) to determine distinct trajectories to the ER, based on reasons for an ER visit and the individuals involved in initiating an ER contact.

Methods

Local Context – Quebec Child Welfare Services

In Canada, child welfare services provide an array of psychosocial, rehabilitation and placement services to youth who have been found to be abused, be neglected, or experience behavioural problems. Although child welfare services can offer interventions designed to address mental health or adaptation problems in youth, youth in child welfare services often use regular-stream mental health services [38]. Canada's healthcare model is a publicly funded, universal system. In the province of Quebec, healthcare is organized geographically, with services planned and delivered to address the needs of a population within defined catchment areas. Mental health services are offered in primary care settings (i.e., local, community-based primary health centres); secondary care settings (i.e., specialized services, hospital-based inpatient or outpatient centres and ERs); and tertiary care settings (i.e., residential programs). Private-sector mental health services are also available, predominantly through private psychologists and psychotherapists.

Ethics

This study was approved by the *Centre Jeunesse de Montréal-Institut Universitaire Institutional Ethics Committee.*

Sample

Our sample included all the youth aged 11-18 years in two specific catchment areas, who received services from Montreal's only two child welfare agencies (*Centre jeunesse de Montréal*, n=142; and *Batshaw Youth and Family Centers*, n=84) between 2010 and 2019. Their child welfare charts were reviewed yearly, and data were collected until each youth turned 18, or earlier if the youth no longer required child welfare services.

Data collection

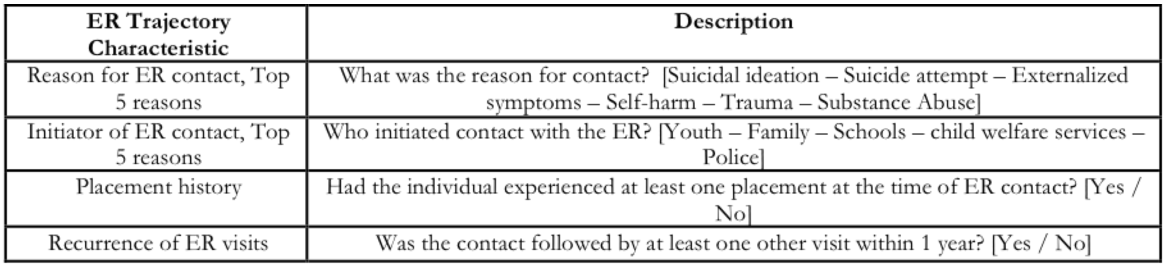
Trained research assistants systematically collected information from the charts, using a detailed template created for the study. Ten percent of all charts were randomly picked for independent review to ensure accuracy. Inter-rater reliability was high (κ =.71). Weekly team meetings were conducted to assure data accuracy. Data extracted from charts included demographic and clinical information. Participants' social and material deprivation were derived by matching their postal codes with relevant indices from the *Institut National de Santé Publique* [43]. These indices were developed from census data using six neighbourhood-level population indicators known to be proxies for deprivation: completion of secondary education; employment status; living situation; average income; marital status; and proportion of single parent family units. To characterize ER trajectories, all details pertaining to ER visits were extracted, including dates for each visit, reason for seeking services, who initiated the ER contact, diagnoses given, and recommendations following the contact.

Statistical Analysis

Objective 1: Characteristics of ER users

Descriptive statistics for characteristics of ER users were calculated. Independent samples t-tests and Pearson's chi-squared tests were used to determine group differences between ER users and non-users. Logistic regression analysis was used to estimate the influence of socio-demographic and clinical factors on ER use. Based on previous findings on characteristics of youth ER users, factors including age, gender, immigration and visible minority status, adversity indicators (emotional neglect or abuse, physical neglect or abuse, sexual abuse), social and material deprivation, and parental history of mental illness were used to compare ER users and non-users. The number of youths who were already in contact (currently or in the previous 30 days) with mental health services at the time of their ER visit was also calculated. Finally, the time to treatment initiation after each ER encounter was examined and compared against the Canadian Psychiatric Association benchmark of 30 days [44].

Objective 2: Distinct trajectories to ER use and their associations with recurrent ER use
Latent class analysis (LCA) was used to identify distinct classes of trajectories to ER services. Latent class analysis models are used to cluster data into subgroups with similar categorical characteristics. Each ER visit was considered a separate event and categorical characteristics for each event were computed. ER trajectory characteristics included reason for visit, initiator, previous mental health contacts, and placement history. The smallest model (1-class) was fit first, followed by sequentially increasing the number of classes selected to a maximum number of five classes. Model fit was determined using Akaike information criterion (AIC), Bayesian information criterion (BIC), and log-likelihood (LL). The Lo-Mendell-Rubin likelihood ratio (LMR-LRT) was also used to compare each subsequent K class model compared to the previous K-1 class model. These indices, in combination with theoretical interpretability, led to the selection of the final model [45]. Finally, for each latent class, we calculated a Kaplan-Meier survival curve to compare the recurrence of ER use within one year among these classes. Differences between the curves were tested with log-rank tests.



ER Trajectory Characteristic	Description
Reason for ER contact, Top 5 reasons	What was the reason for contact? [Suicidal ideation – Suicide attempt – Externalized symptoms – Self-harm – Trauma – Substance Abuse]
Initiator of ER contact, Top 5 reasons	Who initiated contact with the ER? [Youth – Family – Schools – child welfare services – Police]
Placement history	Had the individual experienced at least one placement at the time of ER contact? [Yes / No]
Recurrence of ER visits	Was the contact followed by at least one other visit within 1 year? [Yes / No]

All analyses were performed using JMP software, version 15 Pro.

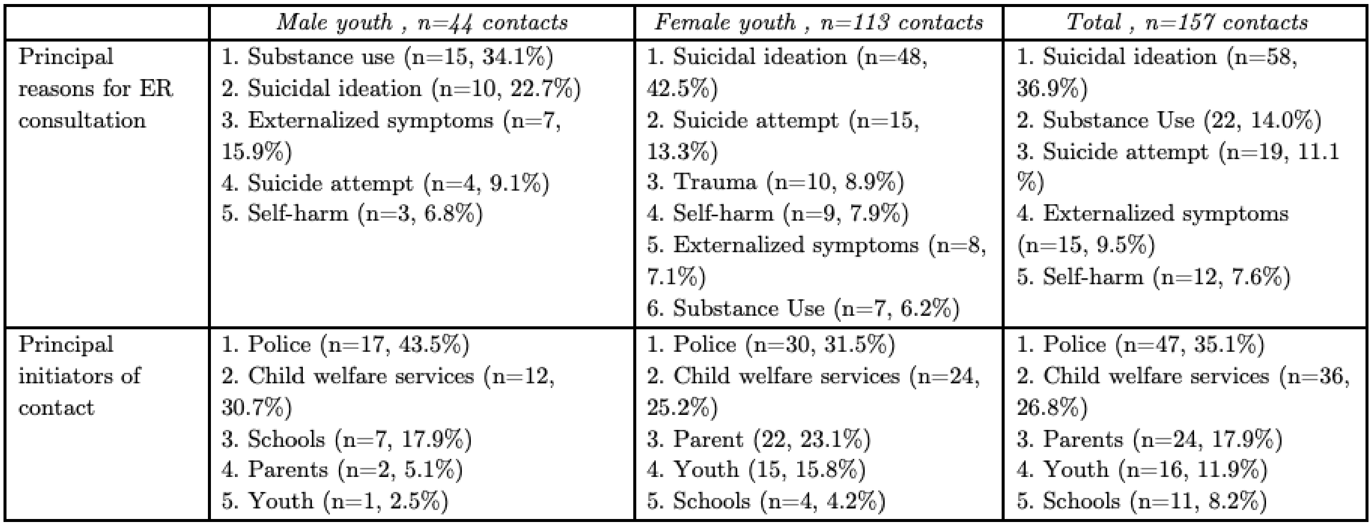
Results

1. Characteristics of ER Use

Over one-third of youth in our total sample (n=74/226) had at least one ER visit over the course of their follow-up by child welfare services and accounted for a total of 157 ER visits. Among ER users, most (47%, n=35) had one visit; 38% (n=28) had two or three visits; and 15% (n=11) had over four ER contacts. For 12 youth (16% of ER users), their ER visit represented their first ever contact with the mental health system.

As indicated in Table 1, the most common initiator of contact with the ER for mental health reasons was the police (35% of cases), followed by child welfare services (27%), and parents (19%). The most common reasons for an ER visit were suicidal ideation, substance use, and suicide attempts. Over 70% of all ER contacts were by females. For males, the predominant reason for ER visits was substance use problems, while suicidal ideation was the predominant reason for females.

Table 1. Reasons for and Initiators of Contact with ERs



	Male youth , n=44 contacts	*Female youth , n=113 contacts*	*Total , n=157 contacts*
Principal reasons for ER consultation	1. Substance use (n=15, 34.1%) 2. Suicidal ideation (n=10, 22.7%) 3. Externalized symptoms (n=7, 15.9%) 4. Suicide attempt (n=4, 9.1%) 5. Self-harm (n=3, 6.8%)	1. Suicidal ideation (n=48, 42.5%) 2. Suicide attempt (n=15, 13.3%) 3. Trauma (n=10, 8.9%) 4. Self-harm (n=9, 7.9%) 5. Externalized symptoms (n=8, 7.1%) 6. Substance Use (n=7, 6.2%)	1. Suicidal ideation (n=58, 36.9%) 2. Substance Use (22, 14.0%) 3. Suicide attempt (n=19, 11.1 %) 4. Externalized symptoms (n=15, 9.5%) 5. Self-harm (n=12, 7.6%)
Principal initiators of contact	1. Police (n=17, 43.5%) 2. Child welfare services (n=12, 30.7%) 3. Schools (n=7, 17.9%) 4. Parents (n=2, 5.1%) 5. Youth (n=1, 2.5%)	1. Police (n=30, 31.5%) 2. Child welfare services (n=24, 25.2%) 3. Parent (22, 23.1%) 4. Youth (15, 15.8%) 5. Schools (n=4, 4.2%)	1. Police (n=47, 35.1%) 2. Child welfare services (n=36, 26.8%) 3. Parents (n=24, 17.9%) 4. Youth (n=16, 11.9%) 5. Schools (n=11, 8.2%)

1.1. Predictors of ER Use

Logistic regression analysis indicated that having a previous experience of sexual abuse (OR =2.85, 95% CI 1.32-6.12), a parental history of mental illness (OR =2.85, 95% CI 1.32-6.12), and having at least one placement outside the family home during child welfare services (OR =2.85, 95% CI 1.32-6.12) significantly predicted likelihood of ER Use (see Table 2). We compared the characteristics of single-visit ER users, repeat users, and non-users, using chi-square analysis, which demonstrated that females (more than males) were likely to be repeat users (See Supplemental Material 1).

Table 2. Odds of ER Use

Characteristics	N (%)			Adjusted		
Demographics	Total Sample	Users	Non-users	OR	95% CI	*p*
	(n=226)	(n=74)	(n=152)			
Gender [Female]	123 (54%)	51 (69%)	72 (48%)	1.46	0.71-2.97	0.29
Visible Minority [Yes]	113 (53%)	39 (55%)	74 (52%)	1.14	0.64-2.01	0.66
Immigration [Yes[a]]	100 (43%)	28 (38%)	72 (48%)	1.4	0.65-3.00	0.39
Social and Material Deprivation [Q4/Q5b]	155 (71%)	55 (77%)	100 (68%)	1.38	0.65-2.93	0.39
Adversity history						
Sexual Abuse	61 (28%)	30 (42%)	31 (21%)	2.76	1.49-5.11	0.0012**
Physical Abuse	122 (56%)	43 (61%)	79 (53%)	0.97	0.49-1.94	0.94
Psychological Abuse	123 (56%)	39 (55%)	84 (57%)	0.99	0.49-1.97	0.98
Physical Neglect	50 (23%)	11 (15%)	39 (26%)	0.81	0.31-2.14	0.67
Parental history of mental illness	169 (77%)	61 (86%)	108 (73%)	2.82	1.06-4.17	0.037*
Child welfare history						
Placement (Yes)	170 (78%)	66 (93%)	104 (70%)	6.47	2.21-18.99	0.0007***

1.2 Timing of ER Visits

We examined the timing of ER visits with respect to child welfare and mental health treatment history for each ER contact (See Figure 1).

Concurrence

Forty-four percent of all ER visits (69/157) occurred during mental health treatment. The most common setting in which youth had been receiving mental health services at the time of their ER visit were hospital outpatient services, followed by community centres and schools. Of the remaining 88 ER visits, which occurred while the youth was not receiving mental health treatment, 20 visits (23%) were linked to a previous episode of mental health care within 30 days prior to the ER contact.

Diagnosis

Most ER visits (75%) were made by youth who had at least one diagnosed mental disorder at the time of their visit. A minority (20%) of ER contacts resulted in a new psychiatric diagnosis for the youth.

Placement

In terms of placement history, 61% of all ER visits occurred after a youths' first placement outside of the home. Individuals whose ER visit represented their first contact with the mental health system were less likely to have had a placement.

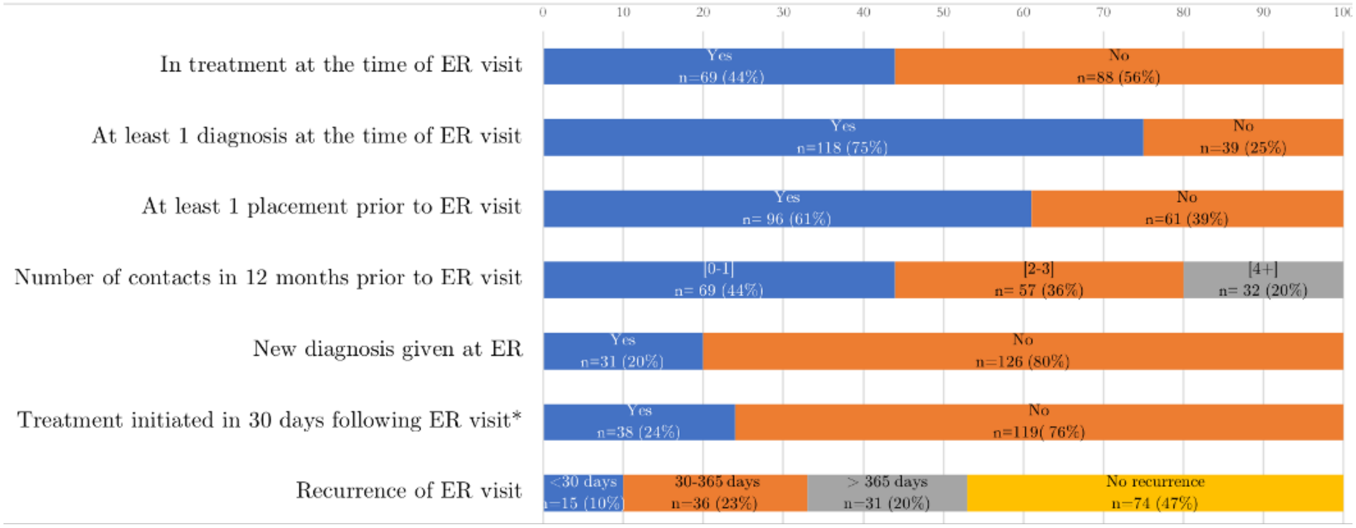
Treatment following ER

We next examined how many youth received treatment within 30 days of their ER contact, based on the Canadian Psychiatric Association's benchmark for treatment initiation [44]. For individuals not currently in treatment at the time of their ER visit (N=87), treatment was initiated within 30 days of their ER contact in 25% of cases.

Repeated ER visit

In our sample, 53% of all ER visits were return visits by an individual within one year of a previous ER contact.

Figure 1. Characteristics at the time of ER contact



2. Trajectories to the ER

2.1 Trajectory classes - Latent class analysis

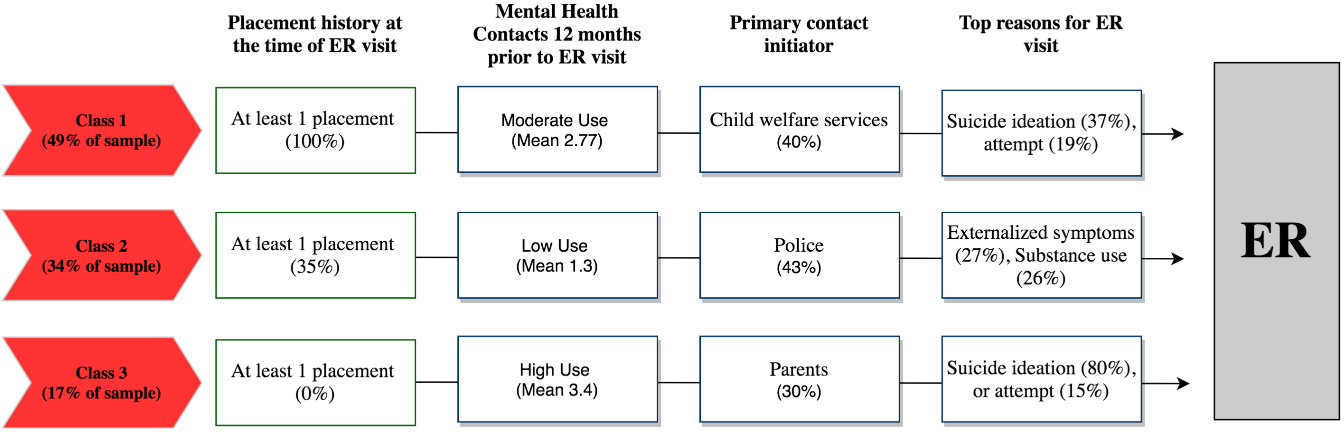
Fit statistics suggested a model with three classes as having the best fit (See Supplementary Materials). Based on these results, three classes of ER trajectories were categorized (See Figure 2).

The first class (49% of cases) represents a trajectory with high child welfare involvement. All youth in this class had been placed outside the family home at least once at the time of their ER visit. ER visits in this class were predominantly initiated by child welfare workers. Reasons for ER contact were largely suicidal ideation or attempts.

The second class (34% of cases) represents a trajectory with high police involvement. Youth in this class had low rates of mental health service use prior to their ER contact. ER visits were predominantly for substance use and externalized symptoms; and were most likely to be initiated by police.

The third class (17% of cases) represents a trajectory with high parental involvement. Youth in this class had not experienced a placement outside the family home; and contact with ER was initiated by parents or youth themselves. Youth in this trajectory had high rates of mental health service use in the year preceding their ER visit. Most commonly, ER contacts were made for suicidal ideation or attempts.

Figure 2. Representation of the three ER Pathways defined by the LCA analysis.



Considering the values of LR Logworth, all the trajectory variables were statistically significant classifiers of latent classes for the selected three-class model, with the timing of the first placement proving to be the most influential factor in segmenting clusters (Table 3).

Table 3. LR Logworth Values

Variable	Effect Size	LR Logworth
Reason for contact	0.72	14.3**
Who initiated help	0.67	11.9**
First placement prior to ER visit	0.80	27.5**
Contacts prior to ER visit	0.46	6.5**

* * Statistically significant classifier of latent classes at $\alpha = 0.01$ significance level.

2.2 Recurrence of ER visits – Kaplan Meier survival curves

A Kaplan-Meier time-to-event analysis was conducted to compare the rates of recurrence within 12 months of the index ER visit. Results indicate that significantly fewer recurrent visits occurred for Class 2 Pathways (high police involvement, 12% recurrence within 1 year), compared to the other two groups (Log-Rank $\chi 2$=13.32, p=.001). The other two groups (Class 1 and Class 3) had similar rates of recurrence (41% and 43%, respectively). However, Class 3 (high parental involvement) had the fastest time to recurrence (mean 145 days; Figure 3).

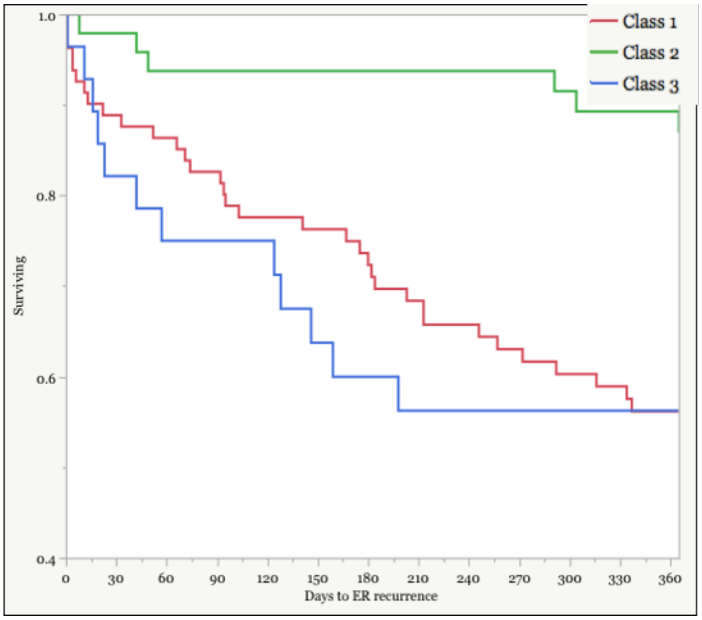


Figure 3. Kaplan-Meier time-to-event curve indicating time to ER recurrence by Pathways Cluster

Discussion

This study examined the use of Emergency Rooms for mental health problems in young people over the course of their involvement with child welfare services. We found that almost a third of all youth in our sample had at least one ER visit.

Youth in the general population often first seek help from the ER, with estimates of almost 50% of youth visiting an ER without any prior contact with outpatient mental health services [46, 47]. Strikingly, our results found that only 16% of our sample had their first mental healthcare contact at the ER, and the vast majority of visits (67%) were made by youth who were currently in treatment or had been seen in outpatient care in the 30 days prior to their ER visit. This suggests that in our sample, the use of the ER rarely represented a failure in recognizing mental health conditions before a crisis, but most likely, that a crisis, or the perception of a crisis, emerged at least partly as a result of a lack of coordinated, continuous care. This also suggests that social systems and child welfare workers ought to be better equipped to reduce the occurrence of such crises and manage them better so as to reduce ER use. This may entail capacity-building to identify which mental health situations are urgent; and improved training in de-escalation and suicide risk assessment.

One challenge in the provision of continuous mental health care for youth in whose cases child welfare services are involved is the patchwork of systems of care involved, with most youth receiving mental health services from three or more different settings, often at the same time [48, 49]. The high rates of repeated visits in our sample, along with treatment often not commencing rapidly after an ER visit, suggest that the ER may represent a further loop in the maze of mental health services received by youth followed by child welfare services.

The police bringing individuals to ERs is representative of an established, and at times contentious, role of police services in responding to mental health emergencies [50, 51]. This role has garnered negative attention both from the perspectives of police [52, 53] and individuals with mental health problems [54]. Among youth populations, police are often called upon to de-escalate familial disputes or to help with crisis situations. Furthermore, both families and youth have sometimes described police involvement during a mental health crisis as stigmatizing and distressing [55]. Yet, at least in our study, ER contact initiated by the police was least likely to result in a repeat ER visit, suggesting that even “negative” pathways to care can have at least some positive outcomes. Overall, a deeper focus is needed on the reasons for and repercussions of police involvement in youth mental health crises.

Our results showed a higher proportion of females in the ER user group, especially among repeat ER users. This is consistent with many studies from the general youth population [12, 29], which has been linked to the higher rates of self-harm and suicidal ideation in adolescent females [56, 57]. This was also notable in our sample, as suicidal ideation represented the top reason for ER visits, and this was predominantly driven by females. The overall prominence of suicidality is a major concern for youth involved in child welfare. As demonstrated by our latent class analysis, the trajectory to the ER followed by the largest number of youth was the one in which child welfare services workers brought youth to the ER for suicidal thoughts and behaviours. This points to a need for child welfare professionals to be well versed in risk assessment and for suicide prevention strategies to be embedded as essential components of child welfare services. In addition, ER use was also more likely among youth with a history of sexual abuse, which was more common amongst females in our sample. This complex intersection between such adversities and ER use is significant as many youth involved in the child welfare system have a complex history of trauma, with high exposure to adverse events during childhood. As such, trauma-informed approaches to both suicide prevention and mental health interventions in child welfare may be beneficial.

In our study, youth with a history of being placed outside the home were more likely to frequent ERs for mental health problems. This finding replicates other work on the association between placement instability and emergency mental healthcare use [37]. Placements outside the family home often entail emotional complications, and studies have demonstrated an increase in psychiatric symptoms and behavioural problems in the 12 months following such placements [58, 59]. On the other hand, youth with complex needs may be likelier to have disrupted family ties and thus require placements; these very needs may also increase their likelihood of requiring emergency services. Further, it has been shown that youth placed outside of kinship care are likelier to receive mental health services than those who stay in their family homes [38, 60, 61]. This suggests that placement itself may serve to trigger evaluations that identify mental health needs and thereby, initiate the pathway to mental health care. The confluence of these findings points to a need for child welfare services to monitor the emotional and psychiatric needs of youth in placement, who are at heightened risk for psychiatric emergencies.

Our study has certain limitations. Due to the nature of our dataset, we lacked clinical information such as severity of symptoms. This limited our ability to determine whether ER visits were for urgent psychiatric problems or for unmet non-urgent needs. Further, while we examined associations between specific variables and ER use, we could not capture mediation or moderation effects, primarily due to sample size limitations. For example, high levels of suicidal behaviour may be mediating the relationship between gender and ER use. Additional research is therefore necessary to examine indirect relationships between the factors identified in this paper. For the latent class analysis, our relatively small sample size precluded us from adding multiple classification variables, thus limiting our understanding of other possible differences between trajectories.

Efforts are currently underway in Quebec [62] to re-assess critical policy and practice standards related to best practices for youth in child welfare settings. Our study underlines that these efforts must have a greater focus on the mental health needs of this population so as to reduce their adverse outcomes. Furthermore, our results speak to the need for stronger coordination between child welfare, youth mental health and ER service systems.

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Chapter 7. Discussion

A. Overview of objectives and results

Delays in and lack of access to appropriate mental health services can often lead to further negative outcomes and undue suffering for young people and their families. Young people are at highest risk of developing mental health problems, but the current mental health system is not adequately configured to respond to their needs for care, especially in a timely manner. A thorough, comprehensive understanding of the patterns of service use and pathways to care for young people dealing with a range of mental health problems is a crucial step towards improving service delivery for this population, with the ultimate goal of improving their clinical and functional outcomes. Collectively, the manuscripts presented in this thesis aimed to provide a more comprehensive picture of the patterns and pathways of mental health help-seeking and service use of young people.In this chapter, the overall findings of this work will be presented and discussed.

The first objective of this thesis was to describe and understand pathways to care for youth populations. Across our four manuscripts, we found that youths' service use and pathways to care included a complex web of mental health services, irrespective of their context, geographic location, mental health problem and of type of healthcare system. Across both our literature reviews, young people and their families reported contacting multiple mental health services before obtaining the care they needed, and our qualitative review demonstrated that this multitude of contacts often led to feelings of confusion, dissatisfaction, and frustration for both youth and their families.

The second objective of this thesis was to describe pathways to mental health services for young people in the context of child welfare services. We found that the vast majority of youth had multiple contacts with the mental health system, cutting across different settings and sectors. Many youth in child welfare services had multiple contacts over the year preceding an ER visit for mental health problems, and youths' pathways to the ER often involved the police.

The pathways to mental health services experienced by youth emerged from a process involving a range of actors. Youth often sought help following advice or encouragement from family members, who also helped initiate care. These interactions fit within the previously described Network Episode Model, which places an individual's pathway to care within a larger social context and a network of relationships that help guide and shape decisions, with pathways being as much a representation of available health services as a product of an interplay between social, contextual and individual factors.

The findings from this thesis demonstrate that globally, the health system is not responsive to the needs of all youth seeking services. This is particularly important given efforts to improve help-seeking behaviours in the population, including the widespread promotion of anti-stigma campaigns and mental health literacy. These efforts are important, and encouraging individuals, especially youth, to seek help in times of need is a valuable endeavour. On the other hand, the existing mental health system is already not meeting the needs of the subset of youth who are currently seeking help. We argue that awareness campaigns that aim to promote help-seeking behaviours need to occur hand in hand with increases in resources and the accessibility of timely, effective, youth-friendly, and integrated mental health care.

Some findings cutting across all four of our manuscripts warrant further discussion. Namely, i) the overarching importance of the social determinants of mental health; ii) the frequent use of ERs by youth with mental health problems; iii) the key role of general practitioners along youths' pathways to care; and iv) the significance of familial support.

i. The overarching importance of the social determinants of mental health

As described previously, social determinants of mental health, known to impact the emergence of mental illness, include such factors as discrimination, social exclusion, adverse childhood experiences, lack of education, employment and housing, and social and material deprivation. Yet, research remains limited in investigating the specific impacts of social determinants on the access to and the patterns of mental healthcare use. A number of studies have investigated the impact of ethnicity on pathways to care in first-episode psychosis [232] and many have described an increased likelihood of ER, police, or criminal justice involvement for ethnic minority groups [233, 234].

Still, the influence of a wider range of social determinants on the pathway to care, especially in youth, is yet to be explored. Our literature reviews revealed that few studies captured information on relevant socio-demographics in their sample (e.g., visible minority status, social or material deprivation, homelessness), and fewer still considered the impact of such factors on patterns of service use. Yet, these factors can impact both the emergence of disease as well as youth's access to care. In Manuscript II, we included findings revealing that advocacy was a key facilitator of obtaining mental health services. Youth's and families' capacity for such advocacy was impeded in situations with cultural or linguistic barriers. This is only one example of how cultural minorities may be at a disadvantage in navigating complex healthcare systems. In Manuscripts III and IV, we noted that over half of our sample of youth in child welfare services were visible minorities. Over 45% were immigrants, or children of immigrants. Social and material deprivation, and parental history of mental illness, were linked to young people's use of mental health services while in the care of child welfare. However, the larger mechanisms resulting in this increased service use, including youths' perspectives, remains to be explored.

Given the evidence of the effects of social determinants on mental health incidence and outcomes, many interventions have been proposed to eliminate such social inequities, including policies to protect families at risk of poverty; to increase access to education, childcare, childhood development programs, affordable housing; to improve working conditions; and to improve the safety of neighborhoods [235, 236]. Other interventions have proven successful in eliminating existing disparities for individuals already experiencing mental health problems. For example, *Individual Placement and Support* employment programs have been shown to be effective in improving employment rates, as well as functioning and wellbeing, in individuals with mental health problems [237] and *Housing First* programs have been linked to improved housing outcomes, and lower rates of hospitalizations, for individuals with mental health problems who are at risk of homelessness [238, 239]. Indeed, public policies and social interventions can have a great impact on the health of populations and community resilience. These long-term goals, which have the potential of promoting mental health and reducing the incidence of mental illness, must be sustained by continued funding and the persistent commitment of people in leadership. As a complement to these efforts, and perhaps with greater immediate potential for impacts on individuals currently in need, the removal of barriers to healthcare that disproportionately disadvantage marginalized and vulnerable peoples should be a priority.

ii. The frequent use of Emergency Rooms for youth seeking mental health care.

The prominence of Emergency Rooms in youths' pathways to mental health services was a core finding across our four manuscripts. The included studies in our quantitative systematic review, Manuscript I, demonstrated that ERs were often youths' first contact with the mental health system, as well as a common referral source to appropriate care. At least one reviewed study linked a first contact with the ER to a shorter duration of untreated illness. This finding complements experiences reviewed in our qualitative synthesis, Manuscript II, as it emerged that for many youths, services only became available when a crisis emerged. Some family members felt relieved when symptoms warranted emergency care, as this could result in a substantial reduction in waiting times. In Manuscript III, we showed that ERs represent the most common setting for mental health services for youth in the child welfare system. This finding was expanded upon in Manuscript IV, in which we found that a history of placements outside of the home, a history of sexual abuse, and a history of parental mental illness all contributed to an increased likelihood of ER use.

Our efforts to examine the determinants of ER use and distinct trajectories to ERs are important because ERs are an increasingly predominant setting for youth seeking mental healthcare [240-242]. However, they are also typically not well resourced to address the needs of young people, especially those in need of proper assessments and ongoing outpatient care [243, 244-246]. Unsurprisingly, repeat ER visits are a common occurrence among youth, with studies from the USA and Canada estimating that up to 45% of all ER visits are made by recurrent users [245, 247, 248]. ER use comes not only at a high cost not only to the healthcare system [249], but also to youth who describe their ER contact as traumatic [250] or shameful [251].

The high rates of ER use found across all four of our manuscripts, and in the scientific literature, reflects a number of larger societal trends, including on the one hand, possible increases in rates of self-harm and acuity of mental disorders and on the other hand, increases in help-seeking behaviours and a perceived or real ability to obtain services more rapidly through emergency care. If high ER usage for youth in need of mental health services is to be reversed, policies and interventions must be put in place to target these trends, including increasing the timely availability of effective community-based resources.

iii. The key role of general practitioners and primary care along youths' pathways to care

In Manuscript I, general practitioners (GPs) were found to be the most common first help-seeking contact by youth seeking mental health services. This was true irrespective of the healthcare system, including gatekeeper and non-gatekeeper healthcare systems. Overall, GPs featured commonly along youth's pathways to mental health care. Interestingly, GPs were most frequently the first help-seeking contact, rather than the 'successful' referral source leading to appropriate mental healthcare. In other words, while GPs were often sought out first for mental health care, they were not the ones to most frequently navigate the youth towards needed mental health care. In Manuscript II, some youth attributed their complex pathways to misdiagnoses or dismissals by general practitioners, while positive encounters included GPs who were able to efficiently refer youth to appropriate services when needed. These findings are in line with previous research demonstrating that more than a quarter of youths' primary care visits are for mental health problems [252], though few go on to receive outpatient mental health treatment even when referred by a GP [253, 254]. As such, these findings point to a need for GPs to be adequately trained to identify mental health problems and offer support or treatment, or coordinate with services that will. This is especially important given some consensus that the integration of mental health services within primary care settings is an essential step to address the current gaps in mental health care delivery [255].

The prominence of the GP role reflected in findings from Manuscripts I and II was not equally found in our study on patterns of service use in child welfare. Very few youth in the care of child welfare were seen by their GP for mental health reasons. Previous studies on mental health service use in this population have not specifically investigated the role of general practitioners, focusing instead on specialty outpatient clinics and professionals such as psychiatrists and psychologists. In our sample, the lack of GP involvement may reflect the fact that youth in child welfare services benefit from links with other professionals, such as social workers and psychologists, who can refer youth directly to outpatient mental health services or in-house services when needed. On the other hand, in a province like Quebec, where individuals have a right to publicly funded services of a GP but are not all automatically assigned a GP, not having a GP may be an additional disadvantage faced by youth in the care of child welfare services.

The primary care system in Quebec is somewhat unique in Canada in that it operates through integrated health and social service systems (Centres intégrés de santé et de services sociaux, CISSS) that serve bounded geographic catchment areas. Within these systems, community-based primary care centres (Centres locaux de services communautaires, CLSCs) are mandated to offer primary health care (including through general practitioners/family doctors) and a range of social services. Furthermore, the last set of reforms in healthcare in Quebec integrated child welfare services with health and social services through the CISSS [256, 257]. This was done to promote seamless strong linkages between healthcare, social services and child welfare. Yet, our data do not bear this out, with the use of primary care (CLSCs) only representing a relatively small proportion of mental health contacts and youth involved in child welfare frequently accessing both private services and ERs. This suggests a failure to achieve the integration of care pathways that was envisioned to result from integrating systems (health, social services, child welfare, etc.) within geographic catchments (although some of our data was collected before the latest iteration of health and social systems integration reform in Quebec in 2015).

Elsewhere in Canada, there has been widespread investment in creating integrated youth services over the past five years (e.g., YWHO in Ontario, Foundry in BC). This has been premised on the co-location and integration of systems. Our findings highlight that ensuring that youth experience seamless pathways to continuous, well-coordinated care may require re-thinking integration from the perspective of the end-user, and not merely the system(s).

iv. The significance of familial support

Families (broadly defined as youths' caregivers, siblings or friends) were found to play a substantial role in youths' pathways to mental health services. In Manuscript I, we noted that families were commonly the among the first ones to be approached by young people with mental health problems or to seek help on their behalf, although not all reviewed studies queried such 'informal' supports in their methodology. Manuscript II allowed for a deeper understanding of the role of familial support in obtaining services, including the role of families in providing advice to seek treatment, recommending sources of help, and directly initiating and advocating for care. Family members themselves spoke of requiring a circle of support – including their own network of neighbors and friends – who helped them advocate for their loved ones. This highlights the overall role of communities in acting as circles of care when a young person experiences a crisis.

In the context of youth protection, families, specifically parents, often initiated care on youths' behalf. In Manuscript IV, we found that a common pathway to the ER included families bringing in a youth following suicidal ideation or a suicide attempt. The role of families in initiating care for youth over the course of their involvement with child welfare is significant in two ways. First, it contradicts the assumption that all youth in the care of child welfare services do not benefit at all from family support or have no or limited familial involvement in their mental health care. Especially for youth who are not placed outside of their home, parents and families appear to play a large role in obtaining mental health services. This finding is significant as the involvement of child welfare services may provide an opportunity to increase the mental health literacy of families and their capacity to seek help on behalf of their young family members. Given that the involvement of child welfare professionals ceases as youth age out of care, those interventions should be emphasized that ensure that families and carers, who can provide ongoing support to these youth, are better equipped to advocate for and support their youth in receiving mental health services.

Overall, the prominent role of families in supporting youths' along their pathways to care, including advocating and initiating care, is often discounted once services have been reached. In Manuscript II, we reviewed findings revealing that family members felt alienated, pushed aside, and out of the loop once mental health treatment had commenced.

This is consistent with previous research showing that families routinely experience feelings of exclusion and a lack of appreciation of their role and experiential knowledge on the part of mental health professionals [258, 259]. A frequently reported barrier to family involvement in care is service providers' interpretation of confidentiality laws, which they believe precludes them from sharing any information about patients with their families. An effective partnership can be developed through conversations between service users, families, and healthcare providers about the meanings and boundaries of confidentiality [260]. Such practices would benefit from clearer policies and guidance [261, 262].

Given families' role in supporting youths at various stages along their journey to care and their continuing involvement upon the initiation of care, the engagement of families must be a priority for healthcare services and providers. In a systematic review of familial involvement in early psychosis programs, Eassom et al. demonstrated that family engagement was related to better outcomes for youth, including fewer relapses and better quality of life [259]. This begins with the acknowledgment that youth and their families have unique experiential knowledge about their health and their treatment. At a systemic level, organizations are increasingly including the perspectives of youth and families at the forefront of their decision-making models through youth and family advisory boards and councils.

B. Implications

The broad implications of the analysis of service use patterns and pathways to care is the identification of enablers of and barriers to treatment, including the key agents involved in this process. This knowledge is crucial to provide timely access to services. The synthesis of the four manuscripts in this thesis highlight the pressing need for improved service coordination, and delivery of high-quality care to young people.

Mental health service reforms have been premised on such popular conceptions as ‘Every door is the right door’ [263, 264] and ‘Right care, First time’ [265]. Far from being simply platitudes, these concepts reflect a real need to simplify mental health pathways to care, which fits with the evidence described across our manuscripts.

Such reforms aim to improve access by transforming the prevailing configurations of care including strict eligibility criteria premised on severity or specific diagnostic criteria. Stepped care models, for example, an evidence-based approach which prioritizes the least intensive, most effective treatments, often starting with a single session approach, have also been successful at reducing wait times and improving pathways to care [266].

In addition to such systemic changes which would decrease the need for multiple transitions across services, we also argue that service providers should, at the very least, aim to improve communication with youths and caregivers to dispel perceptions of being left in the dark. When transitions to a different service are unavoidable, these should follow clear protocols for coordinating care and sharing information about diagnoses and treatment between youths, families, service providers, and other agencies.

Findings from our manuscripts point to the fact that youths’ access to services is often contingent on having strong advocates, such as family members, who can push for services when needed. The need for this type of advocacy can disadvantage groups such as the poor, ethnic and linguistic minorities, or youth without strong support systems. Efforts should be made to improve the mental health literacy of people and institutions (e.g., teachers, police officers, ER workers, general practitioners, schools) who serve and encounter young people, and to build their capacity to advocate for vulnerable youth in times of need. Our findings also point to a strong need for child welfare workers to be adequately trained in the identification of mental health problems and how and where to refer youth in need.

Importantly, some of our findings strongly suggest that reducing structural barriers through systemic changes may only constitute a first step to improving pathways to care. In Manuscript I, youths described complex pathways to care, including ER and police encounters, even when the service they required could be accessed directly, without referral (e.g., as in the case of many early psychosis programs). Thus, the removal of systemic barriers must occur concurrently with other important measures such as mental health literacy promotion and outreach to youth at high risk. Moreover, the importance of human connections in mental health service delivery cannot be discounted. In one study looking at a rapid access intervention between primary care and specialist mental health services, it was found that simply having a direct referral pathway from primary to specialist care was not enough to overcome barriers to treatment. This study showed the need for targeted strategies to facilitate referrals between providers, for example, by having routine videoconference-based 'warm-handoffs' between primary care workers and mental health clinicians from another team. [267].

Improved pathways to care may benefit youth and families not just at the time of their mental health crisis but also positively impact their overall mental health care and recovery journeys. In Manuscript II, we found that previous negative experiences with services could negatively impact youth's desire to seek services again when needed. In a study on resilience and how some vulnerable youth emerge unscathed from difficult situations, researchers found that while no relationship was found between service use history and resilience, service use satisfaction, on the other hand, did show a strong positive relationship with resilience [88]. This further underscores the importance of providing high quality, youth-friendly, and engaging care.

In terms of implications for research, our systematic review in Manuscript I revealed a lack of rigor in the measurement of pathways to care, and missed opportunities for routinely capturing information at youths' points of access. A unified measurement framework for pathways to care, including demographics, durations of untreated illness, and previous healthcare contacts within a delineated timeframe, should be established. This would create the opportunity to consistently evaluate the reach of services, including whether they respond to the needs of historically underserved youth. Such a measurement framework would allow for a clear evaluation of ‘delay times’ until care was reached, which is not currently available in mental healthcare, unlike in many other specialties where wait-times are even increasingly available in real-time [268]. This type of systemic accountability could facilitate sustained changes in service delivery.

C. Future Directions

i. Innovative practices in mental health service delivery

Given the evidence of difficult access to mental health services as evidenced across these four manuscripts, it is important to consider avenues to barriers to care. Among these avenues, there is increasing focus on leveraging novel healthcare technologies to improve service delivery in mental health. Surges in demand and disruptions in traditional in-person consultations caused by the COVID-19 pandemic have provided an opportunity for digital health models to expand their reach. Many services transitioned rapidly to virtual formats, the benefits of which include easier accessibility, flexibility, lower cost and potential for reduced stigma [269, 270]. Early research [271, 272] has demonstrated that youth are interested in using virtual mental health services, with some stating a preference for this model [273]. The promise of virtual care is also important given our findings from Manuscript II that transportation and related accessibility issues (e.g., relying on a parent to take time off work or provide transportation) were major barriers to youth’s access to care. This has also led many to suggest that ‘e-mental health’ may allow for better coverage of mental health care, particularly for those living in rural and remote communities [274]. Despite such promise, caution must be exercised in uncritically embracing virtual modes of mental health service delivery as a silver bullet solution to chronic underinvestment and entrenched inequities in the mental healthcare system.

As the need for youth mental health services continues to increase, future health services research will need to account for virtual practices, including the virtual delivery of traditional mental health services but also novel forms of care such as websites and apps, in their evaluations of service use and pathways to care. Already, in Manuscript I, we found that when studies included web-based services as a possible contact, the majority of youth reported having used such services. However, very few studies on pathways to care enquired about e-services.

ii. Positive encounters

Given that findings from service use research, and specifically pathways to care, are often used to uncover barriers to treatment and causes of undue delays, it may be true that negative experiences are more likely to be reported. Future research specifically aimed at exploring positive mental healthcare experiences of youth is necessary. By specifically investigating the factors which lead to positive encounters and rapid access to care, this type of research may elicit high-quality practices on which to model better services.

To increase the range of service user perspectives, some researchers are now calling for individuals to share their own experiences in a ‘citizen science’ approach. Such research could be used to enquire about and report young people’s positive experiences of accessing and receiving mental health services.

From an organizational viewpoint, further research on specific modes of rapid access to healthcare –strategies used, how they are funded and implemented, barriers to implementation, impacts on young people and at the system level, etc. – is needed. More importantly, knowledge from such research needs to be rapidly and effectively translated into practice and policy, so that the surge of youth mental health service reforms are evidence-based.

iii. Extending the reach of services and of research

Many gaps remain in our understanding of youths' mental health service use and pathways to care. An increased focus on youth who struggle to access traditional mental health services, such as gender minorities, homeless youths, or youths not in education, employment or training [77], etc. Data on social determinants can also help bridge this gap. In 2021, Canada's preeminent health research funding agency included the social determinants of health as a priority for the next decade [275] with a view to addressing health inequities. We argue that this is especially required in mental health services research. Much of the existing research on youths' pathways to care involves youth experiencing psychosis. The perspectives of youths experiencing a wider range of mental health problems is still needed. The new wave of integrated, transdiagnostic youth mental health services rapidly being developed in Canada and around the world provides a clear impetus for further empirical studies on the ability of such services to dismantle barriers and simply youths' pathways to mental health care.

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Appendices

List of Appendices - Supplementary Materials from Manuscripts I-IV

Manuscript 1.

Supplementary 1. Literature Review Search Strategy (MEDLINE)

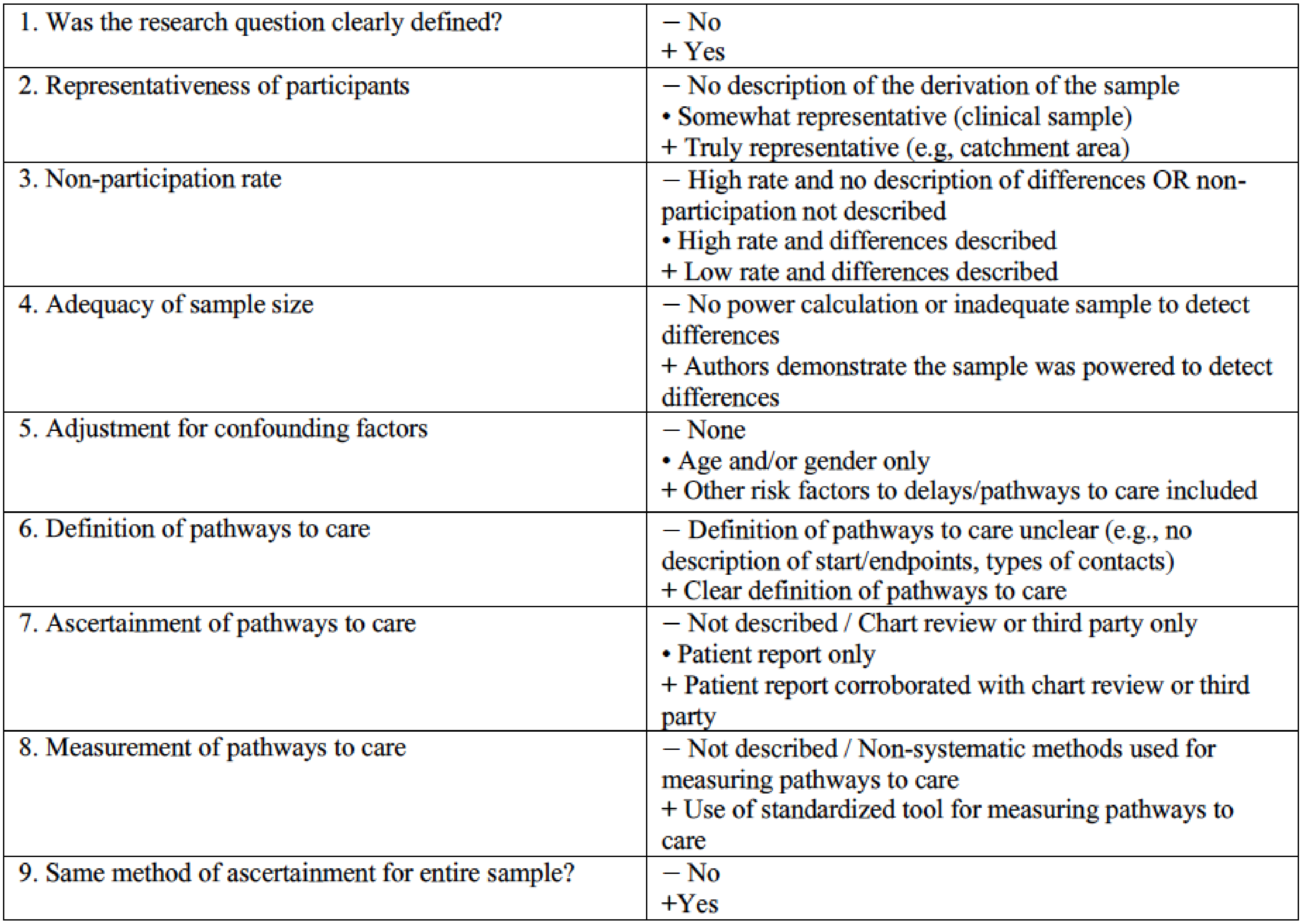
exp Mental Disorders/ or exp Mental Health Services/ or exp Community Mental Health Services/ or exp Mental Health/ or mental health services.mp. or mental illness.mp. or mental disorder*.mp.

AND

((pathway* adj3 care) or (pathway* adj4 mental) or (pathway* adj3 psyc*) or (pathway* adj4 service*) or(pathway* adj3 health) or (pathway* adj4 model) or (pathway*adj3 referral*) or (pathway* adj3 help) or(pathway* ajd4 contact*) or (help-seeking adj3 contact*) or (help-seeking adj4 model) or (healthcare adj3contact*) or (help seeking adj3 experienc*) or (help-seeking adj3 step*) or (help-seeking adj3 pattern*) or (help-seeking adj3 delay) or (help-seeking adj3 duration) or (referral* ajd2 pattern*) or (contact* adj3 service*)or (contact* adj3 professional) or (help-seeking adj4 service) or (Health adj3 contact*) or (system adj3 delay*)or- (systemic adj3 delay*) or (referral adj3 delay*) or (treatment adj4 delay*) or (mental health service ajd3delay) or (care adj3 delay) or (navigator) or (journey of care) or (care contact*) or (point* of entry) or (entryadj2 care) or (entry adj2 service*)).mp

Manuscript 1.

Supplementary 2. Quality Appraisal Checklist



1. Was the research question clearly defined?	– No + Yes
2. Representativeness of participants	– No description of the derivation of the sample • Somewhat representative (clinical sample) + Truly representative (e.g, catchment area)
3. Non-participation rate	– High rate and no description of differences OR non-participation not described • High rate and differences described + Low rate and differences described
4. Adequacy of sample size	– No power calculation or inadequate sample to detect differences + Authors demonstrate the sample was powered to detect differences
5. Adjustment for confounding factors	– None • Age and/or gender only + Other risk factors to delays/pathways to care included
6. Definition of pathways to care	– Definition of pathways to care unclear (e.g., no description of start/endpoints, types of contacts) + Clear definition of pathways to care
7. Ascertainment of pathways to care	– Not described / Chart review or third party only • Patient report only + Patient report corroborated with chart review or third party
8. Measurement of pathways to care	– Not described / Non-systematic methods used for measuring pathways to care + Use of standardized tool for measuring pathways to care
9. Same method of ascertainment for entire sample?	– No +Yes

Manuscript 2.

Supplementary 1. Literature Review Search Strategy (MEDLINE)

exp Mental Disorders/ or exp Mental Health Services/ or exp Community Mental Health Services/ or exp Mental Health/ or mental health services.mp. or mental illness.mp. or mental disorder*.mp.

AND

((pathway* adj3 care) or (pathway* adj4 mental) or (pathway* adj3 psyc*) or (pathway* adj4 service*) or(pathway* adj3 health) or (pathway* adj4 model) or (pathway*adj3 referral*) or (pathway* adj3 help) or(pathway* ajd4 contact*) or (help-seeking adj3 contact*) or (help-seeking adj4 model) or (healthcare adj3contact*) or (help seeking adj3 experienc*) or (help-seeking adj3 step*) or (help-seeking adj3 pattern*) or (help-seeking adj3 delay) or (help-seeking adj3 duration) or (referral* ajd2 pattern*) or (contact* adj3 service*)or (contact* adj3 professional) or (help-seeking adj4 service) or (Health adj3 contact*) or (system adj3 delay*)or- (systemic adj3 delay*) or (referral adj3 delay*) or (treatment adj4 delay*) or (mental health service ajd3delay) or (care adj3 delay) or (navigator) or (journey of care) or (care contact*) or (point* of entry) or (entryadj2 care) or (entry adj2 service*)).mp

Manuscript 2.

Supplementary 2. Critical Appraisal Skills Programme Checklist (CASP) for Qualitative Studies

	Section A: Are the results valid? Is it worth continuing?		Section A: Are the results valid?				Section B: What are the results?			Section C: Will the results help locally?
Study	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into conside ration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Anderson et al. 2010	+	+	+	+	+	-	+	+	+	+
Aisbett et al. 2007	+	+	+	-	+	+	+	+	+	+
Boulter et al. 2013	+	+	Can’t tell	+	+	-	+	+	+	+
Boyd et al. 2006	+	+	+	Can’t tell	+	+	+ *	Can’t tell	+	+
Boydell et al. 2006	+	+	+	+	+	-	+	+	+	+
Boydell et al. 2013	+	+	+	+	+	+	+	+	+	+
Cabassa et al. 2018	+	+	+	Can’t tell	+	-	+	+	+	+
Cadario et al. 2016	+	+	+	+	+	+	+	-	+	+
Carr-Fanning et al. 2018	+	+	+	+	+	-	+	+	+	+
Chen et al. 2014	+	+	Can’t tell	-	+	-	+	+	+	+
Ferrari et al. 2015	+	+	+	+	+	+	+	+	+	+
Ferrari et al. 2016	+	+	+	-	+	+	+	+	+	+
Gerson et al. 2009	+	+	Can’t tell	-	+	-	+	-	+	+
Gronholm et al. 2014	+	+	+	+	+	+	+	+	+	+
Jansen et al. 2015	+	+	+	+	+	+	+	+	+	+
Jansen et al. 2015	+	+	+	+	+	-	+	+	+	+
McCann et al. 2011	+	+	+	- +	+	-	+	+	+	+
McCann et al. 2012	+	+	+	+	+	+	+	+	+	+
Nadeau et al. 2017	+	+	+	+	+	+	+	+	+	+
Narendof et al. 2017	+	+	+	+	+	+	+	+	+	+
Novins et al. 2012	+	+	+	+	+	-	+	+	+	+
Nuri et al. 2018	+	+	+	+	+	-	+	+	+	+
Oruche et al. 2012	+	+	+	+	+	-	+	+	+	+
Pescodolio 1998	+	+	+	-	-	-	+	+	+	+
Platell et al. 2017	+	+	+	+	+	+	+	+	+	+
Sadath et al. 2014	+	+	+	-	+	-	+	+	+	+
Schnitzer et al. 2011	+	+	+	+	+	- +	+	+	+	+
Skubby et al. 2015	+	+	+	+	+	-	+	+	+	+
Tanskanen et al. 2011	+	+	+	-	+	-	+ *	+	+	+
Webster et al. 2009	+	+	+	+	+	-	+	+	+	+
Wong et al. 2007	+	+	+	+	+	-	+*	+	+	+

* Authors contacted, confirmed ethics approval.

Manuscript 2.

Supplementary 3. Themes elicited per study

	Initiating Contact			Service Response				Appraisal	
	Mental health literacy	Structural barriers	Social Support	Complex pathways	Waitlists	Eligibility	Fragmented care	Positive	Negative
Anderson et al. 2013	×		×	×				×	×
Aisbett et al. 2007		×			×	×			
Boulter et al. 2013		×	×	×				×	×
Boyd et al. 2006	×							×	×
Boydell et al. 2006	×	×			×	×		×	×
Boydell et al. 2013	×		×	×	×	×	×	×	×
Cabassa et al. 2018	×		×	×	×		×	×	×
Cadario et al. 2016	×		×	×			×	×	×
Carr-Fanning et al. 2018	×			×	×		×	×	×
Chen et al. 2014	×	×	×				×	×	×
Ferrari et al. 2015	×			×				×	×
Ferrari et al. 2016				×		×		×	×
Gerson et al. 2009	×	×	×	×			×	×	×
Gronholm et al. 2014	×							×	×
Jansen et al. 2015	×		×	×				×	
Jansen et al. 2015			×						
McCann et al. 2011	×	×		×	×	×		×	×
McCann 2012	×	×		×	×	×		×	×
Nadeau et al. 2017		×	×	×			×	×	×
Narendorf et al. 2017	×	×	×	×	×	×	×	×	×
Novins et al. 2012			×	×					
Nuri et al. 2018	×	×	×	×			×		×
Oruche et al. 2012	×	×	×	×		×	×	×	×
Pescodolio et al. 1998		×	×	×					
Platell et al. 2017		×	×	×	×		×	×	×
Sadath et al. 2014	×	×	×	×					
Schnitzer et al. 2011	×		×	×				×	×
Skubby et al. 2015	×		×	×	×			×	×
Tanskanen et al. 2011	×		×	×				×	×
Webster et al. 2009	×		×	×				×	×
Wong et al. 2007	×		×	×				×	

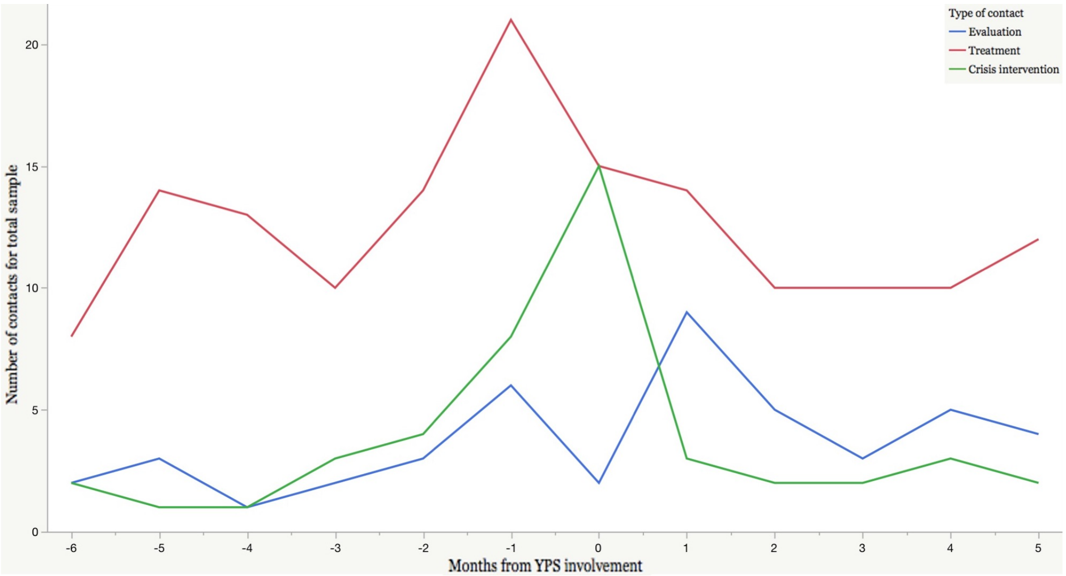
Manuscript 3.

Supplementary 1. Data Extraction Template for Chart Review

Date start episode -- Date end episode	*MM/DD/YYYY - MM/DD/YYYY*			
Type of contact	Evaluation	Treatment	Crisis Intervention	
Type of institution	School CLSC	Private Medical clinic	Rehab Other	Hospital CWS
Name of institution	*Specify institution*			
Type of service	ER Hospitalization Outpatient clinic (2nd line) Outpatient clinic (3rd line) School	Day hospital Medical service CLSC youth mental health team CLSC- childhood team DBT therapy service	Private Rehab CLSC- family crisis team CLSC- youth in difficulty team CWS service	Consultation in 2nd line services Service for intellectual deficiency Other mental health service Community health service – adult mental health team
Who initiated help	ER Youth themselves Parent Hospital	Police School CWS Judge	Medical services Foster family CLSC Parents' social worker	Private Friend Rehab centre Community service
Reason for contact	Suicidal ideation Suicide attempt Self-harm Substance abuse/intoxication Relational difficulties Emotional regulation Internalized symptoms	Externalized symptoms Sexual abuse victim Sexualised behaviour Family functioning Somatisation/physical pain Functional impairment	Developmental symptoms Attachment difficulty Difficulty integrating Canada/Quebec Lack of autonomy Hallucinations/bizarre behaviour Motor ticks	Trauma Eating disorder Victim of bullying Grief/bereavement Obsessive behaviour Labile mood Evaluation of functioning Medical follow-up Dissociation/depersonalization
Was a diagnosis given at this contact?	Yes/No			
Specify diagnosis	Mood disorder (depression and dysthymia) Anxiety disorder Psychotic disorder Eating disorder Bipolar disorder ADHD Substance abuse disorder	Personality disorder Obsessive-compulsive disorder PTSD Asperger's/Autism Language disorder Tourette's Oppositional disorder Parent-child relational problem	Intellectual deficiency Adaptation disorder Intermittent explosive disorder Conduct disorder Borderline personality disorder Learning disorder Dissociative disorder	Antisocial traits Developmental delay Paraphilia Non-verbal learning disorder Cluster B traits Sleep disorder Attachment disorder Separation anxiety disorder
Profession of provider who made diagnosis	Psychiatrist Psychologist Medical doctor	Occupational therapist Speech language pathologist	Social worker Nurse	Neurologist Psycho-educator
Recommendation made following this episode?	Treatment Medication Evaluation	ER Hospitalization Re-evaluation later on	Placement FA/CR Situationnel recommandation	Encadrement Continue current services None given
Was recommendation followed?	Yes/No			
Reason for episode end	Parent refused services/lack of collaboration Youth refused services/lack of collaboration Provider internship ended	Change of provider Change of school Provider no longer available Youth was placed Services transferred Evaluation not completed Service ended	Hospitalization Excluded due to youth behaviour Youth taken in by CWS Youth turned 18 Change of sectors Youth better/service no longer required	Parents lack insurance/finances to cover care Services not helping Travail personnel needed before continuing with services Accessibility issue

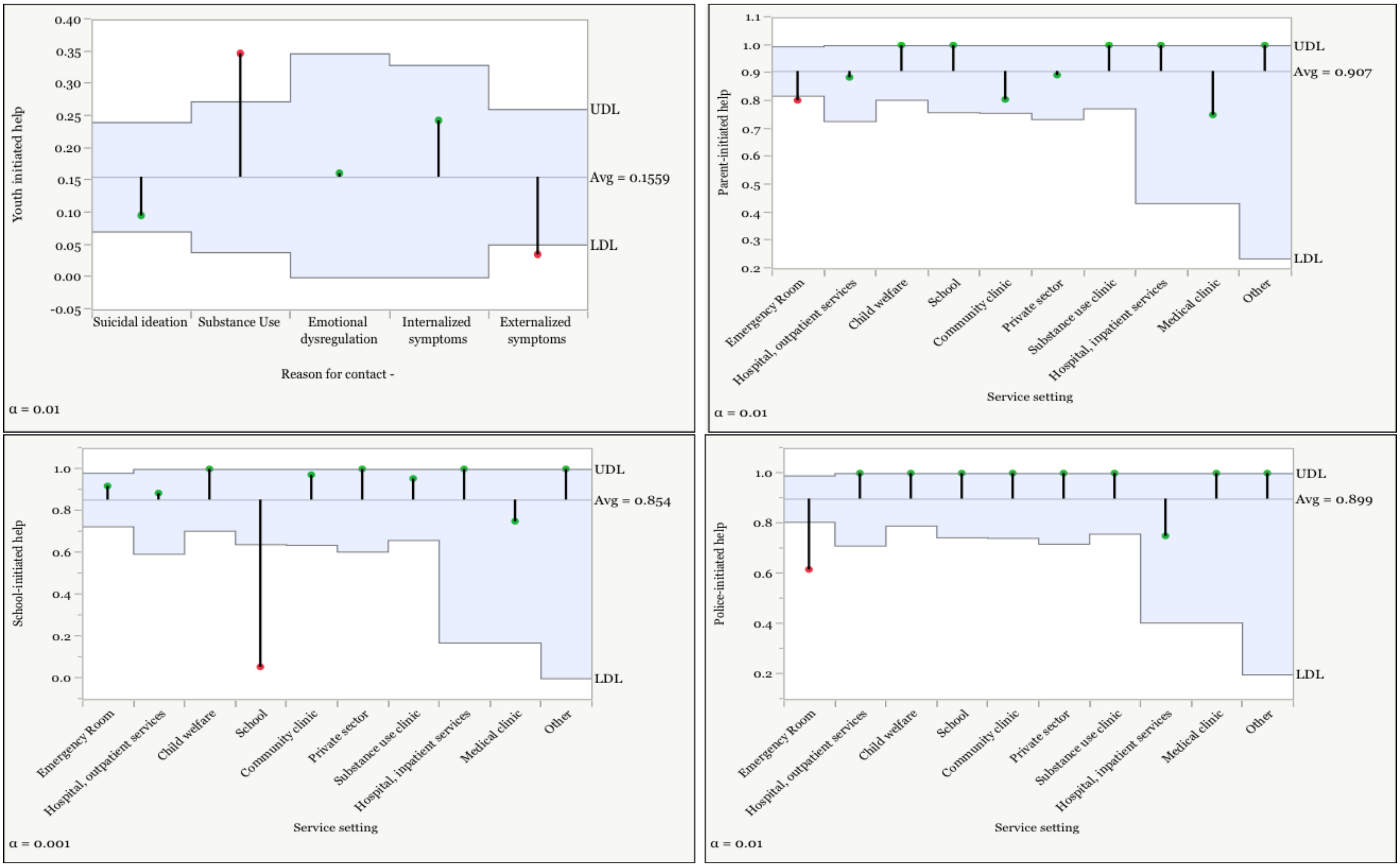
Manuscript 3.

Supplementary 2. Timing of contacts 6 months prior to and following child welfare involvement



Manuscript 3.

Supplementary 3. Analysis of Means of Proportions for Youth- , Parent-, School and Police- Initiated Contacts

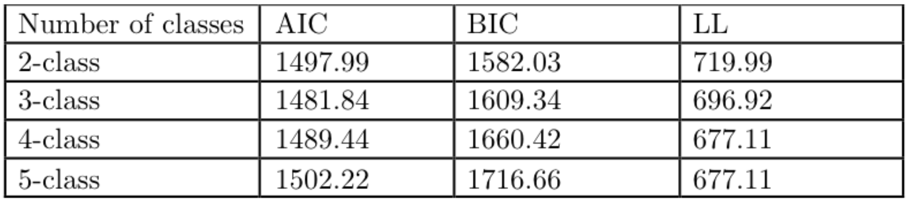


Supplementary 1. Characteristics of repeat-ER users compared to single-use and non-users

Characteristics		N (%)				
Demographics	Total Sample n=226	Repeat ER Users n=39	Single ER visit n=35	Non-Users (n=152)	*X2*	*p*
Gender [Female]	123 (54%)	29 (74%)	22 (62%)	72 (47%)	10.3	0.006
Visible Minority [Yes]	113 (53%)	22 (58%)	17 (52%)	74 (52%)	0.49	0.79
Immigration [Yes[a]]	100 (46%)	15 (39%)	13 (39%)	72 (49%)	1.9	0.76
Social and Material Deprivation [Q4/Q5[b]]	155 (71%)	26 (68%)	29 (88%)	100 (68%)	5.5	0.06
Adversity history						
Sexual Abuse	61 (28%)	18 (47%)	12 (36%)	31 (21%)	11.9	0.003
Physical Abuse	122 (55%)	20 (53%)	23 (70%)	79 (53%)	3.1	0.214
Psychological Abuse	123 (56%)	19 (50%)	20 (61%)	84 (57%)	0.872	0.646
Physical Neglect	183 (84%)	30 (79%)	29 (88%)	124 (84%)	1.04	0.59
Parental history of mental illness	169 (77%)	32 (84%)	29 (88%)	108 (73%)	4.67	0.09
Child welfare history						
Placement (Yes)	170 (78%)	35 (92%)	31 (94%)	104 (70%)	14.25	0.0008

Manuscript 4.

Supplementary 2. Latent class analysis results by class models



Number of classes	AIC	BIC	LL
2-class	1497.99	1582.03	719.99
3-class	1481.84	1609.34	696.92
4-class	1489.44	1660.42	677.11
5-class	1502.22	1716.66	677.11