Identifying Factors Which Affect the Diagnosis and Treatment of Youth with Psychotic Disorders in Newfoundland and Labrador, Canada

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<u>Abstract</u>

Psychotic disorders are considered the most debilitating psychiatric conditions, and youth living with these disorders require significant supports to diagnose and treat their condition. Many youth rely on emergency services such as emergency departments (EDs) to manage their condition. This research sought to answer the question: What are identifiable factors affecting the diagnosis and treatment of psychotic disorders for youth in Newfoundland and Labrador (NL)?

Three separate, though related studies were conducted. The first study examined variables affecting ED utilization for youth with a psychotic disorder in urban versus rural NL. The second examined the effect of COVID-19 on ED utilization for this population. Linear regression modelling was used in the analysis, with generalized estimating equations (GEE) required for study two. Both studies identified rural residence and sex as being associated with increased ED utilization for youth with a psychotic disorder in NL (p<0.05) in the multivariate analyses. ED utilization rose significantly (p=0.01) during the first year of COVID-19 then returned to levels similar to pre-pandemic utilization.

Study three used qualitative methods to add to the quantitative findings. A grounded theory approach was used to collect and analyze data from interviews with clients of mental health services and family members, as well as focus groups with caseworkers. The study: 1) described patterns in clients' developmental history, 2) identified challenges clients and family members experienced getting a diagnosis, managing medications, and receiving adequate support in the community, 3) identified gaps in services experienced by clients and family members and reported their recommendations. Caseworker participants recognized topics appearing in client and family member interviews as consistent with their experiences with this population in their practice.

The results of this research identified existing gaps in services for this population using both quantitative and qualitative methods and reported the recommendations of family members and caseworkers as to how these gaps in service may be addressed. This research is intended to provide school staff, clinicians, caseworkers, and policymakers with the tools to strive to improve the services for one of the most vulnerable populations in our society.

Keywords: access to care, COVID-19, emergency medical services, psychosis, psychotic disorder, rural health, schizophrenia

General Summary

This research examines factors influencing the diagnosis and treatment of psychotic disorders in Newfoundland and Labrador (NL) youth. It focuses on emergency department (ED) utilization, the impact of COVID-19, and insights into challenges clients and their families face. This thesis contains three related studies appearing between the introduction and conclusion chapters.

The first study explored the effects of rural versus urban dwelling on ED use for NL youth with psychotic disorders. It found that both rural residence and sex were significantly associated with an increase in ED utilization.

The second study examined how the COVID-19 pandemic influenced ED use for this group. It revealed a significant increase in ED visits during the first year of the pandemic, after which ED utilization returned to pre-pandemic levels. Additional results also found that rural residence and female sex were linked with higher ED usage during the COVID-19 pandemic.

The third study used interviews with clients of mental health services living with psychotic disorders, as well as family members. Focus groups with caseworkers were also conducted. This study: 1) uncovered patterns in the clients' development as well as changes that occurred after the appearance of the first psychotic symptoms, 2) documented challenges in diagnosis and treatment and difficulties with medication management faced by clients and family members, 3) identified a lack of sufficient

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community-based support for clients and their families, and 4) reported recommendations from clients and family members. The experiences of clients and family members as well as their feedback were aligned with the experiences of caseworkers, who noted the similarities faced by clients and family members in their professional practice.

This thesis highlights significant gaps in mental health services for youth with psychotic disorders and offers actionable recommendations from both family members and caseworkers to address these issues. The findings are aimed at informing educators, clinicians, caseworkers, and policymakers to help improve service delivery for this vulnerable population. By combining different types of data, this study provides a comprehensive understanding of the challenges facing youth with psychotic disorders in NL and offers a foundation for policy and service improvements.

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List of Abbreviations

- ACT: acceptance and commitment therapy
- ADHD: attention deficit hyperactivity disorder
- ASD: autism spectrum disorder
- CBT: cognitive behavioural therapy
- CBTp: cognitive behavioural therapy for psychosis
- CET: cognitive enhancement therapy
- CHR: clinical high risk
- CIHI: Canadian Institute for Health Information
- COVID: coronavirus disease
- CR: client registry
- CRT: cognitive remediation therapy
- DSM-5: Diagnostic and Statistical Manual of Mental Disorders Fifth Edition
- DUP: duration of untreated psychosis
- ED: emergency department
- EIS: early intervention services
- EPS: extrapyramidal symptoms
- FDA: food and drug administration
- GEE: generalized estimating equations
- ICD-10-CA: International Statistical Classification of Diseases, 10th Revision, Canada
- LAI: long-acting injectable
- MGF: master geography file
- NL: Newfoundland and Labrador

PDAD: provincial discharge abstract database

PHAC: Public Health Agency of Canada

PtC: pathways to care

RHA: regional health authority

THC: tetrahydrocannabinol

SD: standard deviation

WHO: World Health Organization

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<u>Chapter 1 – Introduction</u>

1.1 Background and Introduction to Psychosis

Psychosis has been defined as the presence of hallucinations without insight into their nature, delusions, or both (American Psychiatric Association, 2013). In the context of psychosis, hallucinations are defined as the presence of sensory experiences without an external stimulus. Delusions are false beliefs that remain firmly fixed despite evidence that contradicts the belief (Arcinegas, 2015). The term psychotic disorder includes a range of psychiatric conditions for which psychosis is the common symptom (American Psychiatric Association, 2013). In Canada, psychotic disorders affect approximately 4% of people during their lifetime (Lecomte et al., 2022; Perälä et al., 2007). While this is a relatively small percentage of the total population, they represent a disproportionate use of healthcare resources. Research in Ontario (de Oliveira & Tanner, 2024) found that the average patient with a chronic psychotic disorder will cost the healthcare system over 24,000 US dollars during the first year after diagnosis alone due to hospitalizations. This does not include other costs such as employment and housing support, nor does it include indirect costs such as the loss of economic contribution to society for patients and caregivers. Other research identified that these indirect costs can account for over seventy percent of the total costs of psychotic illness (Mayoral-van Son et al., 2019). It is not surprising that research on psychotic disorders has focused on the importance of early intervention, given the ameliorating effects it can have (Tiller et al., 2023; O'Connell et al., 2021).

The onset of active psychosis is usually preceded by a period referred to as the prodromal phase, which typically lasts one to three years (Powers et al., 2020). The prodromal phase usually begins in the late teens to early twenties and may be identified in an individual by a range of psychological, cognitive, and behavioural symptoms not readily diagnosable as a single disorder. Examples of these symptoms include: 1) reduced concentration, 2) disorganized thoughts, 3) reduced motivation and decreased interest in usual activities, 4) social withdrawal, 5) sleep disturbance, 6) suspiciousness, irritability, anxiousness, and depressed mood, 7) deterioration of performance at school or work, and 8) preoccupation with ideas that appear bizarre or disturbing to others (Tsuda et al., 2022). After a period of acute psychosis, the individual may experience what is known as residual symptoms, where acute psychosis has resolved but some signs of disturbance remain (Holland, 2019).

Psychosis and psychotic disorders affect a person's access to housing, employment and relationships (Ajnakina et al., 2021; Lévesque & Abdel-Baki, 2020) and can cause significant cognitive impairments (Sheffield et al., 2018). The specific psychotic disorder diagnosed is associated with the severity of illness outcomes, with schizophrenia unanimously considered the most debilitating of all psychotic disorders (Peritogiannis et al., 2020). The age at onset for psychotic disorders also predicts the severity of long-term symptoms, with an age of onset earlier in adolescence predicting more severe symptoms (Immonen et al., 2017).

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1.2 The Spectrum of Psychotic Disorders

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), released in 2013, marked a shift in the way psychosis and psychotic disorders are considered, with schizophrenia changing from a singular paradigm of psychosis to part of a spectrum of psychotic disorders (Arciniegas, 2015). The severity of symptoms and their type, number, and duration are assessed using the Clinician-Rated Dimensions of Psychosis Symptom Severity scale introduced in the DSM-5. These disorders, however, all still include psychosis as a symptom (American Psychiatric Association, 2013).

The spectrum of psychotic disorders spans milder disorders, including delusional disorder, to schizophrenia and schizoaffective disorder (Arcinegas, 2015). Schizophrenia is characterized by psychosis (hallucinations and/or delusions), as well as the presence of other symptoms. These include disorganized speech and grossly disorganized or abnormal motor behaviours, negative symptoms (e.g. flattened emotional response, diminished motivation, lack of interest in socialization), and significant cognitive deficits which affect work and/or school as well as social functioning. These symptoms must be present the majority of the time for at least one month. There must be signs of a disturbance in the individual continuously for at least six months before a diagnosis of schizophrenia can be considered (American Psychiatric Association, 2013). Schizoaffective disorder is diagnosed when an individual shows symptoms of a mood disorder (either depressive or manic) for the majority of the time while also presenting with symptoms of psychosis. The individual must also experience psychosis without

symptoms of a mood disorder for at least two weeks to differentiate from a mood disorder with psychotic symptoms (American Psychiatric Association, 2013).

1.3 Psychotic Disorders in the Literature

1.3.1 Early Psychosis Research

The word psychosis has a long history in the medical literature. It first appeared in 1841 in the title "Handbuch der medicinischen Klinik" or "Handbook for the medical clinic" (Canstatt, 1841). The term was originally used as an abbreviation of "psychic neurosis" and was exceptionally broad, referring to any mental disorder with no organic origin. This would continue into the early 20th century (Bürgy, 2008). Only eighty years after its initial usage did the term psychosis first receive the meaning that we ascribe to it today (Bumke, 1924).

In 1911, the concept of a psychosis prodrome was first proposed by Eugen Bleuer (Yung et al., 1998). Bleuer stated that the psychological and behavioural changes in a person who later develops psychosis can be identified, though this is often only possible in retrospect. The symptoms of psychosis prodrome were explicitly described in the 1960s (Chapman, 1966) and then later by others (McGlashan et al., 2001). The psychosis prodrome began to be seen as a non-specific pattern of symptoms that covers multiple aspects of a person's life, including social and professional (Larson, et al., 2010).

Starting in the 1950s, coinciding with the first use of antipsychotics, a change in the general view of psychosis began to take place. Adolf Meyer proposed that psychological

and biological "processes" were intertwined and should therefore be studied together (Meyer, 1958). Similarly, Zubin and Spring (1977) later presented their stressvulnerability model, arguing that vulnerability to mental illness could be both inherited and acquired by environmental factors.

1.3.2 Duration of Untreated Psychosis and Formalized Interventions

Research in the 1980s, such as that conducted by Crow et al. (1986), found that the duration of untreated psychosis (DUP) before admission was the variable that best predicted subsequent symptom relapse. The relationship between DUP and subsequent negative health outcomes continues to be researched, with recent studies confirming this association (Tiller et al., 2023; O'Connell et al., 2021; Howes et al., 2021).

The clinical significance of DUP led to the development of early intervention services (EIS), which provided early diagnosis and management of psychotic disorders. The first EIS appeared in Australia in the mid-1990s and quickly spread (McGorry et al., 2008). These services now exist in countries across the world, such as the United Kingdom, the United States, Chile, Italy, Australia, and Canada, which conduct studies to assess their effectiveness (Pelizza et al., 2024; Heinssen & Azrin, 2022; Jones et al., 2021). EIS exist across Canada, and standards and guidelines exist that address the entire continuum of care including: early recognition, barrier-free access to care, required services to facilitate treatment, staffing requirements to support services, and ongoing quality improvement evaluations (Early Psychosis Intervention, 2025). The results assessing the performance of these services show that EIS not only reduces mortality risk and improves outcomes

but also creates a net benefit in terms of healthcare costs (Tarride et al., 2022; Anderson et al., 2018). In Newfoundland and Labrador, EIS are provided by the psychosis intervention and early recovery (PIER) program, which has four main goals: 1) early recognition and treatment of psychosis, 2) assessment, interventions and supports for individuals and families, 3) relapse prevention and recovery, 4) educating individuals and their families, healthcare workers, and the community (Eastern Health, 2023).

Pathways to care (PtC) is a concept that is closely associated with the philosophy of reducing DUP and with EIS. PtC were defined by Rogler and Cortes (1993) as "the sequence of contacts with individuals and organisations 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 of these efforts". Using this definition, PtC are often understood to refer to both help-seeking by individuals and families and the referral process that is offered (Cabassa et al., 2018). A body of literature has been established that identifies the PtC for individuals with psychosis, while also often identifying barriers to care for this population (Oluwoye et al., 2021; Lilford et al., 2020; Halvorsrud et al., 2018).

1.3.3 Risk Factors for the Onset of a Psychotic Disorder

Non-hereditary factors play a significant role in elevating the risk of psychotic disorders by interacting with genetic heritability, with several of these factors being identified in the literature. Complications during pregnancy have been shown to increase the risk of brain anomalies associated with psychotic disorders (Costas-Carrera et al., 2020). Chronic stress caused by childhood trauma is also associated with a greater risk of developing a psychotic disorder (Popovic et al., 2019). Lastly, urbanicity has also been shown to increase the risk of developing a psychotic disorder, though the reasons for this association remain unverified (Stilo & Murray, 2019).

One non-hereditary factor whose close association with the onset of a psychotic disorder has been particularly well studied is cannabis use (Ahmed et al., 2021). Risk factors for the development of psychotic symptoms in cannabis users include: 1) being under 15 years of age at first use, 2) high frequency of use, and 3) consuming products with high levels of THC (Ortiz-Medina et al., 2018). A 2022 survey found that 50% of Canadians aged 20-24 had smoked cannabis, including 37% of those aged 16-19 years old (Health Canada, 2022). The existence of a genetic link between the disordered use of cannabis and psychotic disorders, however, remains widely debated in the literature (Cheng et al., 2023; Johnson et al., 2021; Hjorthøj et al., 2019).

A discussion of risk factors for the onset of psychotic disorders would be incomplete without the mention of genetic heritability. While the lifetime prevalence of schizophrenia in the general population is accepted as being approximately one percent (Jauhar et al., 2022), the condition has a high genetic heritability, with monozygotic twin concordance estimated at roughly 45% (Stilo & Murray, 2019). However, genetic risk for psychotic disorders is relatively poorly understood, and although genetic risk comprises roughly 30-50% of the total risk for psychotic disorders (Pain et al., 2018), mutations in known genes account for only 7-10% of the total variance (Bergen et al., 2019).

1.4 Treating a Vulnerable Population

1.4.1 Barriers and Facilitators to Treating a Psychotic Disorder

One of the most persistent issues affecting youth with psychotic disorders is adequate access to appropriate care. Over the past few years, awareness of this issue has increased in Canada and across the world. The recent Health Accord NL (2022) identified mental health as a serious concern consistently surfacing during their public engagements. Despite this, Newfoundlanders and Labradorians wait longer than other Canadians for mental health services, 33 days on average, 11 days longer than the national average (CIHI, 2024^a).

In other Canadian provinces, research is ongoing to better understand EIS, identify gaps in service, and how these services can be improved. As an example, Bertulies-Esposito et al. (2020) published a study of Quebec EIS for psychosis that identifies the increases in psychosis services that have occurred in that province over the past 30 years. However, the authors note that many of the programs provided still deviated from the guidelines in terms of the referral process and patient-client ratio. They also identified that rural areas routinely struggled with providing EISs.

It has become accepted that those living with psychotic disorders are commonly seen in emergency departments (EDs) (Lawrence & Berstein, 2024). Canadian youth between the ages of 20-29 spend more time in EDs than any other age group for mental healthrelated visits (CIHI, 2019). A study by Chiu et al. (2020) found that the rate of mental health-related ED visits in Canadian children and youth increased by 89% from 2006 to 2017. A study in Norway (Rognli et al., 2023) found that repeated admissions to the ED for substance-induced psychosis increased the risk of being diagnosed with a psychotic disorder. Another study by Myran et al. (2023) showed that cannabis-induced psychosis visits to EDs in Ontario increased after the commercialization of cannabis in 2021.

1.4.2 Considerations when Treating Youth Living with Psychosis

Early intervention is considered essential to the treatment of adolescents living with psychosis. There are, however, two major factors to consider that may affect the delivery of services in a timely manner. The first is difficulty in differentiating symptoms from other psychiatric disorders, such as autism spectrum disorder (ASD) and ADHD (Giannitelli et al., 2020).

The second contributing factor is the characteristics of the age group itself, including a general hesitancy to seek help (Stunden et al., 2020) despite rising mental health disorders in youth (Wiens et al., 2020). Approximately 20-25% of Canadian youth who need mental health services seek it from informal means, and about half that number will seek help from professional healthcare providers (Stunden et al., 2020; Malla et al., 2016). It is during this age range that schizophrenia and its related disorders are most likely to manifest, with 20 years of age being the average onset (Solmi et al., 2022).

Tiller et al. (2023) found that self-stigma brings an additional barrier to help-seeking behaviours in youth. Youth living with psychotic disorders often begin to show signs of irritation, anxiety, and social withdrawal (Tsuda et al., 2022) before the onset of acute psychosis. These challenging behaviours can often lead youth to disconnect from their families, school, and social groups, increasing the risk of dropping out of school (Green et al., 2018) and developing substance abuse disorders (Malla et al., 2018). The role of schools can never be overestimated for this age group. They act as the first point for the formal identification, referral, and early intervention for youth who are beginning to display challenging behaviours (Dalbosco & Sudbrack, 2021; Hoover & Bostic, 2021, O'Reilly et al., 2018).

1.4.3 Pharmacotherapy for the Management of Psychotic Disorders

The primary pharmacotherapy for psychotic disorders is a class of medications known as antipsychotics. Antipsychotics were first developed in 1951 as a surgical anesthetic, but because of their calming effects were quickly adopted in psychiatry to treat the agitation of psychotic patients (Shen, 1999). However, clinicians soon observed concerning adverse effects in psychotic patients who were administered this new medication. These adverse effects included various movement disorders such as muscle tremors, rigidity, and spasms that are collectively referred to as extrapyramidal symptoms (EPS) (Meyer & Simpson, 1997).

Clinical testing was eventually initiated to find an alternative to the first generation of antipsychotics, causing the second generation or atypical antipsychotics to be developed. In 1990, clozapine, the first atypical antipsychotic, was approved by the FDA for general use in the United States. Since the introduction of atypical antipsychotics, the prescription of first-generation antipsychotics has drastically reduced to below ten percent (Radojčić et al., 2023), due largely to decreased adverse effects with the atypical antipsychotics (Shen, 1999). Adverse effects persist with atypical antipsychotics, including the less common but still present risk of EPS, weight gain and significant tranquilization (Llorca et al., 2017).

While antipsychotics are available in pill form to be taken daily, long-acting injections (LAIs) are another form of antipsychotics that have been proven effective. They are introduced as an option relatively early in the treatment of a patient, usually after the patient is unsuccessful with their first trial of medication. Sub-optimal compliance with medication increases the risk of relapse, potentially causing hospitalization and an overall negative impact on health outcomes (Karow et al., 2019; Lin et al., 2019). One of the important aspects of LAIs has been the method of medication delivery. The slow release of the LAI over time causes the level of the drug in the body to remain steady. The use of LAI therapy together with other strategies results in patients experiencing fewer and less serious adverse effects than the use of their oral equivalents (Biagi et al., 2017). Another important benefit of treatment with LAIs is the frequency of the dose required. Since LAIs of antipsychotics are administered far less frequently than oral medication (once or twice a month vs once or twice a day), the likelihood of missing a dose is reduced.

<u>1.4.4 Role of Non-Pharmaceutical Treatments in the Management of Psychotic Disorders</u> A significant part of non-pharmaceutical management of psychotic disorders in youth described in the literature constitutes psychotherapy, most commonly cognitive behavioural therapy (CBT) or CBT for psychosis (CBTp), (Kingdon & Turkington, 2019; Laws et al., 2018). Studies on the effectiveness of CBT and CBTp have been inconsistent (Health Quality Ontario, 2018). The most recent literature on CBTp seeks to identify its strengths and challenges, targeting psychotic disorders where it can be most effective (Lawlor et al., 2022; Lincoln & Peters, 2019). As an example, Lawlor et al. (2022) has developed a shortened program of therapy of the traditionally long and highly intensive CBTp program that only targets a specific symptom. Not only is this less intensive on both staff and patients, but patients are more likely to attend targeted therapy for a specific symptom of a psychotic disorder relevant to them.

A more recent development of CBT is acceptance and commitment therapy (ACT), first described by Hayes et al. (2003). While newer than other therapies, ACT is supported by research describing its effectiveness (O'Brien-Venus et al., 2024; Yıldız et al., 2020). In addition to these therapies, others are available for symptoms associated with psychotic disorders. Cognitive remediation therapy (CRT) is shown to be an effective treatment for managing the debilitating cognitive deficits that appear in psychotic disorders, most prominently in schizophrenia (Gott et al., 2023; Cella et al., 2020). Similarly, cognitive enhancement therapy (CET) is a form of cognitive remediation with efficacy supported by the literature that can be offered to individuals who are clinically stable but struggle with overall functioning and social functioning (Wojtalik et al., 2022; Faith et al., 2019).

Another more comprehensive approach to treatment is the wraparound model developed in the 1980s to address the highly fractured approach to caring for children and youth with complex needs (Stroul & Friedman, 1986). Wraparound care describes an outcomes-based approach to care that: 1) actively seeks perspectives from the patient and the family, 2) consists of a collaborative team of multidisciplinary professionals, 3) is individualized to the patient, 4) is sensitive to the patient's situation, culture, etc., 5) builds on natural supports that already exist in the patient's life, and 6) provides care in the least restrictive setting possible (Bruns et al., 2008). Today, wraparound care describes an individualized and multi-disciplinary approach to care coordination aimed at improving outcomes for youth with complex needs such as a psychotic disorder (Olson et al., 2021; Schurer Coldiron et al., 2017). A similar approach can also be seen in the open dialogue model first pioneered in Finland (Lakeman, 2014).

1.5 Rationale and Research Objectives

Mental health, including youth mental health, is increasingly identified as an area of concern in Newfoundland and Labrador (NL) (Health Accord NL, 2022), however, services continue to lag behind other provinces (CIHI, 2024^a). As far as this author is aware there has been no study conducted in NL that has undertaken a comprehensive examination of factors that affect how youth in the province access pathways to care (PtC) for treatment of psychotic disorders. This research sought to answer the following question: what are identifiable factors affecting the diagnosis and treatment of psychotic disorders in NL youth?

This question was addressed with both quantitative and qualitative methods. The quantitative portion of this research examined NL healthcare databases to determine variables that are associated with ED utilization in NL youth with a psychotic disorder.

Specifically, it asked the following three questions: 1) What variables affect the utilization of services for youth with a psychotic disorder in urban and rural areas of NL? 2) Is there a discernible and significant pattern in the variables? 3) Was there an effect on the data associated with the COVID-19 pandemic?

The qualitative portion of the research adds to the findings of the quantitative studies by collecting and analyzing data from interviews with clients of mental health services and family members, as well as focus groups with caseworkers. Specifically, the qualitative research sought to answer the following three questions: 1) What patterns appear in early symptoms and behaviours of children who will develop a psychotic disorder? 2) What factors affect the treatment and diagnosis of a psychotic disorder from the perspective of clients and families? 3) What are the gaps in services provided to clients living with a psychotic disorder in NL and their families?

1.6 Methods

<u>1.6.1 Introduction to Research Approach</u>

The literature describing youth living with psychotic disorders indicates that significant difficulties would arise in conducting a prospective cohort study of this population due to issues with behaviours and a high risk of attrition. Therefore, health databases were used to analyze patient data retrospectively after diagnosis. Databases allow for the use of anonymized data while also minimizing risk to privacy. Unfortunately, secondary data cannot capture the full range of issues affecting patients living with psychotic disorders making the qualitative portion of the research critical. The interviews and focus groups

add further information and context to the statistical analysis of the data. This in turn created a richer overall picture of PtC for this cohort and variables affecting the diagnosis and treatment of psychotic illness in NL youth.

1.6.2 Quantitative Methods and Analysis

The quantitative portion of this dissertation comprised two studies. Multiple administrative databases of provincial health data were linked by Digital Health NL and a de-identified patient number unique to each individual was created to link the data. Patients aged 15-24 diagnosed with a psychotic disorder between April 1st, 2011, to March 31st, 2022, and who visited an ED at least once were included in the data. Psychotic disorders included in the data included schizophrenia and schizoaffective disorder. ICD-10-CA diagnostic codes were used to identify all patient diagnoses. This study received approval by the Health Research Ethics Authority of Newfoundland and Labrador (HREB #2022.214).

For the first study, the number of ED visits served as the outcome variable. Independent variables included in the analyses completed for this study were: 1) age 2) sex 3) patient regional health authority (RHA), and 4) urban or rural residence as determined by Digital Health NL using the master geography file (MGF). Linear regression modelling was used to examine the significant factors associated with the number of visits to an ED in both the univariate and multivariate analyses. An interaction term was introduced into the model to examine if significant differences in the variables associated with the number of

ED visits existed between: 1) sex and urbanicity, 2) age and urbanicity, and 3) RHA and urbanicity. All analyses were conducted using SAS 9.4.

In the second study, the difference in monthly utilization of EDs during and before the COVID-19 pandemic was the variable investigated. The independent variables included in the univariate and multivariate analyses were: 1) age at diagnosis 2) sex 3) patient Health NL using the MGF, and 5) time-periods as described in the section above. Multiple linear regression with Generalized Estimating Equations (GEE) modelling was used to identify the significant factors associated with mean monthly ED visits in both the univariate and multivariate analyses. Autoregression was the working correlation matrix to meet the needs of the longitudinal nature of the study design. All analyses also used SAS 9.4.

1.6.3 Qualitative Approach to the Study

Grounded theory refers to both the method of conducting research and the product of the method (Bryant & Charmaz, 2007) and is often used when little is known about this topic of research and when explanatory and descriptive theory is required (Birks & Mills, 2015). Answering the specific research questions required that data be collected from individuals to eventually inform a coherent theme that identifies the PtC for clients and families in NL. A grounded theory approach was well suited to the inductive logic required in this research. Participants were deliberately selected in a process called purposive sampling (Charmaz & Bryant, 2011), and data was collected and analyzed concurrently in an iterative cycle (Birks & Mills, 2015). Coding in grounded theory is

divided into three parts as described by Kelle (2007): open, axial, and selective coding. Open coding breaks interview data into discrete blocks that are then compared to each other. Through the use of constant analysis, axial coding was then used to create categories from groups of related individual codes. Finally, selective coding was used to define the relationships between these categories, which is grounded in the data and has explanatory power.

1.6.4 Qualitative Methods and Analysis

This study sought to understand the perspectives of youth with a psychotic disorder who are clients of mental health services and family members as it pertains to receiving a diagnosis and treatment of a psychotic disorder. The methodology employed had to be flexible to accommodate individual insights and perspectives while remaining consistent across interviews. To achieve this, semi-structured interviews were selected to gather this data, and purposive sampling was used to recruit key informants. The study was completed in two phases. In phase one, participants recruited were: 1) clients nineteen years and older diagnosed with a psychotic disorder between fifteen and twenty-four years of age, 2) a close family member who was most knowledgeable about the first participant, usually a parent. An identified weakness of the interview method is that the insights and experiences of only a small portion of the total population can be gathered. In addition, the nature of the population being studied is such that those willing to participate would not include the most vulnerable individuals. To help ameliorate this, phase two of the study involved interviewing caseworkers to add their input into these themes, drawing from their work in the field, and allowing a triangulation of the findings.

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1.7 Overview of Subsequent Thesis Chapters

This thesis is written in the manuscript style. As such, chapters two to four were written to be published as stand-alone journal articles, with co-authorship statements preceding each one. While this thesis has been specifically designed to present its findings in a manner that flows logically between chapters, the thesis style chosen makes some repetition inevitable. Chapter two of this study examined the patterns of utilization of EDs for rural versus urban-dwelling youth in NL living with a psychotic disorder. Chapter three investigated possible variations that appeared in utilization patterns for NL youth using EDs before versus during the COVID-19 pandemic. Chapter four used interviews and focus groups with clients, family members, and caseworkers to: 1) identify patterns appearing in the early symptoms and behaviours of children who develop a psychotic disorder, 2) identify factors affecting the treatment and diagnosis of a psychotic disorder from the perspective of clients and families, and 3) identify the gaps in services provided to clients and family members. Chapter five summarizes and discusses the findings of the preceding three chapters and places them in the context of the broader research questions.

<u>Chapter Two – Impact of Rural Residence on Emergency Department Visits for</u> <u>Youth with Psychotic Disorders in Newfoundland and Labrador, Canada</u>

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Preface and Co-authorship Statement

A version of this study has been submitted for publication to the journal Rural and Remote Health (submission # 9721).

As the primary author of this study, Giovannini-Green contributed to the study concept and design, conducted data interpretation and analysis, drafted the manuscript, and approved the final version. Mugford and Gao contributed to the study concept and design, provided supervision, reviewed the manuscript, and approved the final version.

Abstract

Background: Few studies investigate emergency department (ED) utilization by ruraldwelling youth with psychotic disorders, despite evidence that this constitutes an area of concern. This study examined the difference in ED utilization for urban versus ruraldwelling youth diagnosed with a psychotic disorder in Newfoundland and Labrador (NL).

Methods: Administrative databases were analyzed in a retrospective cohort study. Patients diagnosed with a psychotic disorder between April 1st, 2011, and March 31st, 2022, who were between 15-24 years, and who had at least one ED visit were included. The dependent variable was the average monthly ED visits. Independent variables were: 1) age 2) sex 3) geographic region, and 4) urban or rural residence. General linear regression identified variables associated with ED utilization in the univariate and multivariate analyses.

Results: Multivariate analysis found rural residence was significantly associated with increased average monthly ED visits (B-Coefficient=0.19, p<0.01) over urban residence. Female sex was also found to be significantly associated with increased average monthly ED visits (B-Coefficient=0.13, p<0.01) over male sex.

Conclusions: This study showed rural-dwelling youth with psychotic disorders had significantly higher ED utilization than urban-dwelling youth. Further research is required to develop strategies which elevate conditions for this population. This will financially benefit the healthcare system and improve the well-being of some of society's most vulnerable people.

Keywords: access to care, emergency medical services, psychosis, psychotic disorder, rural health, schizophrenia
2.1 Introduction

2.1.1 Background

Approximately 1.5 million Canadians, or roughly four percent of the population, will be affected by a psychotic disorder during the course of their lifetime (Lecomte et al., 2022; Perälä et al., 2007). Psychotic disorders are now widely believed to be neurodevelopmental in nature (Jonas et al., 2022; Santos et al., 2022). Research on psychotic disorders has therefore focused on the importance of early intervention at the onset of psychosis, given the ameliorating effects it can have on the course of these disorders (Tiller et al., 2023; O'Connell et al., 2021).

The positive effects of early intervention are well-studied and widely accepted. However, challenges present themselves when providing care for youth. While youth in Canada show a rise in the prevalence of the diagnoses of psychiatric disorders (Wiens et al., 2020), they are still unlikely to seek help (Stunden et al., 2020). Only an estimated 20-25% of Canadian youth who require mental health supports will seek them out, and only around half of those youth will contact professional healthcare providers (Stunden et al., 2020; Malla et al., 2016). Answers to why help-seeking is so uncommon may be found in the demographic itself. Self-stigma has been identified as a significant barrier that affects youth willingness to seek necessary supports (Tiller et al., 2023).

Before the onset of acute psychosis youth may begin to withdraw socially, become anxious and irritable, and become preoccupied with bizarre thoughts and ideas (Tsuda et al., 2022). These behaviours challenge the families and friends of these youth and can increase the risk of youth leaving school (Green et al., 2018) and developing substance use disorders (Malla et al., 2018). The combination of the above-mentioned factors creates a situation wherein adequate access to appropriate care becomes a persistent issue for these youth. The last few years have seen an increased awareness of this issue in Canada and globally. This province recently released the Health Accord NL (2022), a document stating that engagement with the public identified mental health as a serious concern for Newfoundlanders and Labradorians.

Across Canada, treatment for psychotic illness is provided through what are referred to as early intervention services (EIS). Elsewhere in the country, these EIS are reviewed to establish how they are performing in terms of the treatment of psychosis and psychotic disorders. These results are largely positive, with EIS showing a reduced risk of mortality and improved outcomes in addition to a net benefit in terms of healthcare costs (Tarride et al., 2022; Anderson et al., 2018). However, challenges with EIS in Canada still exist. A study published by Bertulies-Esposito et al. (2020) published a study of EIS and identified that many of the EIS deviated from the guidelines, particularly in terms of low patient-client ratio. This was flagged as being of concern since it greatly increased the risk of staff burnout. Finally, the EIS in rural areas were shown to struggle with maintaining staff as well as serving a sparsely populated catchment area.

Youth are known to visit emergency departments (EDs) as a means to access care for a psychotic disorder (Lawrence & Berstein, 2024), and Canadian youth as a whole between ages 20-29 spend more time in EDs for mental health-related visits than any other age

group (CIHI, 2019). Use of the ED is not equal across all demographics or all provinces, however. The cost of an average ED visit in Canada for 2018-2019 was estimated at 304 dollars (CIHI, 2020). Newfoundland and Labrador (NL) was also found to have a rate of ED visits nearly twice the national average (922 visits per 1,000 people versus 495 visits per 1,000 people). Moe et al. (2022) identified residents of rural parts of Canada as one of the subgroups more likely to make frequent ED visits. However, as reported by CBC News (Roberts, 2023), there have been multiple closures of EDs in rural parts of the province due to a lack of staffing.

2.1.2 Research Statement

This research will answer the following question: Is there a significant difference in the number of ED visits for youth diagnosed with a psychotic disorder living in urban versus rural areas in NL?

2.2 Methods

2.2.1 Study Population and Data Sources

For this study, administrative databases from the Canadian province of NL was utilized to conduct a retrospective cohort study. Patients aged 15-24 diagnosed with a psychotic disorder between April 1st, 2011, to March 31st, 2022, and who visited an ED at least once were included in the analysis. Psychotic disorders included in the study were schizophrenia and schizoaffective disorder. ICD-10-CA diagnostic codes were used to identify all patient diagnoses. This study has received approval by the Health Research Ethics Authority of Newfoundland and Labrador (HREB #2022.214).

For this study, the following databases were accessed and linked by Digital Health NL:

- The Provincial Discharge Abstract Database (PDAD) tracks the demographic, clinical, and administrative data of individuals when they are discharged from inpatient services or surgical day care services.
- The provincial Client Registry (CR) collects demographic information from individuals presenting at a hospital or pharmacy as well as those applying for a MCP number.
- 3) The Master Geography File (MGF) connects an individual's six-digit postal code to Statistics Canada's standard geographical areas. It is also used to determine in which of the four regional health authorities (RHAs) an individual resides. Finally, the number character in the first three digits of the postal code is used to determine urban or rural residence. According to Statistics Canada, an area is considered urban if it has a total population of as least 1,000 people, and a population density of at least 400 people per square kilometre. All other areas are considered rural (Statistics Canada, 2011).
- 4) The MediTech Data Emergency Department Module is an electronic patient database that collects demographic, clinical, and administrative data. Data collected include date and time of arrival and discharge as well as presenting complaint.

To link together data from various databases Digital Health NL created a de-identified patient number unique to each individual. Upon receiving the de-identified data, a single file was created combining all relevant variables.

2.2.2 Measuring Utilization of Emergency Departments

For this study number of ED visits serves as the outcome variable. Mean monthly ED visits across the period of the study were used as the standard to measure ED visits to control for differences in each individual's data. To achieve this number, the total number of visits to an ED during the study period made by each individual was divided by 132, the number of months in the study period. To achieve a full understanding of how individuals diagnosed with psychotic disorders utilize ED in this province, all visits to an ED were included in this study, not only visits related to the individual's psychotic disorder.

2.2.3 Statistical Analysis

Independent variables included in the analyses completed for this study consisted of the following: 1) age 2) sex 3) patient regional health authority (RHA), and 4) urban or rural residence as determined by Digital Health NL using the MGF. Descriptive statistics were generated to describe the study population, including counts and proportions, and means and standard deviations for categorical and continuous variables respectively. Linear regression modelling was used to examine the significant factors associated with the number of visits to an ED in both the univariate and multivariate analyses. The strength of the association was described as B-coefficient, standard error, and p-value in appendices to this study. An interaction term was introduced into the model to examine if significant differences in the variables associated with the number of ED visits exist between: 1) sex and urbanicity, 2) age and urbanicity, and 3) RHA and urbanicity. All analyses were conducted using SAS 9.4.

2.3 Results

In the period from April 1st, 2011, to March 31st, 2022, 125 individuals ages 15-24 were diagnosed with either schizophrenia or schizoaffective disorder and visited an ED at least once. Of the 125 individuals, the majority were male (75.2%), lived in an urban area (66.4%), and had Eastern Health as their RHA of residence (52.8%). The percentages of individuals in the study living in urban versus rural areas and in the four RHAs were consistent with percentages for the total population. The average age at diagnosis was 20.64 years, and the average monthly number of ED visits was 0.21 (see Table 2.1).

Table 2.1: Overview of Individuals in the Study

Variable ($N = 125$)	Descriptives
Sex, N (%)	
Female	31 (24.8%)
Male	94 (75.2%)
RHA, N (%)	
Central	8 (6.4%)
Western	25 (20.0%)
Labrador-Grenfell	26 (20.8%)
Eastern	66 (52.8%)
Urbanicity, N (%)	
Rural	41 (32.8%)
Urban	83 (66.4%)
Age, mean (SD)	20.64 (2.40)
Mean ED Visits per Month, mean (SD)	0.21 (0.20)

Legend:

RHA = regional health authority

SD = standard deviation

ED = emergency department

In the univariate analysis, rural residence was found to be significantly associated with increased average monthly ED visits (B-Coefficient=0.13, p<0.01). Female sex was also found to be significantly associated with increased average monthly ED visits (B-Coefficient=0.09, p=0.03) (see Table 2.2). A full description of the results of the univariate analyses is available in Table 2. The multivariate regression indicated that youth living in rural areas had significantly higher average monthly ED visits than those living in urban areas (B-Coefficient=0.19, p<0.01). Females also had significantly higher average monthly ED visits than those living in urban areas (B-Coefficient=0.19, p<0.01). Females also had significantly higher average monthly ED visits than males (B-Coefficient=0.13, p<0.01). Finally, youth living in the Central Health region had a significantly lower average monthly ED visits than Eastern Health region (see Table 2.3).

Table 2.2: Univariate Analyses

Variable	B-Coefficient	Standard Error	p-Value	Type 3 p- Value
Sex				
Female	0.09	0.04	0.03*	0.03*
Male	0			
Age	0.01	0.01	0.38	0.38
RHA				0.27
Central	-0.05	0.07	0.51	
Western	< 0.01	0.05	0.97	
Labrador- Grenfell	0.08	0.05	0.09	
Eastern	0			
Urbanicity				
Rural	0.13	0.04	< 0.01*	< 0.01*
Urban	0			

Where * indicates a statistically significant value

Legend:

RHA = Regional Health Authority

Variable	B-Coefficient	Standard Error	p-Value	Type 3 p- Value
Sex				
Female	0.13	0.04	<0.01*	< 0.01*
Male	0			
Age	0.01	0.01	0.38	0.38
RHA				0.14
Central	-0.16	0.07	0.03*	
Western	-0.04	0.04	0.33	
Labrador-	-0.08	0.53	0.13	
Grenfell				
Eastern	0			
Urbanicity				
Rural	0.19	0.04	<0.01*	<0.01*
Urban	0			

Table 2.3: Multivariate Analyses

Where * indicates a statistically significant value

N.B.: No interaction was found between urbanicity and sex, age, or RHA and average

monthly emergency department visits.

Legend:

RHA = regional health authority

2.4 Discussion

2.4.1 Emergency Department Visits in Youth with Psychotic Disorders

This study identified two factors associated with increased ED utilization: rural residence and female sex. These findings are consistent with other studies completed elsewhere in Canada (Clark et al, 2021; Moe et al., 2020). The concept that provinces with higher rates of ED utilization also have a higher prevalence of a rural dwelling population is consistent with what is known about the Canadian population. The Canadian Institute for Health Information (CIHI) found that the Atlantic provinces and the Yukon had the highest rates of ED utilization in the country (2020). The Canadian Census of 2021 indicates that the proportion of the population living in rural areas in these two areas is double the national figure of 17.8% (Statistics Canada, 2022).

Of note is the significant disparity between the frequency of ED use between sexes and between urban and rural residences, as indicated by p-values. In terms of urbanicity, an increase in the use of ED services in rural NL can be understood since those living in rural areas do not have access to the same services as those living in urban areas (Clark et al., 2021; Bertulies-Esposito et al., 2020). In NL, EIS are mostly urban-based and provided by programs such as the psychosis intervention and early recovery program (PIER) (Eastern Health, 2023).

However, the degree to which ED visits for females are higher than males in the province in the multivariate model is not consistent with findings from other studies. The increased rate of ED utilization in females may be attributed to multiple factors. One, all psychotic disorders are slightly more prevalent in males than in females, giving clinicians more experience with male patients. Two, men and women have been shown to have different presentations of psychotic illness, which may affect how they access EDs (Carter et al., 2022; Giordano et al., 2021; Reininghaus et al., 2019). Three, treatment strategies for psychotic disorders are nearly always based solely on male presentations of the illness (Li et al., 2022).

2.4.2 Study Strengths and Limitations

A brief discussion of this study's strengths and limitations should be included so that the results it produced can be fully understood. This study's first strength is the use of regression analysis allowed the authors to identify individual variables related to ED utilization and analyze their contribution in the multivariate analyses. Second, the use of all ED visits for this population gave the authors a greater understanding of their patterns of utilization for EDs. This study also has certain limitations. This study was limited to those aged 15-24 at the time of their diagnosis. Those receiving a diagnosis later in their life may show different patterns of utilization for ED visits of trends, such as visits before versus after diagnosis.

2.4.3 Future Research Possibilities

Future research in this area of psychosis research may address the limitations of the study addressed above. Additionally, further research is required to fully appreciate the differences between the sexes in terms of symptom presentation and facilitate training so that ED staff can more easily recognize these differences. Another direction of research is the pattern of utilization over time for ED visits in this vulnerable population. The effects on utilization caused by the commercialization of cannabis could be a possible avenue of inquiry. On a more global scale, the effects of the COVID-19 pandemic on how youth use EDs would provide useful insight. This line of inquiry will not just serve as a look into the past for what was done for the COVID-19 pandemic but also prepare policymakers and clinicians for any future events of similar impact. As an example, in August of 2024, the World Health Organisation (WHO) declared the clade I strain of mpox to be a public health emergency of international concern (PHAC, 2024). By fully understanding the totality of the effects of the COVID-19 pandemic on this population, we can be adequately prepared for any challenges that arise with the arrival of similar viral outbreaks in Canada.

2.5 Conclusion

This study was designed and implemented to identify utilization patterns for ED visits in youth with psychotic disorders living in NL. The results identified three findings regarding the utilization of EDs. First, rural-dwelling youth are significantly more likely than urban-dwelling youth to use EDs. Second, females are significantly more likely than males to use EDs. Third, those living in the Central Health RHA of the province are significantly less likely than all other youth to use EDs. It is known that NL has a rate of ED utilization that is nearly twice the national average (CIHI, 2020). However, further research is required to understand what is contributing to this high rate of utilization and develop strategies so that these youth have other options for treatment. To support this underserved and vulnerable population there must be a collective effort to recognize the

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ways that we can remove barriers and facilitate access. This will not only prove financially beneficial for the healthcare system but also help ensure the well-being of some of the most vulnerable people in our province.

<u>Chapter Three - Impact of COVID-19 on Emergency Department Visits for Youth</u> <u>with Psychotic Disorders in Newfoundland and Labrador, Canada: A Longitudinal</u> <u>Study</u>

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Preface and Co-authorship Statement

A version of this study has been submitted for publication to the Canadian Journal of Public Health (submission ID: CJPH-D-24-00563).

As the primary author of this study, Giovannini-Green contributed to the study concept and design, conducted data interpretation and analysis, drafted the manuscript, and approved the final version. Mugford and Gao contributed to the study concept and design, provided supervision, reviewed the manuscript, and approved the final version.

Abstract

Objectives: This study examines the trend in emergency department (ED) visits for youth with a psychotic disorder in Newfoundland and Labrador (NL) before COVID-19 and during the pandemic when examined longitudinally.

Methods: This study was a retrospective cohort study. Patients diagnosed with a psychotic disorder between April 1st, 2011, and March 31st, 2022, who were between 15-24 years and who visited an ED at least once will be included. Average monthly visits

were used to measure ED visits to control for differences in each individual's data. Independent variables in the analyses consist of: 1) age 2) sex 3) geographic region, 4) urban or rural residence, and 5) ED visit before or during COVID-19. Multiple linear regression with Generalized Estimating Equations (GEE) modelling was used to identify factors associated with mean monthly ED visits to accommodate the longitudinal nature of this study.

Results: Our multivariate analysis showed the mean monthly ED visits increased significantly during the first year of COVID-19 than before the pandemic (Mean=0.30 vs Mean=0.21, p=0.01). Female sex and rural residence were also significantly associated with higher average monthly ED visits than male individuals (Female=0.51 vs Male=0.21, p<0.01) and urban residence (rural=0.38 vs urban=0.21, p=0.02).

Conclusion: ED utilization by individuals with psychotic disorders increased during the first year of the COVID-19 pandemic while ED use by most Canadians decreased. This study identified demographics of Canadians who require extra support during a health crisis. There is always the possibility of another global pandemic, and the Canadian healthcare system must be equipped to provide adequate services to all Canadians, especially those who are most vulnerable.

Keywords: psychosis, psychotic disorder, access to care, schizophrenia, COVID-19

3.1 Introduction

3.1.1 Background

Approximately 18% of all Canadians will meet the criteria for at least one mental disorder each year (Statistics Canada, 2023). Despite this, in 2020 Canadians waited an average of 22 days to receive potentially life-saving community mental health counselling (CIHI, 2024^a). This results in the Canadians having to resort to accessing emergency departments (ED) to receive some form of care. Indeed, approximately ten percent of Canadians who visit an ED with symptoms of mental or substance use disorder will access an ED four or more times every year (CIHI, 2024^b). Those living with severe psychotic disorders such as schizophrenia are particularly likely to have multiple visits to an ED each year (Slankamenac et al., 2020; Niedzwiecki et al., 2018).

Starting in 2020, the COVID-19 pandemic caused mass disruptions to the healthcare system as nearly all resources had to be suddenly allocated to the management of the virus. This resulted in an overall drop in total ED visits in Canada (Yao et al., 2023; Kwok et al., 2021) and elsewhere (Daoud & Ronen, 2023; Melnick et al., 2022; Molina et al., 2022), especially during the first year of the pandemic. Mental health related ED visits as a whole also decreased overall, again especially during the first year of the COVID-19 pandemic (Gonçalves-Pinho et al., 2021; Joyce et al., 2021; Stroever et al., 2021; Capuzzi et al., 2020). However, an increase in presentations to EDs of individuals with symptoms of psychosis and psychotic disorders during the COVID-19 pandemic has been reported globally (Goldschmidt et al., 2023; Lee et al., 2022; Jagadheesan et al., 2021).

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In NL, there has been a rise in concern about mental health as seen in a 2022 document published by the provincial government (Health Accord NL, 2022). Newfoundlanders and Labradorians have had to wait on average longer than other Canadians for health services. As an example of this, in 2020, the average wait time for community mental health counselling was 33 days, 11 days longer than the national average (CIHI, 2024^a). Of special concern is the mental health of the youth in the province. The average age of onset of schizophrenia and related disorders has recently been reported as approximately 20 years of age according to a large-scale meta-analysis involving 192 studies (Solmi et al., 2022). This adds another level of stress to young people during an already difficult stage in their lives. It also affects the loved ones of those affected. The onset of a psychotic disorder can cause youth to display irritation and anxiety, withdraw from their social lives, and develop bizarre thoughts and ideas (Tsuda et al., 2022). Stigma from the perspective of the individual, both from others and from themselves, has also been shown to delay accessing treatment and prolong the duration of untreated psychosis (Kular et al., 2018). The duration of untreated psychosis (DUP) has long been shown to be significantly associated with outcomes for those who experience psychotic episodes (Tiller et al., 2023; O'Connell et al., 2021).

These factors affect the likelihood of youth actively seeking help for their mental health. In Canada, less than a quarter of youth will seek help of any kind with their mental health, and often from online resources as opposed to mental health professionals (Stunden et al., 2020; Malla et al., 2016). This is despite Canadian research that recommends increased mental health services for youth, given the rise in prevalence of these illnesses in recent years (Wiens et al., 2020). This may result in youth not accessing services until their symptoms become acute, resulting in their necessary utilization of EDs. Despite the effect of this on youth, no literature exists that examines the effects of the COVID-19 pandemic on youth living with psychotic disorders in NL. The decrease in utilization of ED services during the COVID-19 pandemic is well documented in the literature. The increase in the utilization of youth presenting with psychosis symptoms has also been studied. However, most studies conducted on this topic have been cross-sectional with limited follow-up. A longitudinal study is needed to investigate the overall trend of utilization of EDs by youth with diagnosed psychotic disorders during the pandemic in comparison with pre-pandemic levels.

3.1.2 Research Objective

This research will answer the following question: Is there a difference in trend of the number of all ED visits for youth diagnosed with a psychotic disorder before the pandemic (2011-2019) and during the COVID-19 pandemic (2020-2022) when examined longitudinally?

3.2 Methods

3.2.1 Study Population

Administrative databases maintained by Digital Health NL for the Canadian province of NL were utilized for this retrospective cohort study. Study analysis will include individuals diagnosed with a psychotic disorder between April 1st, 2011, to March 31st, 2022, and aged 15-24 who accessed an ED at least once. For this study, schizophrenia

and schizoaffective disorder will be the two psychotic disorders included. Individual diagnoses in the administrative database were identified using ICD-10-CA diagnostic codes. This study has received approval by the Health Research Ethics Authority of Newfoundland and Labrador (HREB #2022.214).

3.2.2 Data Sources

Data relating to ED utilization was collected using the MediTech Data – Emergency Department Module, which contains demographic, clinical, and administrative data, including date and time of arrival and discharge, as well as presenting complaint. The provincial Client Registry (CR) was accessed for demographic information from individuals presenting at a hospital or pharmacy. The Provincial Discharge Abstract Database (PDAD) provided the demographic, clinical, and administrative data of individuals upon discharge from inpatient services or surgical day care services. The Master Geography File (MGF) determined in which of the four regional health authorities (RHAs) an individual resided. This was done by comparing the six-digit postal code to Statistics Canada's standard geographical areas. To determine urban or rural residence, the number character in the first three digits of the postal code was used (Statistics Canada, 2007). Digital Health NL provided the data linkage and created a unique and deidentified patient number to facilitate the linkage of the data from the above databases. Upon receiving the de-identified data, the authors created a single database which included all relevant variables.

3.2.3 Measuring Utilization of Emergency Departments

The difference in monthly utilization of EDs during and before the COVID-19 pandemic was the variable being investigated for this study. For each individual in the study, four means were calculated. The first was the mean monthly visits before the COVID-19 pandemic, which in this study was taken as April 1st, 2011, to December 31st, 2019. The second and third were the mean monthly visits during the first and second years of COVID-19, corresponding to the calendar years of 2020 and 2021 respectively. The fourth was the mean monthly visits during the first three months of the third year of COVID-19, corresponding to 2022, from January 1st to March 31st. To calculate the means, the total number of ED visits was divided by the number of months in the period. This amounted to 105 months in the first period, twelve months in the second and third periods, and three months in the fourth period. All visits to an ED were included in this study to obtain a full understanding of how individuals diagnosed with psychotic disorders utilize EDs in this province.

The independent variables included in the univariate and multivariate analyses consisted of the following: 1) age at diagnosis 2) sex 3) patient regional health authority (RHA), 4) urban or rural residence as determined by Digital Health NL using the MGF and 5) time periods as outlined in the above section.

3.2.4 Statistical Analysis

Descriptive statistics were generated to describe the study population, including counts and proportions, and means and standard deviations (SD) for categorical and continuous variables respectively. Multiple linear regression with Generalized Estimating Equations (GEE) modelling was used to identify the significant factors associated with mean monthly ED visits in both the univariate and multivariate analyses. Autoregression was selected as the working correlation matrix to meet the needs of the longitudinal nature of the study design. All analyses were conducted using SAS 9.4.

3.3 Results

3.3.1 Overview

Between April 1st, 2011, and March 31st, 2022, 125 individuals diagnosed with a psychotic disorder accessed an ED in the province at least once. Out of the 125 individuals, 94 (75.2%) were male 83 (66.4%) resided in urban areas and 66 (52.8%) individuals lived in the Eastern Health RHA. The descriptive statistics in terms of urban residence and percentage living in Eastern Health are consistent with the general population. The individuals in the study had an average age at diagnosis of 20.64 years (SD: 2.40). The mean monthly ED visits before the COVID-19 pandemic was 0.20 (SD: 0.18) rising to 0.30 (SD: 0.47) during the first year of COVID-19 before returning to levels similar to those seen pre-pandemic (see Table 3.1).

Table 3.1: Overview of Individuals in the Study

Variable ($N = 125$)	Descriptives
Sex, N (%)	
Female	31 (24.8%)
Male	94 (75.2%)
RHA, N (%)	
Central	8 (6.4%)
Western	25 (20.0%)
Labrador-Grenfell	26 (20.8%)
Eastern	66 (52.8%)
Urban or Rural Residence, N (%)	
Rural	41 (32.8%)
Urban	83 (66.4%)
Age at Diagnosis, mean (SD)	20.64 (2.40)
Mean Monthly ED Visits, mean (SD)	
Before COVID	0.20 (0.18)
First Year of COVID	0.30 (0.47)
Second Year of COVID	0.23 (0.42)
Third Year of COVID	0.23 (0.66)

Legend:

RHA = regional health authority

ED Visits per Month = Mean number of monthly emergency department visits

SD = standard deviation

First Year = 2020 calendar year

Second Year = 2021 calendar year

Third Year = January 1^{st} to March 31^{st} of 2022

Before Covid = April 1^{st} , 2011, to December 31^{st} , 2019

3.3.2 Effect of COVID-19 on Emergency Department Visits

In the univariate analysis, during the first year of the pandemic, there was a statistically significant increase in the mean monthly number of ED visits over the pre-pandemic figure (B-Coefficient=0.10, p=0.01). The mean monthly number of ED visits then returned to levels similar to the pre-pandemic figure for the rest of the study period. The period variable, however, was not statistically significant (p=0.07). Female sex was significantly associated with an increase in mean monthly ED visits (B-Coefficient=0.27, p<0.01). Residence in a rural area was shown to predict an increase in the mean monthly ED visits (B-Coefficient=0.14, p=0.06), although it is borderline significant. No other variables were significant predictors in the univariate analysis (see Table 3.2).

Table 3.2: Univariate Analyses

Variable	B- Coefficient	Standard Error	p-Value
Sex			
Female	0.27	0.09	<0.01*
Male	0		
Age at Diagnosis	-0.01	0.01	0.58
RHA			
Central	0.14	0.17	0.40
Western	-0.01	0.04	0.84
Labrador-Grenfell	0.17	0.11	0.10
Eastern	0		
Urban or Rural Residence			
Rural	0.14	0.07	0.06
Urban	0		
Mean Monthly ED Visits			
First Year of COVID	0.10	0.04	0.01*
Second Year of COVID	0.03	0.04	0.40
Third Year of COVID	0.03	0.06	0.64
Before COVID	0		

Where * indicates a statistically significant value

Legend:

RHA = regional health authority

ED Visits per Month = Mean number of monthly emergency department visits

First Year = 2020 calendar year

Second Year = 2021 calendar year

Third Year = January 1^{st} to March 31^{st} of 2022

Before Covid = April 1st, 2011, to December 31st, 2019

In the multivariate analysis, the effect of the COVID-19 pandemic on mean monthly ED visits for youth in the study was similar to that shown in the univariate analysis. The increase in ED utilization for the first year of the pandemic was statistically significant (B-Coefficient=0.09, p=0.01), and returned to levels similar to pre-pandemic for the second and third years of the COVID-19 pandemic. Female sex and rural residence also predicted a statistically significant higher mean monthly ED visits (B-Coefficient=0.30, p<0.01; B-Coefficient=0.17, p=0.02). A full description of the results of the multivariate analysis can be found in Table 3.3.

Table 3.3: Multivariate Analyses

Variable	B-Coefficient	Standard Error	p-Value
Sex			
Female	0.30	0.09	< 0.01*
Male	0		
Age at Diagnosis	-0.01	0.01	0.58
Urban or Rural Residence			
Rural	0.17	0.07	0.02*
Urban	0		
Mean Monthly ED Visits			
First Year of COVID	0.09	0.04	0.01*
Second Year of COVID	0.03	0.04	0.39
Third Year of COVID	0.03	0.06	0.66
Before COVID	0		

Where * indicates a statistically significant value.

N.B.: regional health authority was shown not to be significant in predicting mean

monthly emergency department visits and was removed from the multivariate analysis

after all interaction terms were analyzed

Legend:

ED Visits per Month = Mean number of monthly emergency department visits

First Year = 2020 calendar year

Second Year = 2021 calendar year

Third Year = January 1^{st} to March 31^{st} of 2022

Before Covid = April 1^{st} , 2011, to December 31^{st} , 2019

3.4 Discussion

3.4.1 COVID-19 and Emergency Department Visits

This study indicated that the utilization of EDs by those diagnosed with schizophrenia and schizoaffective disorder increased significantly during the first months of the COVID-19 pandemic but then returned to levels similar to pre-pandemic for the rest of the study period. These results are consistent with previous research in other countries (Goldschmidt et al., 2023; Lee et al., 2022; Jagadheesan et al., 2021). However, a decrease was found when examining ED visits for all psychiatric disorders (Gonçalves-Pinho et al., 2021; Joyce et al., 2021; Stroever et al., 2021; Capuzzi et al., 2020). This included research performed in Canada (Kim et al., 2021; Saunders et al., 2021). Research by Stephenson et al. (2023) conducted in Ontario also found that there was significant disruption to all services provided to individuals living with schizophrenia during the pandemic in comparison with pre-pandemic services. This increase in ED utilization was the inverse of what was recorded for ED visits in general during the first year of the pandemic in Canada (Yao et al., 2023; Kwok et al., 2021).

The significant increase in mean monthly ED visits for youth with schizophrenia and schizoaffective disorder demonstrated by this study should be compared to the decrease in ED utilization for all other complaints. This contradiction suggests that those living with severe and persistent psychotic disorders are more vulnerable than those with other types of disorders during a pandemic. It also indicates that vital services for these youth are being compromised, posing serious risks to their recovery and overall health and wellbeing. This has been confirmed in other parts of Canada by the research of Stephenson et

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al. (2023). The idea that those living with severe and persistent psychotic disorders are highly vulnerable to stress is not a new concept. This line of inquiry began with the oftcited work of Zubin and Spring (1977) in the 1970s. In the intervening decades, there has been continued efforts to further examine the correlation between stress and psychosis from a neurobiological perspective (Johannessen & Joa, 2021; Mittal & Walker, 2019). What should also be mentioned here is the decrease of ED utilization after the first year of the pandemic. This is indicative of two factors either separate or in combination: 1) the ability of individuals in the study to adapt to the situation that the pandemic has created, 2) the resumption of services which had been temporarily halted during the first year of the pandemic. Regardless, the sharp increase in utilization during the initial stages of the pandemic is a lesson and a reminder of the effect that this type of crisis has on the most vulnerable in our population.

In addition, this study highlights the role of sex and urbanicity as being factors that predicted increased utilization of EDs during the COVID-19 pandemic. The results of this study are consistent with other research that found females to have had higher utilization rates of EDs than males during the pandemic (Baugh et al., 2021; Solanke et al., 2021; Stroever et al., 2021). This may be attributed to the fact that females were shown to be more often put into the role of caregiver for those diagnosed with the COVID-19 virus (James et al., 2021), raising the stress of individuals and increasing their likelihood of requiring the services of an ED. The risk of increased utilization of EDs in rural areas during the COVID-19 pandemic can be explained by three significant factors. One, rural populations are underserved by medical professionals, with only 12.8% of

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family physicians and 2.2% of specialists serving approximately 18% of Canadians (CIHI, 2023; Statistics Canada, 2022). Two, early intervention services (EIS) in NL are largely available only to urban-dwelling youth and are provided by programs such as the psychosis early intervention and recovery program (Eastern Health, 2023). Three, those living in rural communities are less likely to access medical treatment in general, and when they do their outcomes are poorer (Subedi et al., 2019). When taken together, this creates a situation whereby those living in rural areas must rely on EDs for their critical care.

3.4.2 Study Limitations and Further Research

This study was limited to individuals living in NL who were both diagnosed between ages 15-24 with schizophrenia or schizoaffective disorder and accessed an ED at least once during the study period. This research therefore did not include those who accessed and ED with symptoms of psychosis but without a diagnosis of the above disorders. It also did not include those with a diagnosis that was made before the study period but who accessed an ED. Those who were diagnosed with schizophrenia or schizoaffective disorder after the age of 24 were similarly not included. This population may have a different pattern of utilization for ED. The data provided did not identify the reason for visiting the ED. Only year of visit to an ED was available and not day and month, making analysis of monthly or seasonal trends impossible. Finally, this study was conducted using a study population from NL only. Therefore, generalizing these results to other regions should be done with appropriate caution.

Further research on this topic may be conducted to investigate how the COVID-19 pandemic affected the utilization of youth, specifically those who had pre-existing diagnoses of psychotic disorders. These results may then be compared with individuals who first presented with symptoms of psychosis during the COVID-19 pandemic to find any differences that appear in utilization patterns. Research into trend analysis for the months and seasons during the pandemic may also provide critical information that helps clinicians and policymakers plan the staff and technical resources that will be required to meet the needs of all individuals. This would not be limited to a retrospective analysis of the COVID-19 pandemic. The changing nature of population health is such that new viruses and their subsequent pandemics are a constant possibility and should be prepared for by public health groups. The clade I strain of mpox (previously known as monkeypox) is the most recent virus to gain international attention. In August 2024, it was declared by the World Health Organisation as a public health emergency of international concern (PHAC, 2024).

3.5 Conclusion

This study was conceptualized to investigate how people with diagnosed severe psychotic disorders utilized EDs both before and during the COVID-19 pandemic. The results of this study identified three variables that significantly predicted utilization for youth with severe psychotic disorders accessing EDs before and during the COVID-19 pandemic. First, the utilization of EDs increased significantly during the first year of the pandemic, then returned to levels of utilization similar to those seen pre-pandemic. Second, females were significantly more likely than males to have increased utilization of the EDs during

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the pandemic. Third, rural residence predicted increased utilization of EDs to a level that approached significance. Total utilization of EDs has been shown to have decreased in Canada during the first year of the pandemic (Yao et al., 2023; Kwok et al., 2021). However, those with severe psychotic disorders accessed those services at a time when other Canadians were staying away from hospital EDs. This serves as a reminder of how the most vulnerable and underserved people in our society access care differently from the rest of the population. It is also a reminder that we have a responsibility to provide adequate supports to them so that they are able to have the best possible health outcomes.

<u>Chapter Four - Factors that Affect Pathways to Care for Youth with Psychotic</u> <u>Disorders in Newfoundland and Labrador, Canada</u>

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Co-authorship Statement

As the primary author of this study, Giovannini-Green contributed to the study concept and design, conducted data collection and analysis, drafted the manuscript, and approved the final version. Mugford and Philpott contributed to the study concept and design, provided supervision, reviewed the manuscript, and approved the final version.

Abstract

Background: Youth mental health is becoming an area of concern in Newfoundland and Labrador (NL), with psychotic disorders being some of the most disabling forms of mental illness. However, the pathways to care (PtC) that youth in NL use to access supports for their mental health are not well understood. This research sought to answer three questions: 1) What patterns appear in early symptoms and behaviours of children who will develop a psychotic disorder? 2) What factors affect the treatment and diagnosis of a psychotic disorder from the perspective of clients and families? 3) What are gaps in services provided to clients living with a psychotic disorder in NL and their families?

Methods: This study used a grounded theory approach to conduct semi-structured interviews and focus groups and used purposive sampling to recruit key informants. The study was completed in two phases. In phase one, participants recruited were: 1) clients of mental health services, nineteen years and older, diagnosed with a psychotic disorder between the ages of 15-24, and 2) a close family member most knowledgeable about the client. Phase two of the study involved interviewing caseworkers to add their input to these themes, drawing from their work in the field, and allowing triangulation of the findings.

Results: This study produced three major findings. First, a description of the clients' developmental history and the changes that occurred with the onset of a psychotic disorder. Two, illumination of the challenges clients and family members experienced in getting a diagnosis, managing medications, and receiving adequate support in the community. Third, the study identified gaps in services from the perspectives of clients and family members and reported their recommendations to address the issues. Caseworker participants recognized topics that appeared in client and family member interviews, as well as their recommendations, as consistent with their interactions with clients and family members in their professional practice.

Conclusions: This study used the voices of clients and family members to describe PtC for NL youth living with a psychotic disorder. It is intended as a tool for clinicians, caseworkers, school staff, and policymakers to help develop future policies that improve the lives of this vulnerable population of clients and families, and optimize their futures.

4.1 Introduction

4.1.1 Background

The transition from childhood to adulthood can be difficult even in the most opportune circumstances without the influence of major medical complications. Even with the support of the community, this transition becomes exponentially more difficult when symptoms of psychotic illness appear, causing several symptoms which negatively affect health outcomes. Examining the pathways to care (PtC) that youth and their families use to access diagnosis and treatment has become a formalized area of inquiry. The primary source of data in this research is: 1) clients of mental health services diagnosed with a psychotic illness between the ages of 15-24, and 2) family members of the clients. This necessitates a qualitative approach to the data collection and analysis. Interviews were conducted with both clients and family members to collect experiences and perspectives on their lived experiences with PtC. To help triangulate the data, caseworkers in psychosis management were recruited for focus groups to provide their insights and experiences. What has emerged provides valuable insight into the patterns that form the PtC for this cohort as well as early indicators that could help inform service providers.

<u>4.1.2 Literature Review</u>

A recent study by The Lancet Psychiatry identifies that the burden of mental illness has been rising globally, with some of the highest effects being felt in North America (Kieling, et al. 2022). Each year in Canada, approximately 18% of our population will reach the clinical criteria to be diagnosed with at least one mental illness (Statistics Canada, 2023). In Newfoundland and Labrador (NL), a recent provincial health review (Health Accord NL 2022) reports a rise in concern about mental health, including that of youth. Newfoundlanders and Labradorians must wait on average longer than other Canadians for mental health services. In the 2020 fiscal year, the average wait time for community mental health counselling in NL was 33 days, 11 days longer than the national average. By the 2022 fiscal year, it increased to 67 days, more than double the national average of 31 days (CIHI, 2024^a). These additional days that Newfoundlanders and Labradorians wait without services potentially increase the severity of their symptoms and therefore increase the cost to adequately treat them.

Wait times are particularly problematic for youth transitioning from child to adult health services. The peak age of onset of schizophrenia and related disorders occurs during this transition at approximately 20 years (Solmi et al., 2022). The onset of acute psychosis is often preceded by an early phase of psychosis known as the prodromal phase (Kuharic et al., 2019), usually beginning in adolescence. The onset of the prodromal phase will add additional stressors to youth during an already difficult stage in their development. Symptoms cause distress to both clients and family members including: irritation, anxiety, disturbed sleep, decreased ability to concentrate, withdrawal, academic disruption, and the development of bizarre thoughts and ideas (Tsuda et al., 2022). Stigma, both from others and from themselves, has been shown to delay accessing treatment and prolong the duration of untreated psychosis (Kular et al., 2018). The duration of untreated psychosis (DUP) is accepted as a significant predictor of outcomes for those who experience psychotic episodes (Tiller et al., 2023; O'Connell et al., 2021). This is especially relevant

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in the cases of youth who are exiting the relatively supportive school environment and transitioning from pediatric to adult healthcare.

The effects of these symptoms greatly affect the ability of young people to access help for their mental health. In Canada, only approximately 20-25% of youth will seek out any form of support for their mental health, and when they do it is often from online resources versus health professionals (Stunden et al., 2020; Malla et al., 2016). Canadian research recommends increased mental health services for youth, given the rise in prevalence in recent years (Wiens et al., 2020). In an orchestrated push to understand how health care is sought, the term PtC was formalized in 1993 by Rogler & Cortes, 1993 who defined it as "the sequence of contacts with individuals and organisations 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 of these efforts". PtC are usually conceptualized as two separate but interconnected pathways: the help-seeking pathway by individuals and families, and the referral pathway navigating mental health services (Cabassa et al., 2018). PtC has become a significant area of study to understand the contacts a patient and their families make to access healthcare services, often identifying inequalities that exist in access to those services (Oluwoye et al., 2021; Lilford et al., 2020; Halvorsrud et al., 2018).

4.1.3 Rationale and Research Objective

As healthcare is predominantly the responsibility of the provincial government with the federal government setting guiding principals and providing funding (Government of

Canada, 2024). The PtC for individuals living with psychosis and their families therefore differ across Canada due to diversity in the structure and administration of health care systems (Manns et al., 2024). As far as these authors are aware, this is the first study in NL to: 1) describe patterns of symptoms and behaviours in early childhood and 2) comprehensively describe the gaps in service for this population. Therefore, this research strived to answer the following question: What are patterns in behaviours and experiences that describe the early stages of psychosis? What are the potential factors associated with the diagnosis and treatment of youth with a psychotic disorder in NL? What gaps exist in services for psychosis care in NL?

4.2 Methods

4.2.1 Grounded Theory

Answering these questions required that data be collected from participants to eventually inform a coherent theme which captures the PtC for clients and families in NL. A grounded theory approach was well suited to the inductive logic required in this research. Grounded theory is often used when little is known about this topic of research and when explanatory and descriptive theory is required (Birks & Mills, 2015). Grounded theory refers to both the method of conducting research and the product of the method (Bryant & Charmaz, 2007). Participants are deliberately sought out in a process called purposive sampling (Charmaz & Bryant, 2011), and data is collected and analyzed concurrently in an iterative cycle (Birks & Mills, 2015). Coding in grounded theory is divided into three parts as described by Kelle (2007): open, axial, and selective coding. Open coding breaks interview data into discrete blocks that are then compared to each other. Through the use

of constant analysis, axial coding is then used to create categories from groups of related individual codes. Finally, selective coding is used to define the relationships between these categories, which is grounded in the data and has explanatory power.

4.2.2 Data Collection

The project sought to understand the perspectives of clients and family members as it pertains to receiving a diagnosis and treatment of a psychotic disorder. The methodology employed had to be flexible to accommodate individual insights and perspectives while remaining consistent across interviews. To achieve this, semi-structured interviews and focus groups were selected to gather this data, and purposive sampling was used to recruit key informants.

4.2.3 Study Participants

This study was designed to be completed in two phases. In phase one, participants recruited were: 1) clients of mental health services, nineteen years and older, diagnosed with a psychotic disorder between 15 and 24 years of age, and 2) a close family member who is most knowledgeable about the first participant, usually a parent. An identified weakness of the interview method is that the insights and experiences of only a small portion of the total population can be gathered. In addition, the nature of the population being studied is such that those willing to participate would not include the most vulnerable individuals. To ameliorate this, phase two of the study involved interviewing caseworkers to add their input to these themes, drawing from their work in the field. It should be noted that caseworker input was not meant to confirm the experiences of the

clients and family members but rather to help triangulate and enrich those experiences. This study received ethical approval from the Health Research Ethics Authority of NL (HREB #2022.214).

4.2.4 Recruiting Participants

At the beginning of recruitment, service providers who support clients and/or families likely to meet the criteria were identified and contacted. They were then provided with a study description and participant criteria as well as the principal investigator's contact information. If clients and/or family members in the service provider's practice expressed interest in the study, they contacted the investigator and were presented with an informed consent document for signature. The document clearly explained the study aims, and participant rights, as well as how, where, and how long the data would be stored, as stipulated by university policy. The full consent document for clients and family members can be found in Appendices 3 and 4.

Phase one of the study intended to conduct two separate interviews, first with the client and, with their permission, a follow-up with the family member to form a dyad. The interview with the family member was not to correct or modify the clients' experiences but to gain additional perspectives of client's PtC. Semi-structured interview questions were developed for participants as prompts, allowing them to share their story and share as much information as they were comfortable. Both interviews were designed to last between 45 to 60 minutes. These questions can be found in Appendices 5 and 6.

The recruitment of caseworkers followed a similar process. Caseworkers who were part of the recruitment process in the first phase, as well as others in the field, were individually approached to participate, using a similar consent form found in Appendix 7. Focus groups were designed for small groups of participants and were no more than 50 minutes in length, allowing caseworkers adequate opportunity to speak without taking excessive time from their professional duties. The principal investigator presented a series of eight statements that emerged in phase one for the caseworkers to discuss. These statements can be found in Appendix 8.

4.2.5 Analysis

With participant consent, the interviews and focus groups were recorded using two different sources and then transcribed verbatim using the Otter.ai software. The transcribed document was then checked by the investigator by comparing it with the digital recordings to ensure accuracy. If consent was not received the investigator used jot notes recorded in a Word document.

The coding process for this study was undertaken entirely manually to ensure that the investigator was immersed in the data and attuned to any possible connections that could be developed into an explanatory theory. Phase one and phase two data were analyzed separately until the last stage of coding, with phase one being analyzed first. Clients and family members were viewed as the primary source of data in this study, given their lived experience.

First, open coding was used to break the data into codes. These codes underwent constant comparison with one another within the same interview and between interviews, forming an iterative process. Memoing allowed for impromptu note-taking that documented informal connections and theories that appeared as part of the analysis. Analysis began immediately after the first few interviews, with necessary adaptations being made thereafter. The second step of the analysis involved the consolidation of these individual codes into broader categories using axial coding. Selective coding was used as the final step, where categories identified in both interviews and focus groups were analyzed together. This step defined the relationships that exist between all categories, which established an explanatory narrative grounded in the data.

4.3 Results

4.3.1 Participant Recruitment

The highly vulnerable nature of those living with psychotic disorders presented difficulties in successfully recruiting clients for the study. Several participants initially agreed to be interviewed, but then later withdrew. Recruitment continued for twelve months, during which fifteen interviews were completed: one with a client-parent dyad, three interviews with clients only, and eleven with family members. Early in the interview process, it began to appear that the participants had very similar experiences. After the fifteen interviews were completed, data saturation had been reached. To ensure the privacy of the participants, age and gender were not recorded as part of the study data. Participant characteristics for clients and family members, as well as caseworkers, are described in Tables 4.1 and 4.2.

Participant	Family	Relation	Residence of	Client Diagnosis
		to Client	Client	
Client 1	Family 1	N/A	Urban	St. John's – APD
Family Member 2	Family 2	Parent	Rural	Out of Province
Client 3	Family 3	N/A	Rural then	St. John's – APD
			Urban	
Family Member 3	Family 3	Parent	Rural then	St. John's – APD
			Urban	
Family Member 4	Family 4	Parent	Urban	St. John's – APD
Family Member 5	Family 5	Parent	Urban	St. John's – APD
Client 6	Family 6	N/A	Urban	St. John's – APD
Family Member 7	Family 7	Parent	Urban	St. John's – APD
Family Member 8	Family 8	Relative	Urban	St. John's – APD
Family Member 9	Family 9	Parent	Urban	St. John's – APD
Family Member 10	Family 8	Parent	Urban	St. John's – APD
Family Member 11	Family 10	Relative	Urban	St. John's – CPD
Client 12	Family 11	N/A	Urban	St. John's – APD
Family Member 13	Family 12	Parent	Urban	St. John's – APD
Family Member 14	Family 13	Parent	Urban	St. John's – APD

Table 4.1: Characteristics of Clients and Family Members

Legend:

APD = Adult Psychiatry Department

CPD = Child Psychiatry Department

Table 4.2: Characteristics of Caseworkers

Caseworker	Practice Setting	Scope of Practice
Caseworker 1	Hospital	Older adults
Caseworker 2	Hospital	Clients and families
Caseworker 3	Hospital	Clients and families
Caseworker 4	Community	School-aged children
Caseworker 5	Community	Youth and families
Caseworker 6	Community	Youth and families
Caseworker 7	Community	Adults

4.3.2 Struggles to Gain Access to Health

The dominant theme that emerged from the data was the struggle of clients and their families to gain access to health services. These struggles fell into two major sub-themes: struggles to get information and early assessment during the prodromal stage of psychosis, and struggles to get timely and adequate diagnosis, treatment, and support both in the hospital and the community. As the illness progressed these clients and family members would struggle to differing degrees with these challenges. These sub-themes are elaborated below, including the input of caseworkers.

4.3.3 Struggles During Childhood and the Prodromal Stage of Psychosis

A repeated element across many interviews with family members is their memories of their young child having initially typical development, being sociable, outgoing and active in extracurricular activities. Eight of the thirteen clients showed no signs of struggle until prodromal symptoms first appeared during junior or senior high school, causing the trajectory of their academic route to alter quickly and dramatically. The other five clients had a similar early progression with the exception of some difficulties in concentrating, attention, and performance apparent in early childhood. Of the five clients, three were diagnosed and being treated for ADHD before the end of elementary school. The other two were diagnosed with autism spectrum disorder and dyslexia respectively in early adulthood. Two of the five clients had a full assessment performed by their school and were granted individualized supports and accommodations. As these students moved into the early prodromal stage, they were often labelled as behaviour problems, lazy, or disinterested in school. Eight family members recalled the point where the behaviours of their child caused them to want their child assessed by a health professional, most often the family physician. These interactions were invariably disappointing and frustrating for all involved as the family physician tried various medications to treat more common psychiatric conditions, often ADHD and anxiety. Five family members recalled that clients would take the medications prescribed but quickly discontinued them when they failed to help or when adverse effects developed. These clients then lost faith in the family doctor and refused to return. Three clients also reported this experience. Two clients were referred to a child and adolescent psychiatrist which resulted in a similar experience.

As the prodromal stage of psychosis became more pronounced the clients started to isolate. Family members recalled becoming more and more distressed by the client but `feeling unable to help. This often started their journey of struggling to find information. As one family member stated: "We were often given pamphlets on depression, suicide, mental health services, phone numbers, agencies, organizations, and so on to get a sympathetic ear. That was it, and that was great. That was well-intentioned, it was wellmeaning, but it wasn't what we needed". Meanwhile, clients often struggled to attend school, and six of thirteen left school without graduating. Of those six, three returned as adults to graduate with their high school diploma. One client and two family members of clients recalled the need to enforce school attendance to ensure that the clients graduated. During the school-aged years, clients and family members identified a lack of trained

educational staff to recognize potential psychosis and felt that changes could be made in how services are provided to children, especially streamlining the referral process from schools to the mental health system. They added that there should be a mechanism for clients to self-refer for mental health services.

Substance misuse surfaced as a prominent theme amongst the thirteen families, with participants stressing that the frequency and potency of this use escalated rapidly. Alcohol (eleven out of thirteen) and cannabis (ten out of thirteen) were the most common substances reported as misused, with cocaine (three out of thirteen) also appearing multiple times. Three family members spoke about suspicions that a client was misusing recreational substances but were unable to confirm their suspicions or name specific substances. While substance misuse is not atypical for this age group, what was unique to this group was the dramatic and alarming escalation in usage. The use of cannabis often started slowly and then increased in both frequency and potency until the client was a frequent user of high-potency cannabis. Other recreational substances reported as misused by clients included prescription medications, MDMA, LSD, psilocybin, and heroin. Family members felt that the sudden change in academic progress, coupled with the dramatic escalation of substance misuse, should have been an alarm for schools. They discussed the struggle to have their concerns acknowledged by school staff.

The caseworkers recognized many of these statements made by clients and families as aligning with what they see in their practice. One caseworker spoke specifically about the harm done by labels that a client may receive during the early days of schooling, that being called ungrateful, lazy, or unmotivated creates a label for impressionable children, which they internalize. They report that stigma and "labelling" extends to physicians practicing outside psychiatry. While the caseworkers recognized the prevalence of stigma and discrimination, they felt that it does not prevent clients from seeking treatment. They did identify that community stigma has two major effects on clients and their families. First, clients and families are more isolated, often feeling unable to talk candidly about their struggles with family and friends. Second, there is less understanding and empathy than for those living with physical conditions. This severely limits client and family member access to large advocacy groups with widespread public support.

Caseworkers reported hearing from clients how they lose interest in school because of a lack of ability to focus and engage. Family members voiced concern for the client's struggles with hygiene, cognitive focus, becoming easily agitated, and isolation. Caseworkers also spoke about the efforts families take to get a client assessed by a family physician or other specialists, stressing that many in the province do not have access to a family physician. They recognized that treating youth is a challenging proposition and often takes an extended time, but when misdiagnosed and prescribed ineffective medications, youth become frustrated with both the effects of the medications and the belief that their own concerns are not being taken into consideration. These were reported as major reasons why clients choose to discontinue medications and physician visits, leading to substance misuse. One caseworker, whose main practice is with school-aged children, commented on the quick and dramatic escalation in substance misuse: "everything is on fast-forward" and not only has the rate of misuse increased, but the age

of first use has decreased, often beginning in junior high. Additionally, the substances used by school-aged children are becoming increasingly dangerous, with cocaine and MDMA gaining prevalence, and a smaller but increasing number of youth using LSD and even crack cocaine. Caseworkers expressed the concern that many physicians view substance misuse as a separate issue that must be resolved before a client can be treated for their psychosis, rather than an integrated issue stemming from the psychosis.

4.3.4 Struggles to Get Appropriate Diagnosis and Treatment

By late adolescence, symptoms were so severe that families were much more active in seeking medical support. However, nearly all participants described a long interval between the onset of discernible psychotic symptoms and obtaining a formal diagnosis of a psychotic disorder, often lasting twelve to eighteen months. Most acknowledged that substance misuse complicated this process.

Having a client admitted to an adult psychiatric facility also surfaced in several interviews with family members. They expressed frustration that clients were turned away from the hospital assessment unit without treatment, even when presenting with severe symptoms, often being brought back days later by the police and admitted involuntarily. Several family members reported that their child's first hospitalization resulted in a diagnosis of substance-induced psychosis. The client was then discharged into the care of the family with no further discussion about how the family should proceed to support the client. One family member expressed understanding that psychiatrists are hesitant to diagnose a psychotic illness, but they felt deeply frustrated at being "left out to the wolves after that

first visit". One parent recalled having to "chase around" the staff psychiatrist on their rounds to speak with them after their child was hospitalized. As traumatic as hospitalization can be, family members reported that it was often the only route to the client receiving a diagnosis or treatment.

The services provided by the police and mobile crisis units in dealing with clients also surfaced, with perspectives often differing. Some parents voiced positive experiences and were appreciative of the service, even though they felt an obligation to do the "nasty work" of calling the police when their child became dangerous to themselves or others. Others revealed unresolved frustration at the response of the police, who they felt often lacked sufficient training to handle mental health calls and seldom attempted to deescalate.

Another issue for many family members was that they were excluded from the adult health system, and they were helpless in watching their child struggle without appropriate services. They appreciated the difference between child and adult healthcare systems and the concern for confidentiality and adult autonomy, but felt their inclusion would have expedited the process and lessened their child's struggles. One family member stated that these policies were indeed well-intentioned, but did not consider the realities of a client living with the effects of a psychotic illness. Another family member stated, "I can say with all authority that it's been the hardest thing in the world to try and get him some help". They felt that the health system needs to embrace the family in the decisionmaking process for clients to a greater degree. Family members have knowledge and

insights into client history and symptoms that mental health staff do not possess, which they feel was vital information. As an example, a family history of mood, anxiety, and/or substance use disorders was a recurring topic in interviews, with two families having close relatives diagnosed with a psychotic disorder. Many family members discussed the need for the mental health system to treat the family as a whole, not just the client. Three families were able to either send clients to other provinces in Canada for care or move permanently to other provinces. Participants were unanimous that decreasing the time a client spends in untreated psychosis would improve health outcomes. The system of psychiatric assessment and admission should be altered, with easier access to psychiatric beds and faster access to psychiatrists.

Caseworkers recognized these statements relating to access to services and supports. One caseworker added that often when they first meet their clients in hospital, they do not know why they are inpatients and have not yet been told their diagnosis or have had it accurately explained. Another caseworker stated that the staff in adult psychiatry will not make a diagnosis of a psychotic disorder if the client is under the effects of recreational substances, preferring to offer a diagnosis of substance-induced psychosis. Several caseworkers stated they understood this hesitancy, stressing that clinicians will only diagnose a psychotic disorder when they feel that a client has crossed a clinical threshold, and no other disorder could be responsible. Caseworkers commented on the diversity of family experiences with the psychiatric assessment units and crisis response teams, particularly with getting support at the assessment unit. They stated that the mobile crisis response teams units are effective but say that the criteria for detaining clients under the

Mental Health Act are so stringent that police seldom use it as a means of detaining a client. This results in family members having to decide if they wish to have a client released immediately back into their care or detained on criminal charges.

4.3.5 Struggles with Medication Management

In addition to struggles with ineffective medications before diagnosis, struggles with accessing appropriate medications post-diagnosis surfaced. These struggles can be divided into three sources: getting a medication adjusted, getting a prescription filled, and experiencing adverse side effects. First, participants identified an issue in getting an appointment with their psychiatrist to review their medications. Family physicians stated that psychosis management was out of their scope of practice, yet getting an appointment with a psychiatrist was challenging. This was exacerbated by the reality that it often requires several changes in medication to find the appropriate medication and dose to manage the client's symptoms. During this wait time, clients and family members had to deal with the adverse effects of the medications. Families living in rural areas were particularly affected by this, where wait times to see a psychiatrist can exceed six months.

Second, once a medication is prescribed, there can be challenges in getting it filled. Clients who live in rural areas reported delays in getting their vital medications shipped to their local pharmacies. Insurance coverage for medications, including the provincial drug plan, also surfaced. Several participants discovered that their insurance would not cover the prescription, leaving them the choice of paying themselves or risking a relapse, especially for prescriptions of long-acting injectable (LAI) medications, often prescribed

by psychiatrists when a client has difficulty taking oral medications daily. Another issue reported was the stipulation that two antipsychotic prescriptions could not be covered at once. Family members described these issues as being exceptionally frustrating to watch and a major obstacle to stabilization.

Third, the adverse effects of antipsychotic medications surfaced, especially heavy sedation and conspicuous weight gain. Other adverse effects included vomiting, heart issues, and difficulty urinating. The feeling of being overly sedated was often named as a reason for discontinuing antipsychotics in favour of attempting to self-medicate with recreational substances. Family members reported worrying about how heavy sedation affected clients and their ability to be employed. One parent worried that her child's sedation was so severe that he might not wake up if his smoke detector activated during the night. Another parent living in a rural area of the province explained the difficulty of finding health specialists in their area to address the adverse effects caused by the medication.

The complications of accessing appropriate medications, adverse effects, and their resultant impact on chronic substance misuse were recognized by the caseworkers. They identified these issues as a leading cause of relapse in substance misuse, with clients struggling with compliance and returning to using substances after they were unable to tolerate antipsychotics. They added that difficulties in having prescribed medications covered by the provincial drug program is a widespread issue that has a disproportionate impact on these clients.

4.3.6 Struggles with Family Relationships

The relationship between family members and clients repeatedly surfaced as a topic throughout the interviews. All participants were in various stages of the journey through a psychotic illness, with some families having a member with a new diagnosis, while others were diagnosed many years ago. Family members often spoke positively of finding a peer support network with specific experience in supporting clients with psychotic illness and their families. They credited these groups with giving them the tools to better understand client behaviours and constructively interact with them. Despite this, many family members reported struggling in their relationships with clients. An absence of the client having a clear understanding of their symptoms or acceptance that their behaviours and beliefs were out of the ordinary seemed to fuel this. Client anger and frustration directed at family members for their hospitalization was also common. These emotions would often resolve, but in other cases, the client remained upset and mistrustful of the family members.

Many families discussed their own journey as their child progressed through their illness. Two elements of these conversations appeared across many interviews. The first was the independent search for information on schizophrenia and related disorders as well as available treatment methods. Family members identified a lack of accurate general knowledge about psychosis and psychotic illness in the general public. Many recalled that the media was often the only source of information they had. The second element was a kind of grieving process that was carefully described by many family members. Family members would often fondly recall how a client presented during their childhood in comparison to how they presented as adults. Their emotions stemmed from the acceptance process and the slow realization that their child's life would be different than envisioned.

Interviews with three family members discussed the involvement of the client with the criminal justice system. Family members commented on the prevalence of severe and persistent mental health issues in the criminal justice system, feeling that they would be better treated by the mental health system. A criminal record was discussed as a point of trauma for the clients attempting to reintegrate into society with the added stigma of criminality. Those families voiced a need for trauma support in coping with their experiences with the justice system.

Caseworkers recognized the strain put on family relationships when a child has a psychotic illness. One caseworker specifically commented on how parents often would recount in detail how different their children were before the onset of psychotic symptoms. The difficulty family members have in convincing their loved one to seek professional mental health care was identified by several caseworkers as a significant stressor. One caseworker also stated that several clients she supported opted for the criminal courts rather than the mental health courts to avoid being officially labelled with a psychotic illness.

4.3.7 Struggles with Community Supports

Accessing community supports and services was another prominent topic, especially in rural areas. A parent living in a rural area expressed deep frustration that services for their family member were only available in the city, resulting in them having to stay in the city. Housing was a gap that surfaced with several families, with periods of homelessness being common for many clients. Relapses and hospitalizations often caused housing instability, and several participants reported that landlords discriminate against clients with psychotic illness. Discrimination continued to be a subject of many conversations, extending to employment. Clients and families reported striving toward steady employment as a symbol of client independence. Family members often reported worrying that employers would not hire a client with a psychotic illness.

Another break in services was access to appropriate mental health counselling. Family members reported that hospitals discharged clients as quickly as possible, regardless of whether counselling supports were in place or if they had other services or supports to help with reintegration into the community. Family members often discussed struggles with the community-based teams dealing with clients living with psychosis, describing those teams as focused solely on ensuring a client is taking their medications regularly and not a threat to themselves or others. Other areas of required services included applying for employment insurance and returning to post-secondary education. Existing services in the community were described by one family as being "dots" of support, disconnected and often difficult to access. Multiple family members called for an

overarching organization to coordinate services in consultation with the mental health system to prevent the struggle with access.

Caseworkers recognized these gaps in service as congruous with their caseloads. They called for psychiatric assessment units to create a wraparound service to provide community-based treatment plans for individuals experiencing distress. Caseworkers also spoke about their efforts to stop evictions as well as the isolation and loneliness observed in clients, especially among older clients, resulting in an increased risk of substance misuse and suicide. Multiple caseworkers spoke about the need for enough resources to meet demand, as well as a single organization to coordinate programs. One caseworker mentioned that those with severe and persistent mental illness and little community supports often prefer to stay in a psychiatric hospital where they feel safer and have less judgment.

4.4 Discussion

4.4.1 Identifying Emerging Patterns in Early Childhood and the Psychosis Prodrome

Specific symptoms predicting clinical high risk (CHR) for psychosis are well studied and include attenuated psychotic symptoms, presence of psychological stressors, family history of a psychotic disorder, and male sex (Fernández et al., 2023; Catalan et al. 2021; Montemagni et al., 2020). Research is now examining the area of brain imaging and proteins found in blood samples as methods for the early diagnosis of psychotic illness (Zhang et al., 2023; Caballero et al., 2023). While this is exciting, there will be a waiting period before this knowledge may be translated into clinical practice. Additionally, the heterogeneity of individuals in terms of clinical presentations and biomarkers complicates the research being conducted (Palaniyappan, 2023).

Early recognition of youth who are at a clinical high risk (CHR) for a psychotic illness is vital. While only a portion of youth with CHR status will progress to being diagnosed with a psychotic disorder, those who are not diagnosed will continue struggling with mental illness for years into adulthood (Moran, 2024). This research project describes the trajectory that clients and family members travel on their journeys after the symptoms of psychosis appear. It also details the struggles they must contend with in accessing treatment.

4.4.2 Identifying Gaps in Services for Psychotic Illness

The third focus of this research was to identify gaps in services. Three distinct areas emerged: schools' awareness of psychosis and ability to identify warning signs, the mental healthcare system's ability to provide timely and effective treatment, and community supports. Identified gaps in supports and the suggestions provided by the participants were often in line with existent literature. Participants consistently described gaps across multiple services including education, healthcare, pharmacy, justice, housing, and social services. It named a need for a system of early alarms, especially when the apparent trajectory of a youth's life shifts and is coupled with substance misuse. The literature in education identifies these roles as being essential in fostering student well-being (Dalbosco & Sudbrack, 2021; Hoover & Bostic, 2021, O'Reilly et al., 2018).

The involvement of family members in diagnosis has also emerged in research (Catalan et al. 2021), specifically that it increases the accuracy and speed of diagnosis. Finland's open dialogue approach emphasizes a flexible strategy that incorporates several vital elements: a rapid response to acute psychosis, family-centred therapy as well as individual therapy, and interactions between the treatment team, the client and their entire social network (Lakeman, 2014). Research is ongoing on how this approach can be adapted to other settings (Cotes et al., 2023; Pilling et al., 2022). A similar approach to management is the wraparound care model pioneered in the 1980s by Stroul & Friedman (1986) and still used today to support youth with complex needs (Olson et al., 2021; Schurer Coldiron et al., 2017). Finally, financial losses caused by psychosis can be costly, with a client's first year after diagnosis costing hospitals 24,000 US dollars on average (de Oliveira & Tanner, 2024). Community-based supports such as those for employment and housing are not included in this number. These indirect costs can account for up to 70 percent of the total financial losses inflicted by psychotic illnesses (Mayoral-van Son et al., 2019).

4.4.3 Study Strengths and Limitations and Possibilities for Future Research

The voices of this cohort of participants offer a unique look into the lived experience of clients and family members, along with the additional insights of caseworkers. While the more vulnerable and stigmatized clients were excluded, the perspectives of case workers helped to triangulate the emergent themes against a much larger client base, over time and geography. The information presented in this study relates only to the province of NL.

Future studies comparing the lived experiences of clients and family members across other regions would be a valuable addition to the literature.

4.4.4 Implications on Practice

The results of this study have implications for clinicians, caseworkers, school staff, and policymakers. The research described here serves four important purposes. First, it gives an insight into the beginning stages of psychosis as it appears in youth and how the illness progresses into adolescence and adulthood. Second, it equips those interacting with clients and family members with the knowledge to be able to recognize patterns of symptoms, behaviours, and access-seeking that may predict the onset of psychosis, and to provide appropriate supports. Third, it identified gaps in services as experienced by clients and family members. Fourth, this study presents recommendations of those with lived experience and their caseworkers on how the current system can be changed to improve services and increase the likelihood of positive health outcomes. Policymakers and clinicians can refer to the existing framework laid out by Early Psychosis Intervention (2025) for a comprehensive guideline as to how early psychosis intervention services can be structured.

4.5 Conclusions

Psychosis and psychotic disorders are a devastating reality for clients and family members. The stigma attached to psychosis and psychotic disorders has meant that for many, they are unable to get the support that they require to face the consequences that come with a severe and persistent mental illness. This study is an examination of the pathways that clients and family members pursue to gain access to information, diagnosis, and treatment. It adds the experiences and knowledge of caseworkers to enrich those experiences, offering insight into the experiences of highly vulnerable clients and their families. It is presented as a tool to guide clinicians, caseworkers, school staff, and policymakers. Its purpose is to improve the services provided to clients and families and optimize their futures.

Chapter Five - Discussion and Conclusion

5.1 Summary of Research

This research examined the factors associated with pathways to care (PtC) for youth in the Canadian province of Newfoundland and Labrador (NL) receiving diagnosis and treatment for a psychotic illness. Mental health has emerged as an area of concern in NL (Health Accord NL, 2022). Youth mental health in particular is identified as a concern across Canada, with many not accessing the care they need (Stunden et al., 2020). The transition process that youth experience as they move from child to adult services corresponds with the peak onset of schizophrenia and its related disorders, at approximately 20 years of age (Solmi et al., 2022). Across Canada, youth receive treatment from early intervention services (EIS) for psychotic symptoms which have been shown to improve healthcare outcomes and reduce the financial costs of illness (Tarride et al., 2022). However, a study by Bertulies-Esposito et al. (2020) found that most EIS deviated from official guidelines regarding services provided with rurally located EIS struggling to meet staffing quotas. The literature has established that individuals with schizophrenia and its related disorders often access emergency departments (EDs) to access care (Lawrence and Bernstein, 2024). Youth with mental health issues in Canada are particularly high users of EDs, with those 20-29 spending longer in an ED for mental health-related visits than any other age group (CIHI, 2019).

This study employed both quantitative and qualitative methodologies to allow for a more comprehensive understanding of the ways youth in NL access care for a psychotic illness.

The primary research question was: what are identifiable factors affecting the diagnosis and treatment of psychotic illness in NL youth? The quantitative research studies focused on NL healthcare databases and analyzed (ED) utilization data using linear regression modelling. These studies examined the role of urban versus rural environments and the COVID-19 pandemic in affecting PtC. These studies addressed the following questions: 1) What variables affect the utilization of services for youth with psychotic illness in urban and rural areas of NL? 2) Is there a discernable and significant pattern in the variables? 3) Was there an effect on the data associated with the COVID-19 pandemic?

The qualitative research study used a grounded theory approach to interpret data gathered from interviews with clients of mental health services and family members as well as focus groups with caseworkers. This study addressed the following research questions: 1) What patterns appear in early symptoms and behaviours of children who will develop a psychotic illness? 2) What factors affect the treatment and diagnosis of a psychotic illness from the perspective of clients and families? 3) What are the gaps in services provided to clients living with a psychotic illness in NL and their families?

This chapter will first outline the key findings of the three studies and then discuss how the findings answered the research questions posed. It will then identify the strengths and limitations of the studies as well as their significance to the literature and implications for clinicians and policymakers.

5.2 Summary of Results

The first two studies of this dissertation used quantitative analysis to examine factors associated with how youth with a psychotic disorder access care in NL. Study one examined the differences in the average monthly utilization of EDs for urban and rural-dwelling youth living with a psychotic disorder from April 1st, 2011, to March 31st, 2022, in NL provincial databases. The average monthly ED utilization was found to be 0.21, indicating that this population made an ED visit every five months during the study period. The multivariate analyses showed that rural residence and female sex were significantly associated with increased utilization of EDs (p<0.05, and p<0.01, respectively) after controlling for other potential confounders.

Study two examined potential differences in the average monthly ED utilization in youth with a psychotic disorder before and during the COVID-19 pandemic. These two periods were designated as April 1st, 2011, to December 31st, 2019, and January 1st, 2020, to March 31st, 2022, respectively. The multivariate analysis showed the average monthly utilization of EDs rose significantly during the first year of the COVID-19 pandemic (0.20 to 0.30) and then returned to a level similar to what was observed pre-pandemic (0.23). This trend was observed in both the univariate and multivariate analysis (p=0.01 for both). Female sex was associated with increased ED utilization overall in both the univariate and multivariate analysis (p=0.02)

Study three employed qualitative methodology to examine the lived experiences of both clients living with psychotic illness and their family members, as well as the perspectives of caseworkers. This study used a grounded theory approach to conduct the study in two phases. First, participants were recruited for in-depth interviews. Participants in this phase were: 1) clients of mental health services nineteen years and older diagnosed with a psychotic disorder between fifteen and twenty-four years of age, 2) a close family member who is most knowledgeable about the first participant, usually a parent. The second phase of the study recruited caseworkers whose work involved providing service to clients experiencing psychotic illness and their families. These caseworkers were presented with statements of themes taken from the interviews and their reflections and perspectives were recorded.

Four clients and eleven family members participants completed in-depth interviews, representing thirteen clients and their families. Seven caseworkers were also recruited to participate in the study. What emerged was a description of the client's developmental history and the changes that occurred with the onset of the prodromal stage of illness. The study continued to describe the challenges clients and family members experienced in getting a diagnosis, managing medications, and receiving adequate support in the community. Those participants living in rural areas of the province spoke of the increased challenges presented in getting access to services where they live. Finally, the study identified gaps in services experienced by clients and family members in the ways they are diagnosed, manage medications, and are supported in the community. Caseworker

participants recognized topics that appeared in client and family member interviews as being consistent with their experiences with clients and family members in their practice.

5.3 Discussion

5.3.1 Identifying Early Factors, Patterns, Prodromal Phase

The qualitative study in this research used in-depth interviews with clients and family members, with input from caseworkers to triangulate and enrich these experiences. Part of the scope of this research was to identify patterns of early behaviours that preceded the onset of acute psychosis, causing a deterioration in client functioning. Five clients in the study showed early deficits in attention and performance in school that appeared before the onset of acute symptoms. Three of these were diagnosed and being treated for ADHD from an early age, the other two were diagnosed in early adulthood with autism spectrum disorder (ASD) and dyslexia, respectively. These results support research in the literature arguing that schizophrenia is a neurodevelopmental disorder causing cognitive impairments (Sheffield et al., 2018) that is affected by genetic and environmental factors that overlap with other neurodevelopmental disorders such as ADHD and ASD (Schmitt et al., 2023).

Despite apparent typical early developmental trajectories, beginning in late junior high to high school all clients began showing signs of disinterest in schoolwork and were often labelled as lazy or inattentive. This led to their struggling in school and sometimes leaving school altogether. This trajectory is consistent with research previously conducted elsewhere (Green et al., 2018). Family members then described a pattern of social withdrawal, disturbed sleep patterns, and the development of bizarre ideas. These symptoms are consistent with the prodromal phase of psychosis (Tsuda et al., 2022). The prodromal phase of psychosis is defined as the phase of illness in which youth present attenuated or intermittent symptoms of the disorder, which do not meet the diagnostic criteria (Althwanay et al., 2020; Gonçalves et al., 2018).

Family member interviews confirmed this pattern of a sudden change in their apparent trajectory with escalating behaviours in the client that led to the family member taking the client to a physician for assessment. These were often the family physician but in the case of two clients, a referral was made to a child psychiatrist. The physician would assess the child and make a diagnosis of either ADHD or an anxiety disorder, then prescribe medications for the client. The client would at first be compliant with the treatment but when there was no improvement in symptoms and/or adverse effects began to appear, the client would discontinue the medication and refuse to return to the physician's office. Clients then began using recreational substances with increasing frequency and of increasing potency in an attempt to self-medicate, with alcohol and marijuana being the most common. This pattern is consistent with research conducted in other parts of Canada (Malla et al., 2018).

The lack of knowledge of staff in schools to recognize early signs of psychosis and offer timely and appropriate interventions appeared consistently in family member interviews as an identified gap in service. Research in education has produced a body of literature that identifies the ability to provide early identification and support as vital to ensuring student well-being (Dalbosco & Sudbrack, 2021; Hoover & Bostic, 2021; O'Reilly et al., 2018). This stance is in line with the medical literature, which emphasizes shortening the duration of untreated psychosis (DUP) as a key principle (Oliver et al., 2018). This is due to research indicating that this approach positively affects long-term health outcomes for these individuals (Tiller et al., 2023; O'Connell et al., 2021).

5.3.2 Effects of Rural Residence on Access to Care

This research identified a significant gap in services for rural-dwelling youth living with a psychotic disorder. Study results indicate that rural residence was significantly associated with increased utilization of EDs for youth diagnosed with a psychotic disorder. These results indicate a fragility in the healthcare services that are available to rural-dwelling youth, where the ED was the only healthcare service available to provide treatment. The in-depth interviews from the qualitative study of clients and family members also showed that participants experienced a significant disadvantage if they lived in a rural area of NL. Participants identified this increased difficulty in accessing healthcare as detrimental to client well-being. Participants from rural areas discussed difficulties in receiving basic psychosis management since family physicians often refused to take patients with a psychotic illness and the wait times to see a psychiatrist often exceeded six months. Participants in urban areas, by comparison, frequently mentioned the services they were able to take advantage of such as the psychosis early intervention and early recovery (PIER) program. In addition, nearly all clients represented in the study required their medications to be changed due to adverse effects. The long wait for an appointment with

a psychiatrist forced the client to decide either to continue with the dose causing the effects or risk stopping the medication altogether.

These findings are consistent with the findings of previous research. A Quebec study by Berutlies-Esposito (2020) found that rural areas of that province struggled to find staff to provide early intervention services for youth with psychosis. This reliance on EDs in rural areas is also seen elsewhere in the world. A study by Greenwood-Ericksen et al. (2019) from the United States found that the utilization of rural EDs increased by over 50% during the 12-year study period and rapidly outpaced ED utilization in urban areas. A major contributing factor to the reliance of rural-dwelling youth on EDs is the dearth of healthcare professionals to provide adequate care. In Canada, only 12.8% of family physicians and 2.2% of specialists serve the roughly 18% of Canadians who live in rural areas (CIHI, 2023; Statistics Canada, 2022). This distribution of physicians does not necessarily ensure adequate care is being provided to rural areas. Those living in rural areas are shown to have poorer health outcomes in general compared to those who live in urban areas where healthcare services are more plentiful and accessible (Subedi et al., 2019).

5.3.3 Variables Identified in the Quantitative Studies

The second quantitative study of this dissertation identified a gap in services provided to women living with a psychotic disorder. Female sex emerged as a variable associated with increased ED utilization for youth with a psychotic disorder in both quantitative studies. Given the difference in research questions, these results provide distinct insights into how the experience of psychotic illness may differ by sex. The results from the first study concerning sex indicate that female sex is significantly associated with ED utilization showing an increase of 0.13 over males. Two factors may contribute to this: 1) psychotic disorders are seen slightly less frequently in females, and 2) males and females have different presentations of psychotic illness with symptoms that may require an ED visit (Giordano et al., 2021; Reininghaus et al., 2019). The second study shows that the COVID-19 pandemic affected female ED utilization more than male utilization with a 0.30 increase in female utilization over male utilization found during the study period. Females were found by previous research to be more likely than men to be placed in caregiver roles during the pandemic (James et al., 2021), increasing stress levels and increasing the risk of requiring ED services. These results bring attention to the need for clinicians to appreciate and adjust their care based on the individual characteristics of their patients.

The second quantitative study of this dissertation focused on the effect of the COVID-19 pandemic on the ED utilization of youth diagnosed with a psychotic disorder. Results indicated the utilization of EDs increased significantly during the first year of the pandemic before returning to levels similar to those seen pre-pandemic. Previous studies conducted outside of Canada found similar results (Goldschmidt et al., 2023; Lee et al., 2022; Jagadheesan et al., 2021). These results become more interesting when compared with the ED utilization of those with any type of psychiatric disorder. Both outside Canada (Gonçalves-Pinho et al., 2021; Joyce et al., 2021; Stroever et al., 2021) and within Canada (Kim et al., 2021; Saunders et al., 2021), ED utilization showed the opposite

pattern, first decreasing and then returning to normal. Studies conducted elsewhere in Canada also confirm that this pattern of decreasing ED utilization during the first months of COVID-19 and then a return to normal is seen in the way the general populace accessed EDs during the pandemic (Kim et al., 2021; Saunders et al., 2021). This study identified a gap in services that were provided to those with a psychotic disorder during a major public health crisis. Special consideration is therefore required by clinicians and policymakers to ensure that the appropriate supports are in place for this vulnerable population for any future public health emergencies.

5.3.4 Factors Identified by the Qualitative Study as Affecting Care

The overriding theme of the qualitative study identified by clients and family members and enriched by caseworker input was a struggle to access care. This section will discuss the specific gaps in service described by clients, family members, and caseworkers as affecting care.

The road to a formal diagnosis of a psychotic disorder was often long and arduous. The client would often first be diagnosed with a substance-induced psychosis and be discharged shortly after into the care of the family. These experiences were recognized and confirmed by the caseworkers. They also align with a perennial clinical dilemma discussed in the literature around psychosis which identifies the struggle in differentiating substance-induced psychosis from a psychotic disorder (Fiorentini et al., 2021). However, due to the lack of supports existing outside the hospital setting, family members often found it difficult to provide adequate care for the client. They also stated deep

frustration that the hospital inpatient setting proved to be often the only way that the client was diagnosed. Family members estimated that the total time between the client showing the first signs of acute psychotic symptoms, and a diagnosis of a psychotic disorder was between eighteen and twenty-four months. This is considerably longer than the twelve-week DUP recommended by the World Health Organisation and the Internation Early Psychosis Associated and subsequently validated by Dama et al. (2019).

Family members repeatedly shared a deep frustration at how little they were permitted to be a part of the care of their loved ones. Caseworkers also confirmed that many family members struggle with a feeling of powerlessness when trying to support a client. Family members often stated that their unique perspective on the client makes them a vital part of the care team and that their inclusion would increase the likelihood of positive health outcomes for clients. This is consistent with research by Catalan et al. (2021) who found that family member involvement in patient treatment increased the speed and accuracy of diagnosis. Integrating family members into patient care is one of the key features of the open dialogue (OD) approach started in Finland (Bergström et al., 2018). The OD method emphasizes several vital elements which must be combined to provide flexible support to an individual: a rapid response to acute psychosis, family-centred therapy as well as individual therapy, and interactions between the treatment team, the client and their entire social network (Lakeman, 2014). The approach has gained attention across much of the world and research examining its effectiveness and feasibility of its use elsewhere is ongoing (Cotes et al., 2023; Pilling et al., 2022).
The adverse effects of the antipsychotic medication used to treat psychotic disorders were a major topic of conversation in interviews with both clients and family members. The adverse effect most commonly described by both clients and family members and found to be the most debilitating was severe sedation. Both clients and family members identified that the sedation caused by antipsychotics can be severe enough to significantly interfere with daily activities. Weight gain as a source of client discomfort was also mentioned by both clients and family members. These participant experiences are consistent with adverse effects as described in the literature (Kaar et al., 2020). Caseworkers identified this issue as a common struggle faced by many clients and their families. They also stated that these adverse effects increase the risk of the client discontinuing the medication and instead self-medicating with recreational substances. The existing research confirms the commonality of comorbid substance use disorders and psychotic disorders and the prevalence of self-medication to treat symptoms among psychiatric patients (Broman et al., 2019; Khokar et al., 2018). This research is, however, inconclusive about the precise mechanisms that underlie the relationship between psychosis and substance use (Khokar et al., 2018).

Interviews with family members often included detailed descriptions of how relationships with the client were permanently changed by their diagnosis. Family members described a sort of grieving process whereby they had to come to grips with the reality that the client's diagnosis meant that their life would be very different from what had previously been imagined. Family members also described strain on their relationship with the client due to client symptoms, which often included poor judgment and self-awareness, leading to the refusal of their medications. Family members reported that this non-compliance with medication often led to substance misuse and interactions with police and the criminal justice system, making stable housing and employment a significant challenge. The call for a unified mental health service that provided a single service point for client needs was a recurring topic in interviews with both family members and caseworkers.

Family members reported significant stress and psychological burden as a result of their role as caregivers. Family members also struggled with understanding what was happening to the client and with understanding the ramifications of the diagnosis. They stated that before the client's diagnosis, they did not know what a psychotic disorder entailed, aside from the dramatized and inaccurate portrayals common in entertainment media. Family members described an independent journey of finding resources that helped them understand the client's symptoms and identify community support groups. These experiences are consistent with research which found high levels of psychosocial burden in close family members of individuals with psychotic disorders (Caqueo-Urízar et al., 2017). Lack of understanding of client symptoms by family members and the refusal of the client to take medication have been identified as the most common reasons for conflict within families (Wan & Wong, 2019).

5.4 Strengths and Limitations of the Research

A strength of this study is the use of both quantitative and qualitative methodologies to examine the research questions. This expanded the type of data that could be collected, adding texture, context and outcome to the profile that emerged. It also allowed for the comparison of results from these two types of studies to identify commonalities. In the qualitative study, the in-depth interviews of fifteen clients and family members, enriched by the input of seven caseworkers, provided insight into how individuals in NL living with a psychotic disorder as well as their families began their journey with the early phases of the illness and how that journey progressed. The use of linear regression analysis in the quantitative studies allowed for the identification of individual variables relating to ED utilization, the analysis of their contribution in the multivariate analyses, and the identification of any possible interactions. The use of GEE modelling in study two allowed for the longitudinal study of average monthly ED utilization across the study period. Finally, examining all ED visits made during the study period by this population at not only mental health visits produced a more comprehensive understanding of ED utilization.

This research was limited by the fact that all participants in the qualitative study and all data from healthcare databases are located in NL. A second limitation was the data set used. NL Health Services continues to phase in electronic medical records resulting in incomplete and limited data available for a large-scale study. For example, only the year of an ED visit was available not day and month, making an analysis of monthly or seasonal trends difficult. The analysis was limited to those who were both diagnosed with schizophrenia or schizoaffective disorder between ages 15-24 and had at least one ED visit during the study period. Individuals who only met one of those two criteria were therefore excluded from the study. Furthermore, given that this research specifically examines psychotic disorders in youth, only those aged 15-24 at the time of their

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diagnosis were included in this study. Those receiving a diagnosis later in their life may show different patterns of utilization for ED visits. As these databases expand future studies will be able to take advantage of advancements in data management.

For the qualitative study, those who are most vulnerable and stigmatized by their illness as well as their family members were unlikely to agree to participate in this research. Their experiences, therefore, could not be recorded and incorporated into the research. Finally, the findings of this research were the result of data obtained and analyzed from the province of NL only. Given the difference in healthcare services and organizations in other regions, care should be taken when generalizing the results reported in this research.

5.5 Impact of the Research and Future Research Possibilities

This research provides a unique way to understand the experiences of those in NL living with a psychotic disorder, as well as their family members. The combination of methodologies provides a rich and textured interpretation of the experiences of these people that relates personal stories, identifies patterns of symptoms of behaviours, and uses statistical modelling to identify factors that indicate the onset of psychosis and affect PtC. The quantitative and qualitative results of this study also identified significant gaps in service that affect the PtC for both clients and their families.

Future studies in this area could benefit from the involvement of clinicians and caseworkers specializing in working with highly vulnerable youth and their families. A particularly useful line of inquiry could be addressing the challenges of differential diagnosis for this cohort, especially since substance misuse so often clouds clinical assessment. Professionals working in clinical settings may be able to interview vulnerable clients who would otherwise be difficult to reach. Advances in data collection and storage in the provincial health database would also facilitate research that addresses the limitations of the research discussed above. Research in trend analysis examining month and season would be an interesting and useful avenue of enquiry, particularly relating to the years of the COVID-19 pandemic. Other areas for research include an investigation into how total service utilization differs in rural versus urban populations of clients with a psychotic disorder. Finally, further research is required to gain a comprehensive understanding of how differences in sex and gender affect the symptoms presentation and treatment of psychotic disorders.

5.6 Impact on Practitioners and Policymakers

These findings offer implications for school staff, clinicians, caseworkers (in hospital and community settings), and policymakers. It could serve several important purposes. It describes the beginning of a psychotic disorder as it appears in youth, and how the illness progresses into adolescence and adulthood. It also equips professionals interacting with clients and family members with the knowledge to recognize early patterns of symptoms, behaviours, and access-seeking that predict the onset of psychosis and access to appropriate supports. Early Psychosis Interventions (2025) can be used as a source of referral for practitioners and policymakers as a starting point for improvements to existing services.

This research also identified specific gaps in services as experienced by clients and family members and reported by caseworkers. The suggestions of family members and caseworkers as to how these gaps can be addressed can also serve as a groundwork for creating future policies. It also identified how clients with psychotic disorders access PtC during a public health emergency and how this pattern of access-seeking differed from the general population. These results, therefore, contain information that is of importance to both clinicians and policymakers and do not merely constitute a retrospective analysis of the COVID-19 pandemic. The changing nature of population health ensures that novel viruses and their subsequent pandemics are a constant possibility and should be prepared for by public health authorities and frontline hospital workers alike.

5.7 Conclusion

A psychotic disorder is a chronic condition that affects all aspects of a youth's life. The severity of impairment caused by this illness often requires a family member to assume the role of caregiver. This research used both quantitative and qualitative methods to identify factors that are associated with the way youth with psychotic disorders are diagnosed and treated in Newfoundland and Labrador. The results also identified existing gaps in services for this population and reported the recommendations of family members and caseworkers as to how these gaps in service may be addressed. Multivariate linear regression analysis of healthcare data allowed for the identification of additional variables that affect the PtC those diagnosed with a psychotic disorder use to access care. These results include the analysis of how the utilization of services by those with a psychotic disorder changed during the COVID-19 pandemic, which differed significantly from that

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of the general population. This research is intended to provide educational workers, clinicians, caseworkers, and policymakers with additional knowledge to continue to improve services for a highly vulnerable and marginalized group in our province.

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Appendix 1 – Most Recent HREA Approval Document (March 28th, 2024)

Researcher Portal File #: 20231128

Dear Mr. Zachary Giovannini-Green:

This e-mail is to inform you that your amendment event – Event No. 641555 - for study HREB # 2022.214 – Identification of Variables Associated with Time to Treatment in Youth with Psychotic Disorders - was reviewed by the Chair and has been approved and/or acknowledged (as indicated in the Researcher Portal). You may view this decision by logging into the Researcher Portal.

It is your responsibility to seek the necessary organizational approval from the Regional Health Authority (RHA) or other organization as appropriate. You can refer to the HREA website for further guidance on organizational approvals.

Thank you,

Research Ethics Office Health Research Ethics Authority 760 Topsail Road Mount Pearl, NL A1N 3J5 (e) <u>info@hrea.ca</u> (t) 709-864-8871 (f) 709-864-8870 (w) <u>www.hrea.ca</u>

Appendix 2 – Digital Health NL/NLCHI Approval Letter



August 23rd, 2023

Zachary Giovannini-Green Faculty of Medicine Memorial University 300 Prince Philip Drive, St. John's NL A1B 3V6 Dear Mr. Giovannini-Green: RE: Identification of Variables Associated with Time to Treatment in Youth with Psychotic Disorders Our Reference *IN13921*

This is to advise you that the chair of the Centre's Secondary Uses Committee has reviewed your application to request Record-Level Information for Secondary Use. Having consulted with the chair, I authorize the disclosure of the requested data.

The approval of your application and use of the requested data is conditional upon the following:

- The data accessed must be used only for the purposes of this request. Future uses and/or disclosures of the data collected must have Health Research Ethics Board (HREB) approval as well as approval from the Centre;
- Prior to being granted access to the Data Lab, all users of the Data Lab will review and sign The Centre's Data Lab Terms and Conditions of Use;
- All users of the Data Lab must comply with The Centre's policies and procedures for privacy, security, and data storage;
- Members of the project team are not permitted to allow other individuals to use their credentials to access the Data Lab. This includes other project team members working on the same project or any colleagues associated with the project;
- Members of the project team accessing the data will not attempt to re-identify the subjects of the released data;

- The data must remain in the Data Lab and removal from the Data Lab is not • permitted. Aggregate level results may be removed once approved by The Centre;
- If there are changes with the research study and/or research team then the Centre must provide approval for these changes. Any amendments or updated ethics approval(s) will be supplied to the Centre accordingly;
- Cell counts or statistics based on cell counts less than 5 are not published;
- The Centre will retain the data in the Data Lab for five years post publication of results;
- The Principal Investigator will notify The Centre when the initial data analysis is complete. At this time, the data and results will be archived but will be made available upon request within the five year data retention period;
- The Centre reserves the right to conduct an audit review of requestors who have been disclosed record-level data.

Please sign below and return to acknowledge you accept the above conditions of approval.

Signed: _____ Date: _____

On behalf of the Centre, I wish you every success with this initiative. Sincerely, Kendra Lester Director, Analytics and Data Access NL Health Services Cc: Alicia Blackmore, Manager, Data and Information Requests

Appendix 3 – Client Consent Form

The Researcher

- This research study is being done by Zachary Giovannini-Green and supervised by Dr. Gerald Mugford
- This research study is sponsored by Memorial University of Newfoundland and Labrador
- Zachary Giovannini-Green and Dr. Gerald Mugford are with the Faculty of Medicine, Memorial University of Newfoundland and Labrador
- Contact information for Zachary Giovannini-Green and Dr. Gerald Mugford can be found on the last page of this form

The Research

- You are being invited to take part in a research study being done by Zachary Giovannini-Green and supervised by Dr. Gerald Mugford
- Taking part in the study involves being interviewed for about an hour along with a family member
- The interview can take place either in person or online, you and your family member may consent to being recorded if you are comfortable
- The purpose of this interview is gaining better understanding of patient and care giver experiences with psychotic disorders, as well as their experiences navigating the mental health system in Newfoundland and Labrador
- The interview topics will include: your experience living with psychotic disorders, experiences with mental healthcare, experiences with community support, the impact of a psychotic disorder on your school and work, and moving towards independence
- There may be a risk of discomfort or distress as you talk about your history with psychotic disorders or experiences with the mental health system in Newfoundland and Labrador
- There may be a risk that your parent will disclose sensitive information during the interview

- If you experience distress during the interview, it will be paused or stopped, and you will be encouraged to contact any of the agencies listed on the last page of this form
- The benefit of participating in this research is the ability to research that will improve the health outcomes of youth in Newfoundland and Labrador living with psychotic disorders
- There will be no direct benefits to participating in this research study (e.g. financial compensation)

The Participant

- You as the participant have the following rights:
 - You are under no obligation to participate in this study
 - You are free to withdraw from the interview at any time or refuse to answer any questions without any consequences whatsoever
 - Agreeing to participate in this research study does not mean that you give up any of your legal rights
 - Throughout the research you will be given all relevant information that allows you to decide whether to continue or withdraw from the study
 - In this research study you have the right to withdraw your consent up to six weeks after your interview, in which case all your data will be deleted

Privacy and Confidentiality

- If you choose to participate the data collected from you will be your answers given in response to the interview questions
- Though the research team will keep interview responses confidential, they are unable to stop the other interview participant from repeating interview responses to others
- Zachary Giovannini-Green and Dr. Gerald Mugford will be the only two researchers with access to any of the data for this research study
- Staff from the Health Research Ethics Board may look at study records and personal information under supervision of the researchers to check if information is correct and if all laws and guidelines are being followed
- All consent forms and recordings will be collected by Zachary Giovannini-Green and kept by Dr. Gerald Mugford on a password protected computer in a locked office for five years

- All transcripts where all identifying information has been removed will be kept on a separate file by Dr. Gerald Mugford for five years on the same computer
- This research may be used in dissertations, conference presentations, published journal articles, and reports to other agencies
- If the researcher (Zachary Giovannini-Green) is informed that the participant or someone else is at risk of harm, he may report this to the relevant authorities

Conflicts of Interest

• Zachary Giovannini-Green and Dr. Gerald Mugford have no conflicts of interest to declare

Use of the Research

- This research study will be used to write the dissertation of the researcher as well as to create conference presentations, published journal articles, and reports to be sent to other agencies
- The identity of all participants will be disguised in any work resulting from this research study and will not be directly identifiable
- All questions about the research study itself should be directed to the researcher, Zachary Giovannini-Green, whose contact information can be found on the last page of this form
- All ethical questions about this research study should be directed to the Human Research Ethics Authority (HREA), whose contact information can be found on the last page of this form

Participant Consent

I ______ agree to participate in this research study

Signature of research participant

Signature of participant

Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

Signature of researcher

Date

<u>Researcher:</u> Zachary Giovannini-Green, MSc PhD Candidate, Clinical Epidemiology Faculty of Medicine Memorial University of Newfoundland and Labrador Email: a75zegg@mun.ca

<u>Supervisor:</u> Gerald Mugford, PhD Associate Professor of Medicine and Psychiatry Faculty of Medicine Memorial University of Newfoundland and Labrador Email: gmugford@mun.ca

If you have questions about your rights as a research participant, please contact:

<u>Health Research Ethics Authority (HREA)</u> Tel: (709) 777-6974 Email: <u>info@hrea.ca</u>

In case of mental distress, please contact:

Doorways Tel: (709) 752-4903

Mobile Crisis Response Team Tel: 811

<u>Adult Central Intake</u> Tel: (709) 752-8888 - (for St. John's area only)

Bridge the Gap online Website: bridgethegap.com

Or any Hospital Emergency Room

Appendix 4 – Family Member Consent Form

The Researcher

- This research study is being done by Zachary Giovannini-Green and supervised by Dr. Gerald Mugford
- This research study is sponsored by Memorial University of Newfoundland and Labrador
- Zachary Giovannini-Green and Dr. Gerald Mugford are with the Faculty of Medicine, Memorial University of Newfoundland and Labrador
- Contact information for Zachary Giovannini-Green and Dr. Gerald Mugford can be found on the last page of this form

The Research

- You are being invited to take part in a research study being done by Zachary Giovannini-Green and supervised by Dr. Gerald Mugford
- Taking part in the study involves being interviewed for about an hour
- The interview will take place via Webex, you can consent to being recorded if you are comfortable
- The purpose of this interview is gaining better understanding of care giver experiences with psychotic disorders, as well as their experiences navigating the mental health system in Newfoundland and Labrador
- The interview topics will include: your experience as a family member to someone living with a psychotic disorder, your experiences helping them with mental healthcare, experiences with any community support, the impact you see of a psychotic disorder on your family member's school and work, and moving towards independence
- There may be a risk of discomfort or distress as you talk about your experience with a family member living with a psychotic disorders or experiences with the mental health system in Newfoundland and Labrador
- If you experience distress during the interview, it will be paused or stopped, and you will be encouraged to contact any of the agencies listed on the last page of this form

- The benefit of participating in this research is the ability to research that will improve the health outcomes of youth in Newfoundland and Labrador living with psychotic disorders
- There will be no direct benefits to participating in this research study (e.g. financial compensation)

The Participant

- You as the participant have the following rights:
 - You are under no obligation to participate in this study
 - You are free to stop the interview at any time or refuse to answer any questions without any consequences whatsoever
 - Agreeing to participate in this research study does not mean that you give up any of your legal rights
 - Throughout the research you will be given all relevant information that allows you to decide whether to continue or withdraw from the study
 - In this research study you have the right to withdraw your consent up to six weeks after your interview, in which case all your data will be deleted

Privacy and Confidentiality

- If you choose to participate the data collected from you will be your answers given in response to the interview questions
- The research team will keep all individual interview responses confidential
- Zachary Giovannini-Green and Dr. Gerald Mugford will be the only two researchers who have access to any of the data collected for this research study
- Staff from the Health Research Ethics Board may look at study records and personal information under supervision of the researchers to check if information is correct and if all laws and guidelines are being followed
- All consent forms and recordings will be collected by Zachary Giovannini-Green and kept by Dr. Gerald Mugford on a password protected computer in a locked office for five years
- All transcripts where all identifying information has been removed will be kept on a separate file by Dr. Gerald Mugford for five years on the same computer
- This research may be used in dissertations, conference presentations, published journal articles, and reports to other agencies

• If the researcher (Zachary Giovannini-Green) is informed that the participant or someone else is at risk of harm, he may report this to the relevant authorities

Conflicts of Interest

• Zachary Giovannini-Green and Dr. Gerald Mugford have no conflicts of interest to declare

Use of the Research

- This research study will be used to write the dissertation of the researcher as well as to create conference presentations, published journal articles, and reports to be sent to other agencies
- The identity of all participants will be disguised in any work resulting from this research study and will not be directly identifiable
- All questions about the research study itself should be directed to the researcher, Zachary Giovannini-Green, whose contact information can be found on the last page of this form
- All ethical questions about this research study should be directed to the Human Research Ethics Authority (HREA), whose contact information can be found on the last page of this form

Participant Consent

I ______ agree to participate in this research study

Signature of research participant

Signature of participant

Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

Signature of researcher

Date

<u>Researcher:</u> Zachary Giovannini-Green, MSc PhD Candidate, Clinical Epidemiology Faculty of Medicine Memorial University of Newfoundland and Labrador Email: a75zegg@mun.ca

<u>Supervisor:</u> Gerald Mugford, PhD Associate Professor of Medicine and Psychiatry Faculty of Medicine Memorial University of Newfoundland and Labrador Email: gmugford@mun.ca

If you have questions about your rights as a research participant, please contact:

<u>Health Research Ethics Authority (HREA)</u> Tel: (709) 864-8871 Email: info@hrea.ca

In case of mental distress, please contact:

Doorways Tel: (709) 752-4903

Mobile Crisis Response Team Tel: 811

<u>Adult Central Intake</u> Tel: (709) 752-8888 - (for St. John's area only)

Bridge the Gap online Website: bridgethegap.com

Or any Hospital Emergency Room

Appendix 5 – Client Interview Questions

Introduction:

Thank you for agreeing to take part in this interview. Your answers will be helpful in understanding the way people access care for psychotic illnesses.

Before we begin the interview, I would like to clarify a few things:

- This interview will be used for research purposes. No identifying information will be included in the final study report.
- During this interview, you can take a break at any time you want. You may also choose to not answer any question. You also can stop the interview at any time.
- After the interview, you have up to six weeks to request that your interview not be included. In which case all data collected from you will be destroyed.
- After five years all the data from the study will be destroyed. This is a Memorial University rule.
- Earlier you told me you do/do not wish this interview to be recorded. Is that still what you want?
- You can think of it as more of an informal conversation. I would like to hear your story in your own words. I ask the same questions to everyone. I do this to help me understand and find any themes and shared experiences.
- If you have any questions or comments about this interview that you do not want to speak to me about, you can contact my supervisor Dr. Gerald Mugford. You can also contact or the Health Research Ethics Board. I will put their contact information in the chat box/ Here is the sheet with their contact information.

Are you ready to begin?

(<u>Note to reader</u>: the subsequent interview questions are intended to flow in a conversational manner. The indicated probe questions will only be asked if the interviewer deems it to be necessary to collect relevant information)

A. Demographic information

Alright, let's start of with asking some basic information:

- 1. How old are you?
- 2. What's your highest level of education?
- 3. Are you currently working? How long have you been [*status*]?
- 4. Where are you living now? How long have you been [arrangement]?
- 5. What medical professionals are you seeing now? How long have they been following you?
- 6. Have you seen professionals in the past that you're not seeing now? If so, which ones? How long did you see them for? Do you know what age you were?

B. Educational information

Let's start by focus in on your experiences in school. Can you describe those years for me?

Clarify

- favourite teachers
- favourite subjects
- extra curricular
- academic struggles
- attendance patterns
- level of education completed
- types of supports received in schools
- individualized plans created
- referrals to other professionals
- school counsellors used
- post secondary experiences

C. Community information

Let's focus on your social experiences. Can you tell me a little bit about that?

Clarify

- Community supports while growing up (family, friends, etc.)
- Current community supports (family, friends, etc.)
- Use of alcohol/tobacco
- Use of recreational drugs
- Interactions with the police

D. Medical information

Let's shift focus and talk about medical interventions. Can you describe what accessing medical supports has been like for you? What helped, what was challenging for you?

Clarify

- when referred for psychiatric assessment(s)
- waitlist to see professionals
- professionals seen (counsellor, psychologist, MH nurse, GP, Psychiatrist, etc.)
- who's following you now
- meds currently taking, do they help, are there side effects
- meds previously taken, how long did you take them, when was this
- current diagnosis/es, is/are they accurate
- transition from child to adult services
- family history of psychiatric illness and/or substance abuse
- emergency room visits

E. Reflection

- 1. Looking back, is there anything more you wish had been done to help you?
 - school system
 - health care system
 - justice system (if applicable)
- 2. What do you feel like is your current state of wellbeing?
- 3. What do you feel you need right now, if anything, to improve your wellbeing?
- 3. This study is looking to understand the experiences of people with your history, in the

hope of helping others. Do you have any final thoughts or comments that you would

like to share?

• any topic not covered you think should have been

Thank you for your time.

Are you comfortable with me interviewing your parent to help understand your medical and educational history?

Appendix 6 – Family Member Interview Questions

Introduction:

Thank you for agreeing to take part in this interview. Your answers will help understand how people access care for psychotic illnesses.

Before we begin the interview, I would like to clarify a few things:

- This interview will be used for research purposes. No identifying information will be included in the final study report.
- During this interview, you can take a break at any time you want. You may also choose to not answer any question. You also can stop the interview at any time.
- After the interview, you have up to six weeks to request that your interview not be included. In which case all data collected from you will be destroyed.
- After five years all the data from the study will be destroyed. This is a Memorial University rule.
- Earlier you told me you do/do not wish this interview to be recorded. Is that still what you want?
- You can think of it as more of an informal conversation. I would like to hear your story in your own words. I ask the same questions to everyone. I do this to help me understand and find any themes and shared experiences.
- If you have any questions or comments about this interview that you do not want to speak to me about, you can contact my supervisor Dr. Gerald Mugford. You can also contact or the Health Research Ethics Board. I will put their contact information in the chat box/ Here is the sheet with their contact information.

Are you ready to begin??

(<u>Note to reader</u>: the subsequent interview questions are intended to flow in a conversational manner. The indicated probe questions will only be asked if the interviewer deems it to be necessary to collect relevant information)

I've met with [*client's name*] and we had a good conversation. I'm not going to ask you the same questions, rather collect your memories of their experiences. I may also be asking some clarification questions if any come up.

A. Background Information

Let's begin by you telling me about your perspective of [*client's name*]'s struggles with mental health.

Clarify:

- when did they start?
- how did they progress?
- what was your experience with this?
- parent's current relationship with [*child's name*]?

B. Education information

Let's focus in on [*client's name*]'s school experience. How did you feel that impacted [*client's name*]. Can you describe those years for me?

Clarify

- supports that were needed in school
- type of supports
- accessing those supports
- counselling support
- transition from school to post-secondary/work
- individualized support plans
- attendance
- assessments made by school staff

C. Community information

Let's focus in on [*client's name*]'s social experiences and how you felt that was impacted. Can you tell me a little bit about that?

Clarify

- community supports while growing up (family, friends, non-profits, etc.)
- current community supports (family, friends, non-profits, etc.)
- any difficulties that [*child's name*] experienced in the community (drugs, police interactions, etc.)

D. Medical information

Now, let's focus on medical interventions. Can you describe what accessing medical supports has been like for [*client's name*]?

Clarify

- to whom referrals were made
- when were they made
- accessing supports
- transition from child to adult health
- frustrations or challenges encountered
- family history of learning or mental health issues
- substance abuse
- history of medications taken
- which medications helped, which didn't help
- exact history and chronology of diagnosis

E. Reflection

- 1) Looking back, do you think more could have been done to help [client's name]?
 - school system
 - health care system
 - justice system (if applicable)
- 2) This study is looking to understand the experiences of people with [*child's name*]'s history, in the hope of helping others. Do you have any final thoughts or comments that you would like to share?
 - any topic we did not cover that you think should discuss

Thank you for your time.

<u> Appendix 7 – Caseworker Consent Form</u>

The Researcher

- This research study is being done by Zachary Giovannini-Green and supervised by Dr. Gerald Mugford
- This research study is sponsored by Memorial University of Newfoundland and Labrador
- Zachary Giovannini-Green and Dr. Gerald Mugford are with the Faculty of Medicine, Memorial University of Newfoundland and Labrador
- Contact information for Zachary Giovannini-Green and Dr. Gerald Mugford can be found on the last page of this form

The Research

- You are being invited to take part in a research study being done by Zachary Giovannini-Green and supervised by Dr. Gerald Mugford
- Taking part in the study involves being part of a focus group for about 90 minutes along with other caseworkers providing services to individuals living with psychosis and their families
- The focus groups will take place online via Webex, you can consent to being recorded if you are comfortable, during the recording you may choose to switch off your camera
- The intention of these focus groups is not to have caseworkers speak for clients and families, but rather to help triangulate research findings
- Themes identified by analysing interview data with patients and families will constitute the topics discussed during these focus groups
- There may be a risk of discomfort or distress as you talk about your experience as a caseworker within the mental health system in Newfoundland and Labrador
- If you experience distress during the focus group, you can choose to exit the focus group, and you will be encouraged to contact any of the agencies listed on the last page of this form
- Given the relatively small number of caseworkers providing services to individuals and families living with psychosis, confidentiality cannot be guaranteed as others may assume that you participated. However, no identifying information will be referenced in any documents produced by this research

- The benefit of participating in this research is the ability to actively contribute to research that will improve the health outcomes of youth in Newfoundland and Labrador living with psychotic disorders
- There will be no direct benefits to participating in this research study (e.g. financial compensation)

The Participant

- You as the participant have the following rights:
 - You are under no obligation to participate in this study
 - You are free to withdraw from the focus group at any time or refuse to answer any questions without any consequences whatsoever
 - Agreeing to participate in this research study does not mean that you give up any of your legal rights
 - Throughout the research you will be given all relevant information that allows you to decide whether to continue or withdraw from the study
 - In this research study you have the right to withdraw your consent up to six weeks after the focus group, in which case all your data will be deleted

Privacy and Confidentiality

- If you choose to participate the data collected from you will be your answers given in response to prompts based on identified themes from patient and family member interviews
- The research team will keep all responses confidential
- Zachary Giovannini-Green and Dr. Gerald Mugford will be the only two researchers who have access to any of the data collected for this research study
- Staff from the Health Research Ethics Board may look at study records and personal information under supervision of the researchers to check if information is correct and if all laws and guidelines are being followed
- All consent forms and recordings will be collected by Zachary Giovannini-Green and kept by Dr. Gerald Mugford on a password protected computer in a locked office for five years
- All transcripts where all identifying information has been removed will be kept on a separate file by Dr. Gerald Mugford for five years on the same computer

- This research may be used in dissertations, conference presentations, published journal articles, and reports to other agencies
- If the researcher (Zachary Giovannini-Green) is informed that the participant or someone else is at risk of harm, he may report this to the relevant authorities

Conflicts of Interest

• Zachary Giovannini-Green and Dr. Gerald Mugford have no conflicts of interest to declare

Use of the Research

- This research study will be used to write the dissertation of the researcher as well as to create conference presentations, published journal articles, and reports to be sent to other agencies
- The identity of all participants will be disguised in any work resulting from this research study and will not be directly identifiable
- All questions about the research study itself should be directed to the researcher, Zachary Giovannini-Green, whose contact information can be found on the last page of this form
- All ethical questions about this research study should be directed to the Human Research Ethics Authority (HREA), whose contact information can be found on the last page of this form

Participant Consent

I ______ agree to participate in this research study

Signature of research participant

Signature of participant

Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

Signature of researcher

Date

<u>Researcher:</u> Zachary Giovannini-Green, MSc PhD Candidate, Clinical Epidemiology Faculty of Medicine Memorial University of Newfoundland and Labrador Email: a75zegg@mun.ca

<u>Supervisor:</u> Gerald Mugford, PhD Associate Professor of Medicine and Psychiatry Faculty of Medicine Memorial University of Newfoundland and Labrador Email: gmugford@mun.ca

If you have questions about your rights as a research participant, please contact:

<u>Health Research Ethics Authority (HREA)</u> Tel: (709) 864-8871 Email: info@hrea.ca

In case of mental distress, please contact:

Doorways Tel: (709) 752-4903

Mobile Crisis Response Team Tel: 811

<u>Adult Central Intake</u> Tel: (709) 752-8888 - (for St. John's area only)

Bridge the Gap online Website: bridgethegap.com

Or any Hospital Emergency Rooms

Appendix 8 – Caseworker Focus Group Statements

Introduction to Focus Group:

- Thank you for being part of today's focus group, your participation is deeply appreciated.
- As outlined in the consent form this focus group may be recorded. You have the right to turn off your camera at any point.
- No information that can be used to identify you will be included in any final documents produced by this research. Given the relatively small number of caseworkers in this area, however, confidentiality cannot be guaranteed as your participation may be assumed.
- You are kindly asked to refrain from identifying any individual client during the focus group. If you do accidentally give identifying information, it will not be included in the transcript of the focus group.
- Are there any questions before we begin?

As you know my study focuses on one research question: what are variables and indicators that affect pathways to care for youth in Newfoundland and Labrador accessing treatment for psychosis and psychotic illness? These variables and indicators may be present before or after the onset of frank psychosis. However, their identification will contribute to strengthening early intervention and treatment and lessen the duration of untreated psychosis in this vulnerable population.

Today, I am seeking your perspective on themes that emerged from the interviews that I've conducted with these clients and their family members. I'm looking for your insights into how common these themes are, given your unique position of providing services to clients and families living with psychosis and psychotic illness. Your participation today will be used to help improve current pathways to care models in the province for those accessing services for psychosis and psychotic illness.

Topics for Discussion:

 a. Many clients reported doing well during the earlier grades, and even into the junior high years, but then starting to struggle academically in high school. Several reported being identified with learning disabilities and anxiety (diagnosed in high school) and some were diagnosed with ADHD (although medication often did not help and was eventually discontinued). Is this typical of your clients? Has it changed over the years? What are your thoughts on how it may affect access to care?

b. These struggles in high school led to these individuals falling behind and becoming disengaged, with many failing to complete high school. Several reported being described as lazy. Is this pattern typical in your caseload? Has it changed over the years? What are your thoughts on how it may affect access to care? Are there early alerts that could be identified during the school years for this cohort? Or...In your experience, should this dramatic change in their academic pathway and progress be an early alert?

- 2. These clients were often followed by a family doctor who was described as becoming increasingly frustrated by their struggles to help stabilise their needs, despite sincere efforts. This was often exacerbated by the clients moving into adulthood when the parent could no longer accompany them to medical appointments, and/or the client missing appointments. Is this pattern typical of your clients? What are your thoughts on how it may affect access to care? How do you think family members might become more integrated into pathways to care for adult patients?
- 3. One theme that emerged was the use of recreational drugs, beginning in early high school but escalating very quickly, much faster than that of their peers. Is this quick escalation in recreational drug use typical of your clients? Has it changed over the years? How do you think has impacted their access to care?
- 4. Families reported dealing with behaviours that were so severe that they felt the need to call the police yet hesitated to do so for fear of the police and possible outcomes. Those who did call the police reported regret for doing so and described the experience as traumatising. Is this a common theme among your families? What are your thoughts on how it may affect access to care?
- 5. Parents of clients report that client struggled with symptomology often for years, before eventually finding support. This process can take even longer in rural communities. Many clients and families reported several hospitalizations before being diagnosed with a psychotic illness and receiving appropriate care. Many family members report it was and remains difficult to get healthcare workers to listen to them? Is this typical of your clients? What are your thoughts on how it may affect access to care? Do you think there might be early alerts for a health team that could expedite access to care during these hospitalisations?

- 6. Once diagnosis made, access to appropriate medications also arose as a common theme across interviews. This included accessing a clinician who will prescribe appropriate medications, as well getting prescriptions filled in a timely manner. In your caseload, are you seeing these issues being raised by clients and families? Has it changed over the years? What are your thoughts on how it may affect access to care?
- 7. The adverse effects of antipsychotic medication especially heavy tranquillisation and conspicuous weight gain constituted a frequent theme in interviews with clients and family members. s These interviews also identified and a lack of concern or support from health care in dealing with this. Is this common to your caseload? What are your thoughts on how it may affect access to care?
- 8. Stigma and a lack of support and understanding in the community also surfaced as a hinderance to accessing care. Family members commented that their loved one can find it difficult to access community supports even when they're well. They also have difficulty accessing all types of medical care due to the symptoms of their psychosis. Is this a common issue in your case load? Has it changed over the years? What are your thoughts on how it may affect access to care?