HEALTH SERVICES USE AND TREATMENT DELAY FOR PATIENTS EXPERIENCING A FIRST-EPISODE OF PSYCHOSIS: A MIXED METHODS STUDY

by

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TABLE OF CONTENTS

ABSTRACT

Background: Long delays in initiating treatment for a first-episode of psychosis (FEP) are associated with poor clinical and functional outcomes. However, the modes and routes by which patients access care are complex, thus contributing to delays in treatment initiation and extending the duration of untreated psychosis.

Objective: To identify determinants of service use preceding a FEP, and to examine the impact of these patterns on treatment delay and engagement with specialized services.

Design: A mixed-methods multilevel triangulation design was used, which involved both quantitative and qualitative methods to examine health services use by patients with FEP in Montréal at the population, clinical, and individual levels.

Project #1 – Population Level: We used population-based administrative data from physician billings, hospitalizations, and public health clinics to examine the use of services prior to a first diagnosis of psychosis. Incident cases of psychosis occurring from 2004 through 2006 among individuals aged 14 to 25 years were identified, and mental health contacts preceding the index diagnosis were analyzed. Of the 456 cases identified, 32% had no contact with services preceding the index diagnosis. Nearly 50% of cases received the index diagnosis in the emergency department. Individuals who were in contact with primary care services had a reduced likelihood of contact with the emergency department and inpatient services, but also had a longer time to diagnosis and time to contact with a psychiatrist.

Project #2 – Clinical Level: We estimate the association of several socio-demographic and clinical factors with the pathway to care and treatment delay among FEP patients from an early intervention program. We also assessed the impact of the pathway to care on time to disengagement from services. Our findings suggest that patients who were in contact with primary care had a reduced likelihood of negative pathways to care, but also had longer referral delays. Socio-demographic and clinical factors were more relevant for predicting subsequent engagement with services, and indicators of negative pathways to care were not associated with service disengagement.

***Project #3 – Individual Level*:** Using a qualitative descriptive approach, we conducted semi-structured interviews with sixteen patients recruited from a specialized early intervention program. Participants described the crucial role of significant others in initiating contact with services, and both self-stigma and a lack of knowledge regarding the symptoms of psychosis and availability of services emerged as barriers to help-seeking. Participants typically described a complex series of contacts on the pathway to care, resulting in feelings of being misunderstood and losing control, but many individuals identified unexpected benefits of their experience.

***Conclusions*:** Our findings suggest that few socio-demographic or clinical factors determine pathways to care. Rather, service-level factors, such as having access to a primary care provider, have a stronger impact on patterns of health service use across multiple indicators. Improving access to primary care may reduce the burden on emergency services, however primary care providers may need additional training in the symptoms of early psychosis and referral protocols.

RESUMÉ

Contexte : Un retard important pour la mise en route d'une prise en charge thérapeutique suite à un premier épisode psychotique (PEP) est associé à un mauvais pronostic clinique et fonctionnel. Cependant les différents modalités et parcours d'accès aux soins de ces patients sont complexes, ce qui contribue à retarder l'initiation du traitement et à augmenter la durée de la phase durant laquelle la psychose n'est pas traitée.

Objectifs : Décrire les différents parcours d'utilisation des services de soins avant un PEP, puis à examiner l'impact de ces parcours sur le délai de prise en charge et engagement avec des services spécialisés.

Méthodologie d'étude : Des méthodes combinées de triangulation multi-niveaux, impliquant à la fois des méthodes quantitatives et qualitatives aux niveaux populationnel, clinique, et individuel, ont été appliquées, afin d'examiner le recours aux services de santé par des patients présentant un PEP à Montréal

Projet #1 - Niveau Populationnel : Les données sur le recours aux services de soins avant un premier diagnostic de psychose ont été extraites des bases administratives de la population générale à partir des facturations médicales, des hospitalisations, et des centres de soins publics. Les cas incidents de psychoses parmi les individus âgés de 14 à 25 ans entre 2004 et 2006 ont été identifiés, et les contacts avec les services psychiatriques avant le diagnostic ont été analysés. Parmi les 456 cas identifiés, 32% n'avaient eu aucun contact avec un service de soins avant que le premier diagnostic ne soit posé. Le premier diagnostic de psychose avait été établi dans un service d'urgences pour presque la moitié des cas. Les individus en contact avec des soins de première ligne avaient une probabilité plus faible de contact avec un service d'urgences ou d'hospitalisation, mais c'est dans cette catégorie de patients que les

délais étaient les plus importants avant le diagnostic et avant une consultation avec un psychiatre.

Projet #2 - Niveau Clinique : Nous avons étudié l'association entre des facteurs sociodémographiques et cliniques et, d'une part les modalités d'accès aux soins, et d'autre part le délai de traitement, de patients présentant un PEP et inscrits à un programme d'intervention précoce. Nous avons également évalué l'impact du schéma d'accès aux soins sur le délai d'abandon du programme d'intervention précoce. Nos résultats suggèrent que les patients en contact avec des soins de première ligne ont une probabilité plus faible de trajectoires négatives d'accès aux soins, mais consultent un spécialiste dans des délais plus longs. Les facteurs sociodémographiques et cliniques prédisaient de manière plus pertinente l'engagement par le patient avec les services spécialisés, et les indicateurs de trajectoires négatives d'accès aux soins n'étaient pas associés à un désengagement avec les services spécialisés.

Projet #3 - Niveau Individuel **:** A partir d'une approche qualitative descriptive, nous avons conduit des entretiens avec 16 patients recrutés au sein d'un programme d'intervention précoce. Les participants décrivaient le rôle crucial de tierces personnes dans l'initiation du contact avec les services de soins. L'auto-stigmatisation par le patient, le manque de connaissance des symptômes de psychose, et la disponibilité insuffisante des services, ont émergé en tant qu'obstacles à la recherche d'aide. Les participants décrivaient typiquement des séries complexes de contacts sur le cheminement d'accès aux soins, aboutissant à des sentiments d'être mal compris et d'une perte de contrôle de soi. Cependant, de nombreux patients identifiaient également dans cette expérience des bénéfices inattendus.

***Conclusions*:** Nos résultats suggèrent que le recours aux soins dépend peu de facteurs sociodémographiques ou cliniques. Les facteurs propres aux services de santé, tels que l'accès aux soins de première ligne, ont un impact plus important sur les modalités de recours aux services spécialisées, et ceci à travers de multiples indicateurs. Améliorer l'accès aux soins primaires pourrait ainsi diminuer la charge de travail des services d'urgences, à condition de former les intervenants des centres de soins de première ligne à mieux identifier les symptômes précoces de psychose et à orienter ces patients vers des services spécialisés.

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STATEMENT OF ORIGINALITY

Each of the five manuscripts presented in this thesis make an original contribution to the literature on health services use in first-episode psychosis. In Manuscript I, we conduct a systematic review of existing studies on the topic, and conclude that there is insufficient knowledge on the determinants of health services use in first-episode psychosis, and its impact on treatment delay. In Manuscripts II and III, we use administrative data from several health and social service providers in Montréal to estimate the incidence of first-episode psychosis, and to examine patterns of service use and treatment delay at the population-level. This study is only the second to use routinely collected administrative data for research on first-episode psychosis, and the first to do so in Canada. In Manuscript IV, we use data obtained from a specialized first-episode psychosis program to examine the determinants of the pathway to care, and its impact on treatment delay and engagement with services. Few studies to date have looked at the socio-demographic determinants of the pathway to care in first-episode psychosis, and none have estimated the impact of negative pathways to care on subsequent engagement with services. In Manuscript V, we conduct qualitative interviews with first-episode psychosis patients to obtain a subjective description of their experiences seeking help for their psychotic symptoms. Few qualitative studies have been done from the perspective of the patients themselves, as prior research on this topic has typically involved family members. Finally, our study is the first to use a mixed method study design for research on health services use in first-episode psychosis, which allowed us to triangulate findings from the population-, clinical- and individual-levels.

CONTRIBUTION OF AUTHORS

Manuscript I: The Pathways to Mental Health Care of First-Episode Psychosis Patients – A Systematic Review

Authors: Kelly K. Anderson, Rebecca Fuhrer, & Ashok K. Malla

This manuscript was published in *Psychological Medicine* (2010), 40, 1585-1597.

Kelly Anderson was involved in the conception and design of the study, in the acquisition of data, in the analysis of data and interpretation of findings, and in writing the first draft. *Rebecca Fuhrer* and *Ashok Malla* were involved in the conception and design of the study, in the interpretation of findings, and in the critical revision of the article for intellectual content.

Manuscript II: The Incidence of First-Episode Schizophrenia-Spectrum Psychosis in Montréal – An Estimate from Administrative Data

Authors: Kelly K. Anderson, Rebecca Fuhrer, Michal Abrahamowicz, & Ashok K. Malla

This manuscript is under review.

Kelly Anderson was involved in the conception and design of the study, in the acquisition of data, in the analysis of data and interpretation of findings, and in writing the first draft. *Rebecca Fuhrer* and *Ashok Malla* were involved in the conception and design of the study, in the interpretation of findings, and in the critical revision of the article for intellectual content. *Michal Abrahamowicz* was involved in the in the analysis of data and interpretation of findings, and in the critical revision of the article for intellectual content.

Manuscript III: Patterns of Health Services Use by Patients with First-Episode Schizophrenia-Spectrum Psychosis - The Impact of Primary Care

Authors: Kelly K. Anderson, Rebecca Fuhrer, Willy Wynant, Michal Abrahamowicz, David L. Buckeridge, & Ashok K. Malla

This manuscript is under review.

Kelly Anderson was involved in the conception and design of the study, in the acquisition of data, in the analysis of data and interpretation of findings, and in writing the first draft.

Rebecca Fuhrer, *David Buckeridge*, and *Ashok Malla* were involved in the conception and design of the study, in the interpretation of findings, and in the critical revision of the article for intellectual content. *Willy Wynant* and *Michal Abrahamowicz* were involved in the analysis of data and interpretation of findings, and in the critical revision of the article for intellectual content.

Manuscript IV: The Social and Clinical Determinants of the Pathway to Care and the Impact on Service Disengagement in First-Episode Psychosis

Authors: Kelly K. Anderson, Rebecca Fuhrer, Norbert Schmitz, & Ashok K. Malla

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Kelly Anderson was involved in the conception and design of the study, in the acquisition of data, in the analysis of data and interpretation of findings, and in writing the first draft. *Rebecca Fuhrer* and *Norbert Schmitz* were involved in the conception and design of the study, in the interpretation of findings, and in the critical revision of the article for intellectual content. *Ashok Malla* was involved in the conception and design of the study, in the acquisition of data, in the interpretation of findings, and in the critical revision of the article for intellectual content.

Manuscript V: 'There's too many steps before you get to where you need to be' – The Help-Seeking Experiences of Patients with First-Episode Psychosis

Authors: Kelly K. Anderson, Rebecca Fuhrer, & Ashok K. Malla

This manuscript is under review.

Kelly Anderson was involved in the conception and design of the study, in the interviewing of research participants, in the analysis of data and interpretation of findings, and in writing the first draft. *Rebecca Fuhrer* and *Ashok Malla* were involved in the conception and design of the study, in the interpretation of findings, and in the critical revision of the article for intellectual content.

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LIST OF ABBREVIATIONS

ASSS	Agence de la Santé & des Services Sociaux
BPRS	Brief Psychiatric Rating Scale
CHSLD	Centre Hospitalier Soins de Longue Dureé
CI	Confidence Interval
CLSC	Centre Local de Services Communautaires
CORS	Course of Onset and Relapse Schedule
DRG	Diagnosis Related Group
DUI	Duration of Untreated Illness
DUP	Duration of Untreated Psychosis
ED	Emergency Department
EI	Early Intervention
FEP	First-Episode Psychosis
GP	General Practitioner
HR	Hazard Ratio
ICC	Intraclass Correlation Coefficient
ICD	International Classification of Diseases
IQR	Inter-quartile Range
MAR	Missing at Random
OR	Odds Ratio
PAS	Premorbid Adjustment Scale
PEPP	Prevention and Early Intervention Program for Psychosis
PH	Proportional Hazards
PS	Propensity Score
RAMQ	Régie de l’Assurance Maladie du Québec
RR	Risk Ratio
SD	Standard Deviation
SES	Socioeconomic Status
SSP	Schizophrenia-Spectrum Psychosis

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

CHAPTER 1 - BACKGROUND

An episode of a psychotic disorder, the most serious form of mental illness, is a very confusing, frightening, and difficult time for patients and their family members. It is characterized by delusions, which are false beliefs not shared by others, and hallucinations, which involve the experience of auditory, visual, olfactory, or other sensations that are not actually present (American Psychiatric Association, 2000). Patients may also experience disorganized thought and speech patterns, erratic or unusual behaviour, and impairment in reality testing . Taken together, these features are known as positive symptoms. Psychosis also involves negative symptoms, such as apathy, emotional withdrawal, depressive and anxiety symptoms, and blunted affect (American Psychiatric Association, 2000). Psychotic symptoms can occur in the context of several different conditions, including schizophrenia spectrum disorders, delusional disorder, bipolar illness, and major depressive disorder with psychotic features. It has been estimated that over 3% of the general population will experience a psychotic episode at some point during their lifetime (Perala *et al.* 2007), and the annual incidence of first onset psychosis is approximately 30 per 100,000 population (Proctor *et al.* 2004).

Psychosis is associated with a significant amount of personal, familial, and societal cost. The first psychotic episode typically occurs during a person's late teens and early twenties (Kessler *et al.* 2007a), and thus has the potential to interfere with the substantial social, educational, and professional development that occurs during this stage. Prior research suggests that psychosis is associated with reduced rates of marriage and reproduction (Hutchinson *et al.* 1999), and a loss of future goals and aspirations (Tarrier *et* *al.* 2007). A significant proportion of patients with psychosis also report experiences of stigma, harassment, and social exclusion, which may consequently lead to trauma-related symptoms (Tarrier *et al.* 2007). Patients with psychosis are more likely to engage in unhealthy lifestyle behaviours, such as tobacco (de and Diaz, 2005) and cannabis use (Koskinen *et al.* 2010), and are at an increased risk of self-harm (Harvey *et al.* 2008), suicide (Pompili *et al.* 2011), violence (Large and Nielssen, 2011), and homicide (Nielssen and Large, 2010). At the familial level, the relatives of psychotic patients often experience a great deal of psychological distress (Addington *et al.* 2003; Harvey *et al.* 2001) and feelings of guilt (Reed, 2008), and may also suffer financial strain as a consequence of their loved one's illness (Reed, 2008). Lastly, psychosis has a significant cost to society, and estimates from Canada indicate that schizophrenia alone accounts for $2.02 billion annually in direct societal costs (Goeree *et al.* 2005). This figure increases to $6.85 billion when lost productivity due to morbidity and premature mortality are factored in (Goeree *et al.* 2005).

Recent efforts in the field of psychotic disorders have focused on the first-episode of psychosis, which is typically defined on the basis of one of the following three indicators: (i) the first treatment contact for a psychotic disorder; (ii) the requirement for cases to not have received prior treatment with an anti-psychotic agent for longer than a specified period of time; (iii) the duration of psychotic symptoms (Breitborde *et al.* 2009). Although the precise details of the definition vary across clinical and research settings, it is generally expected that cases will be previously untreated and in the early stages of illness. This burgeoning interest in first-episode psychosis has occurred because findings from several literature reviews have confirmed that delays between the onset of psychotic symptoms and the initiation of antipsychotic treatment, known as the duration of untreated psychosis (DUP), are associated with poor clinical and functional outcomes (Marshall *et al.* 2005; Norman *et al.* 2005;

Norman and Malla, 2001; Perkins *et al.* 2005). Specifically, a long duration of untreated psychosis is associated with lower overall functioning, a greater number of positive and negative symptoms, lower quality of life, and a reduced likelihood of achieving remission (Marshall *et al.* 2005) as well as poor symptomatic recovery (Norman *et al.* 2005; Norman and Malla, 2001; Perkins *et al.* 2005). There is also evidence that these effects may persist into the chronic stages of illness (Perkins *et al.* 2005). Additionally, trajectories of outcome are generally defined within the first two years following the first psychotic episode (Harrison *et al.* 2001), making the early stages of a psychotic disorder a critical period for detection and intervention. Further, FEP samples lack the confounding effects of prolonged treatment and the impact of relapses, which allow for a better understanding of the course of psychotic disorders.

This evidence has led to an increase in the development and implementation of services targeting patients in the early stages of psychosis. These early intervention programs focus on symptom detection and comprehensive care during the initial stages of illness, as well as attempts to shorten the DUP (McGorry *et al.* 2007). Most early intervention services use a modified assertive case management strategy, combined with psychological, pharmacological, and vocational interventions (Malla and Pelosi, 2010). Evidence from a large randomized controlled trial found that specialized early intervention services resulted in a reduced risk of relapse and service disengagement, as well as improved social and vocational outcomes (Petersen *et al.* 2005), although these effects may not be sustained over time (Bertelsen *et al.* 2008). Meta-analyses of other randomized and non-randomized trials also suggest that these programs improve clinical and functional outcomes for patients with first-episode psychosis, relative to standard care (Bird *et al.* 2010; Harvey *et al.* 2007). Additionally, early intervention services have been found to be cost-effective over long-term follow-up; for example, one study from Australia found that patients in specialized programs demonstrated more favourable outcomes at approximately one third the cost of treatment in general psychiatric services (Mihalopoulos *et al.* 2009). Findings from the United Kingdom and Canada also suggest that early intervention services are likely to be cost effective (Goldberg *et al.* 2006; McCrone *et al.* 2010).

Although one of the stated objectives of early intervention is a reduction in the duration of untreated psychosis, changes to service configuration alone are likely not sufficient for reducing treatment delay (Lloyd-Evans *et al.* 2011). Other potential interventions include education of service providers, public awareness and anti-stigma campaigns, and targeted interventions with young-people. A recent systematic review found scant evidence on the effectiveness of interventions aimed at reducing the duration of untreated psychosis, and the studies that have been done have yielded varied findings (Lloyd-Evans *et al.* 2011). In order to more effectively develop interventions for reducing the duration of untreated psychosis, we need a comprehensive understanding of the complex processes underlying treatment delay.

Delays in treatment of the first-episode of psychosis can be conceptualized as consisting of two phases: (1) a help-seeking phase, encompassing the time between the onset of psychotic symptoms and first contact with health services; (2) a referral phase, encompassing the period between first contact with mental health services and entry into an appropriate treatment program. Research to date suggests that patient-level factors may be more likely to influence the help-seeking component of treatment delay, whereas system-level factors are associated with the referral component of delay (Bechard-Evans *et al.* 2007). Indeed, referral delays may be responsible for a substantial portion of the duration of untreated psychosis (Bechard-Evans *et al.* 2007; Norman *et al.* 2004), and may be an efficacious target for reducing treatment delay.

Given the contribution of the referral component of delay to the overall duration of untreated psychosis, research on the use of health services by patients with first-episode psychosis can potentially have a significant impact on the body of knowledge aimed at reducing this delay in treatment. In Chapter 2, we review the previous literature on utilization of services by patients with first-episode psychosis, and highlight areas that warrant further investigation to help identify some of the barriers patients face when seeking help for a psychotic episode. Irrespective of the association between the duration of untreated psychosis and outcome, it is desirable to provide services as quickly as possible for patients with first-episode psychosis in order to lessen the immediate suffering of patients and their families, and to reduce the secondary consequences of a psychotic episode, such as impairments in functioning and social deterioration (Etheridge *et al.* 2004).

CHAPTER 2 - LITERATURE REVIEW

The emphasis on early detection and reduction of treatment delay in first-episode psychosis (FEP), described in Chapter 1, has led to an interest in the modes and routes by which patients with psychotic disorders access help. These pathways to care are defined as "the sequence of contacts with individuals and organizations prompted by the distressed person's efforts, and those of his or her significant others, to seek help, as well as the help that is supplied in response to such efforts."(Rogler and Cortes, 1993, p.555) These pathways are not random, but rather intersect with social, cultural, and health services factors which shape both the direction and duration (Rogler and Cortes, 1993). The pathways to care are triggered by the distress caused by psychiatric symptoms, and encompass not only the help-seeking behaviour of the patient and their family members, but also the accessibility of mental health care and the identification of, and response to, psychiatric symptoms by each contact on the pathway to care (Singh and Grange, 2006)

Goldberg and Huxley have put forth a filters model to explain how patients come into contact with various service providers on the pathway to care (Figure 2.1, pg. 7) (Goldberg and Huxley, 1992). This model proposes a filter between different levels of care, and various patient characteristics, physician attributes, and systemic barriers may influence whether an individual will progress from one level to the next. The first level of the model is the community, where a considerable proportion of individuals suffer from psychiatric symptoms or psychological distress (Kessler *et al.* 2007b). At the second level are the subset of these symptomatic individuals who seek help from their primary care physician, whether for psychiatric symptoms or for other somatic complaints (Wang *et al.* 2007). When symptomatic individuals do seek health care, the physicians may only recognize psychiatric illness in a subset of patients, which comprises the third level. The fourth level consists of patients who are diagnosed as having a psychiatric disorder and are referred to mental health services, and the fifth level includes patients who present to mental health services and are subsequently hospitalized for more intensive inpatient care (Goldberg and Huxley, 1992).

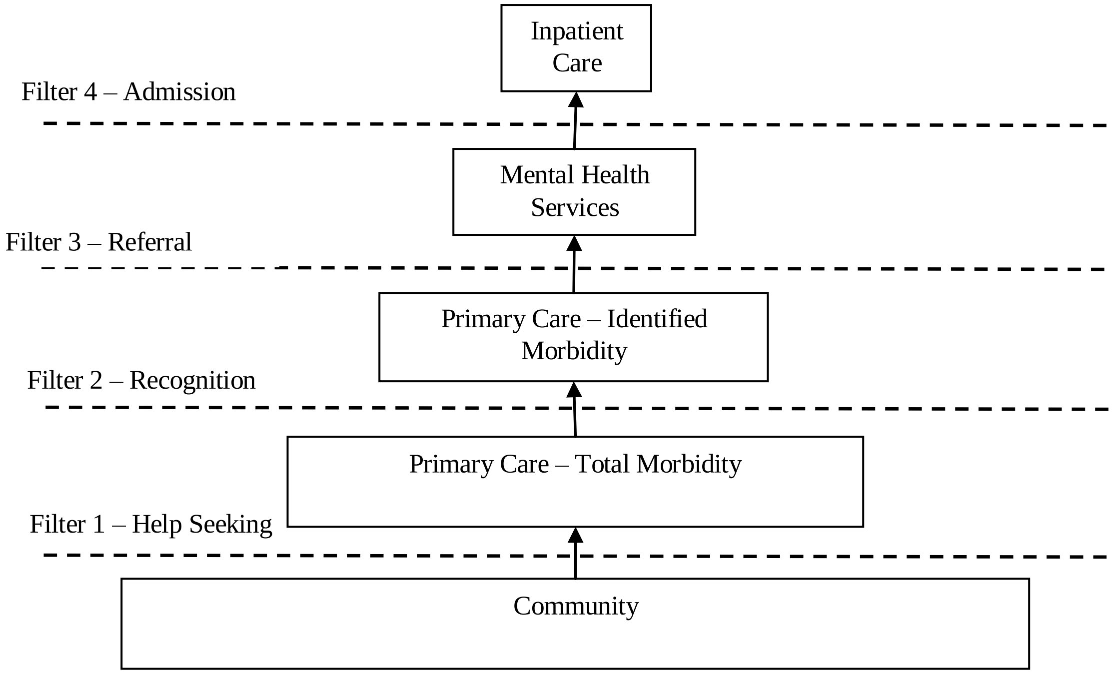

Figure 2.1 - Goldberg & Huxley's pathways to care model

Thus, there are four filters separating each of the five levels of care in the proposed model, and various patient-, physician-, and service-level factors influence the probability that a patient will proceed along the care pathway. Additionally, progression through each filter correspondingly increases the severity of the cases at each level. There will consequently be a greater proportion of cases suffering from severe mental illnesses that are unlikely to resolve without treatment, such as schizophrenia and bipolar disorder, at the level of psychiatric and inpatient services, while a greater proportion of cases at the community level will exhibit symptoms that may remit without treatment, such as milder forms of depression and anxiety (Goldberg and Huxley, 1992).

Empirical evidence on pathways to mental health care presents a much more complex picture of the types and sequence of contacts made by individuals suffering from psychiatric symptoms than the model proposed by Goldberg and Huxley. In addition to primary care providers and mental health services, help-seeking pathways may involve such diverse contacts as emergency services, social services, the criminal justice system, school counsellors, and religious agencies. The model also assumes that the pathway to care begins with the general practitioner, which may not always be the case. A large, multinational study was conducted on behalf of the World Health Organization to examine the pathways to mental health care of patients in eleven different countries (Gater *et al.* 1991). The nature of the pathway varied substantially depending on the region and the availability of services. In areas with many mental health resources, patients took a more direct route from the community to mental health services, similar to the pathway described by Goldberg and Huxley; however, in areas with few mental health resources, patients took a wide variety of different pathways that often included indigenous or faith healers (Gater *et al.* 1991). In addition to this variation between regions, there is also a great deal of variation within regional health care systems. For example, a recent systematic review on pathways to mental health care in the United Kingdom found that black patients had more varied and complex care pathways than white patients (Bhui *et al.* 2003). Thus, social, cultural, and health service factors have a significant impact on both the between- and within-country variation in the pathway to mental health care.

Although the majority of research on pathways to care has focused on mental health in general, numerous studies have examined the care pathways of patients with a first-episode of psychosis specifically. Indeed, the filter model proposed by Goldberg and Huxley is hypothesized to be “selectively permeable” to more severe psychiatric disorders (Goldberg and Huxley, 1992), and prior research has shown that patients with psychotic disorders have a much higher odds of passing through a given filter than patients with other mental health conditions (Marino *et al.* 1995). Additionally, the incidence of psychotic disorders is relatively low (Proctor *et al.* 2004), which prevents primary care providers from developing the knowledge and skill-sets necessary to recognize the signs of early psychosis. As such, it follows that patients suffering from psychosis have substantially different pathways to mental health care than patients suffering from less salient and acute psychological distress. The concept of pathways to care is of particular importance in first-episode psychosis, given that poor functional and clinical outcomes are associated with a long duration of untreated psychosis (Marshall *et al.* 2005; Norman and Malla, 2001; Perkins *et al.* 2005).

There exists an extensive literature on pathways to care in first-episode psychosis. Manuscript I presents a systematic review of the pathways to mental health care of first-episode psychosis patients, with a focus on the socio-demographic determinants of the pathway to care, and the impact of the care pathway on subsequent treatment delay. The objective of the review was to provide a comprehensive summary of the literature, and many of the included studies were descriptive in nature and do not use multivariable models to adjust for confounding, making standard critical appraisal tools of little relevance for this body of literature. As such, we do not assess the quality of the included studies, nor do we exclude studies on account of poor quality; therefore, our findings should be interpreted in light of this limitation. Nevertheless, our systematic review provides a thorough synopsis of pathways to care in first-episode psychosis, allowing us to contextualize this thesis in the current state of knowledge and to identify the gaps to be addressed by this research.

Manuscript I: The Pathways to Mental Health Care of First-Episode Psychosis Patients – A Systematic Review

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Abstract

Background: Although there is agreement on the association between delay in treatment of psychosis and outcome, less is known regarding the pathways to care of patients suffering from a first psychotic episode. Pathways are complex, involve a diverse range of contacts, and are likely to influence delay in treatment. We conducted a systematic review on the nature and determinants of the pathway to care of patients experiencing a first psychotic episode.

Methods: We searched four databases (MEDLINE, Healthstar, EMBASE, PsycINFO) to identify articles published between 1985 and 2009. We manually searched reference lists and relevant journals and used forward citation searching to identify additional articles. Studies were included if they used an observational design to assess the pathways to care of patients with first-episode psychosis.

Results: Included studies (n=30) explored the first contact in the pathway and/or the referral source that led to treatment. In 13 of 21 studies, the first contact for the largest proportion of patients was a physician. However, in nine of 22 studies, the referral source for the greatest proportion of patients was emergency services. We did not find consistent results across the studies that explored the sex, socioeconomic, or ethnic determinants of the pathway, or the impact of the pathway to care on treatment delay.

Conclusions: Additional research is needed to understand the help-seeking behaviour of patients experiencing a first-episode of psychosis, service response to such contacts, and the determinants of the pathways to mental health care, to inform the provision of mental health services.

Introduction

Recent efforts in psychosis research have focused on the period from the onset of psychotic symptoms to appropriate psychiatric intervention, known as the duration of untreated psychosis (DUP). Findings from literature reviews suggest that delays in the treatment of the first episode are associated with poor clinical and functional outcome, and that it may be possible to reduce the duration of this delay (Marshall *et al.* 2005; Melle *et al.* 2004; Norman and Malla, 2001; Perkins *et al.* 2005). Although there is little consensus as to what constitutes a long DUP, it is consistently associated with lower overall functioning, more severe positive and negative symptoms, lower quality of life, and a reduced likelihood of achieving remission (Marshall *et al.* 2005), as well as poor response to psychiatric treatment (Perkins *et al.* 2005). This evidence has sparked substantial efforts in secondary prevention and early intervention for psychosis (McGorry *et al.* 2007).

The emphasis on early detection and reduction of treatment delay in first-episode psychosis (FEP) has led to an interest in the modes and routes by which patients experiencing psychotic symptoms access help. These pathways to care are defined as “the sequence of contacts with individuals and organizations prompted by the distressed person’s efforts, and those of his or her significant others, to seek help…”(Rogler and Cortes, 1993, pg. 555) Care pathways are not random, and are influenced by social, cultural, and health service factors. The pathways to care encompass not only the help-seeking behaviour of the patient and family members, but also the accessibility of health services and the identification of, and response to, the symptoms of early psychosis by each contact on the pathway (Singh and Grange, 2006). This concept is of particular importance in FEP, given the poor functional and clinical outcomes associated with a long DUP (Marshall *et al.* 2005; Norman and Malla, 2001; Perkins *et al.* 2005), and the suffering endured by patients and their families. Both help-seeking and referral delays impact the length of time that psychotic symptoms go untreated, and there is evidence that referral delays may be responsible for a substantial proportion of the DUP (Bechard-Evans *et al.* 2007; Norman *et al.* 2004).

Prior research on the pathways to care of patients with FEP presents a complex picture. In addition to general practitioners and psychiatrists, the pathways may involve such diverse contacts as emergency services, social services, police, school counsellors, and religious agencies. Involuntary and negative contacts are frequent (Garety and Rigg, 2001), such as with police or emergency services, and may be subsequently associated with poor engagement in treatment(Compton, 2005) and dissatisfaction with services (Bhugra *et al.* 2004). Thus, gaining an understanding of the factors that influence the pathways to care of patients with FEP is crucial to achieving the objectives of improving access to treatment through early symptom detection and reductions in treatment delay.

The objective of this systematic review was to summarize the literature on the pathways to care of patients with FEP, and to describe the sex, socioeconomic, and ethnic determinants of these pathways, to the extent that they are known in the nascent research literature. Additionally, we sought to examine the evidence on the association between the pathway to care and the duration of untreated psychosis (DUP).

Methods

Definition of Terms

The term *Care Pathway Contact* refers to the individual, agency or service provider with whom the patient came into contact on the pathway to mental health care. The *First Contact* refers to the care pathway contact from whom help was first sought after the onset of psychotic symptoms. This is of interest because it gives an indication of how patients and family members initiate help seeking and highlights the care pathway contacts who could be targeted for early intervention. The *Referral Source* denotes the care pathway contact who suggested or arranged for contact with mental health services or a specialized treatment program. This care pathway contact highlights the service providers who are most involved in facilitating connections with mental health services and is of interest for informing policies on access to specialized services, whether through an open referral system or a gatekeeper mechanism.

Search Strategy

We conducted an electronic search using the MEDLINE (1950-2009), HealthStar (1966-2009), EMBASE (1980-2009), and PsycINFO (1985-2009) databases. The MEDLINE search terms are presented in Appendix A. This search strategy was developed in consultation with a professional librarian, and was adapted for EMBASE, PsycINFO and HealthStar using analogous terms.

We obtained further studies via a manual search of 15 relevant journals (Appendix B). We also manually searched personal files and the bibliographies of all relevant studies and review articles, and forward citation searching was done using the ISI Web of Knowledge to locate all articles that had cited the included studies. Finally, we located a systematic review that focused on the psychometric properties of pathways to care instruments for patients with FEP (Singh and Grange, 2006), which was used to corroborate the findings from our search strategy. We regularly updated all segments of the literature search, with the final update in December 2009.

Selection of Relevant Studies

We screened the titles and abstracts of all citations and obtained the full-text version of relevant studies to review for inclusion eligibility. The studies were included if they employed an observational design and presented quantitative data on the pathways to care of patients with FEP. We did not impose any language restrictions in our search strategy.

We used a cutoff publication year of 1985 given that the concept of pathways to psychiatric care was first introduced by Goldberg and Huxley in 1980 (Goldberg and Huxley, 1980), and the earliest article identified by the systematic review by Singh and Grange was published in 1989 (Singh and Grange, 2006).

Data Extraction and Synthesis

For all studies that met the inclusion criteria, two independent reviewers extracted data on the proportion of patients seeking help from each type of care pathway contact. We extracted the data using pilot tested forms, and we resolved discrepancies by consensus. Authors were contacted for further information or clarification when the data were aggregated or unclear.

Studies were subdivided based on whether they examined the first contact on the pathway to care or the referral source. Contacts were categorized as follows: (a.) Physician – includes general practitioners, psychiatrists, or outpatient mental health services; (b.) Non-Physician – includes private psychologists, counsellors, social workers, religious agencies, or self referral (referral source only); (c.) Emergency – refers to emergency departments, crisis teams, or inpatient units. The care pathway contacts were grouped as "Emergency Services" given that involuntary and negative pathways to care are associated with poor engagement with services (Compton, 2005). Additionally, we aggregated contacts with "Physician Services" because many health care systems require a physician referral to access specialized mental health services. Studies differed on whether they included family and/or police as care pathway contacts. When they were included, we grouped these data in the non-physician and emergency categories, respectively.

Substantial clinical, statistical, and contextual heterogeneity precluded a meta-analysis, therefore we synthesized the data descriptively. This heterogeneity likely resulted from the variation in study settings, as studies were conducted across several countries and health care systems. The lack of a validated tool with established psychometric properties for measuring pathways to care also prevented a meta-analysis (Singh and Grange, 2006), as the included studies used a variety of different definitions of pathways to care and methods for assessment.

Results

The electronic database search retrieved 1110 studies, of which 45 were deemed relevant for this review. The manual search additionally retrieved 14 studies that were missed in the electronic search, likely due to the lack of a standardized search term for pathways to care (Appendix A). In total, 59 full-text articles were identified, and we excluded 35 of these studies because they did not use a FEP population (n=18), provide quantitative data on pathways to care (n=12), and/or use an observational design (n=9), or because they presented duplicate data that were available in another article (n=4) (Bhugra *et al.* 1999; Cougnard *et al.* 2004a; Fuchs and Steinert, 2002; Morgan *et al.* 2005b). An additional six studies were located through regular updates of the literature search. Thirty studies met the inclusion criteria for our review (Appendix C). Specifically, 21 studies examined pathways to care generally, and nine explored the sex, SES and ethnic determinants of the pathways (Figure 2.2, pg. 17). Additionally, 15 studies examined the impact of the pathway to care on the DUP.

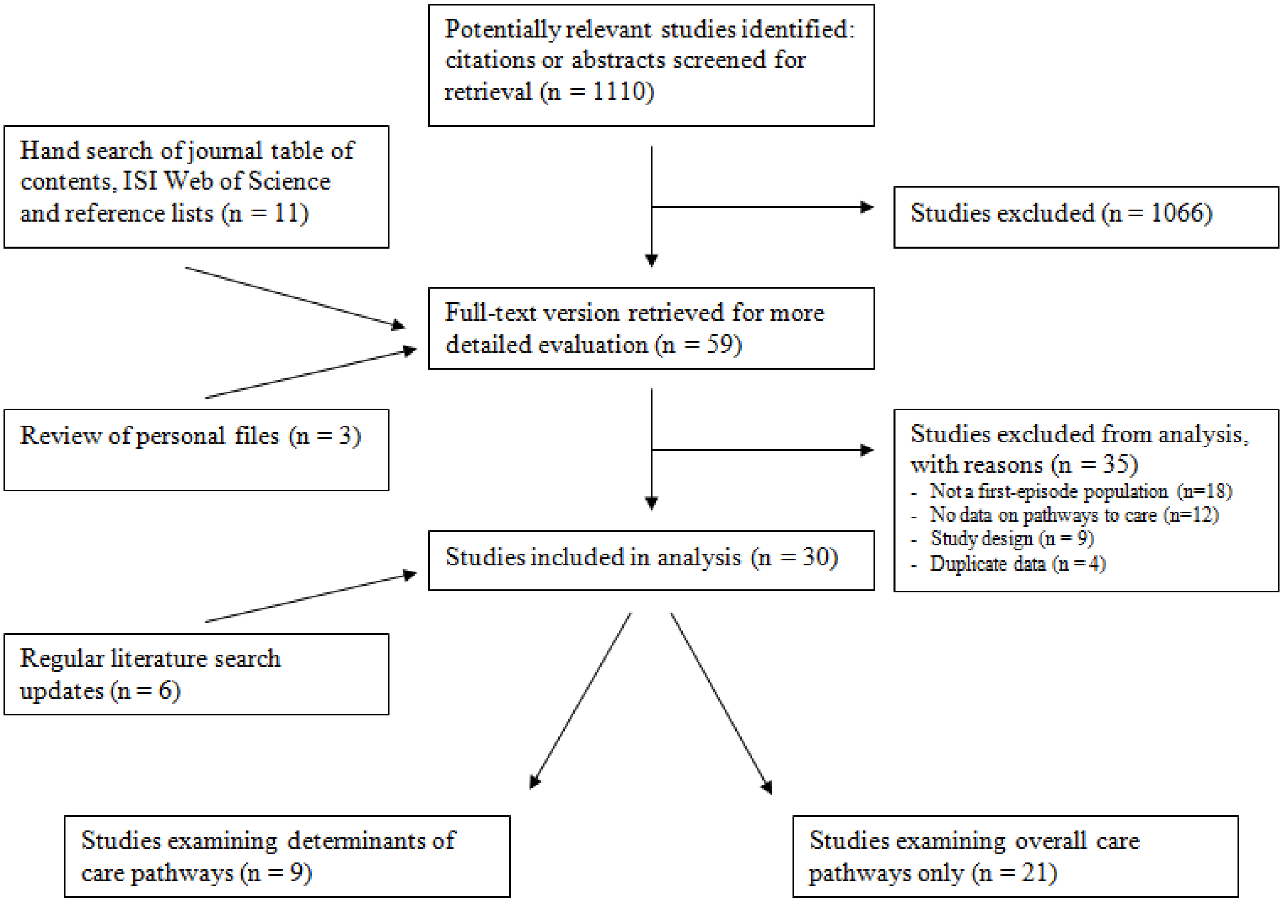

Figure 2.2 - Flow chart of systematic review search strategy and study inclusion.

Study Characteristics

The characteristics of included studies are summarized in Table 2.1 (pg. 19). Studies were conducted in a variety of countries (n=16), and one was published in a language other than English (Kohn *et al.* 2004). The sample sizes varied substantially, ranging from 21 to 462 participants (median across studies=86). The studies generally employed a descriptive and cross-sectional design. Given that there is no validated instrument for measuring pathways to care (Singh and Grange, 2006), the data collection methods varied across the studies, which used some combination of patient, family, or clinician interviews, and/or medical records (Table 2.1, pg. 19).

The studies used different indices of the pathway to care, with eight examining the first contact, ten examining the referral source, and twelve presenting data on both (Table 2.1, pg. 19). Additionally, twelve studies assessed the total number of care pathway contacts (Table 2.1, pg. 19), with the median number of contacts ranging from 1 to 4.5 (median across studies=3). In some circumstances, the first contact on the pathway to care was also the referral source into treatment, but only five studies provided the data in sufficient detail to allow the impact of this to be assessed (Chiang *et al.* 2005; Chong *et al.* 2005; Fuchs and Steinert, 2004; Kohn *et al.* 2004; Sharifi *et al.* 2009). Finally, six studies included family members and 19 included police as potential care pathway contacts (Table 2.2, pg. 22; Table 2.3, pg. 24), highlighting differences across studies in the definition of the pathway to care.

Table 2.1 - Characteristics of studies included in the systematic review.

Study	n	Country	Pathways Data Source	Sample Source	% Male	% Schiz. Spectrum	Care Pathway Contact	# Contacts Median (Range)	Covariates of Interest
Lincoln, Harrigan & McGorry, 1998[c]	62	Australia	PI	SP	65%	52%	First Contact	4.5 (1-17)	-
Addington et al, 2002	86	Canada	PI, FI	SP	66%	100%	Referral Source	2 (1-6)[e]	-
Scholten et al, 2003	134	Canada	PI, FI, MR	SP	74%	84%	Referral Source	-	DUP
Norman et al, 2004	110	Canada	PI, FI, CI, MR	SP	80%	76%	Both	-	-
Addington & Addington, 2006	373	Canada	N/A	SP	N/A	75%	Referral Source	-	DUP
Bechard-Evans et al, 2007	98	Canada	PI, FI, CI, MR	SP	69%	81%	First Contact	-	DUP
Archie et al., 2010	200	Canada	PI, FI, CI, MR	SP	78%	100%	Both	3 (N/A)	Sex, SES, Ethnicity
Chiang et al, 2005	35	China	PI, FI	SP	40%	N/A	Both	1 (0-3)	DUP
Cougnard et al, 2004	86	France	PI, FI	IP	64%	62%	First Contact	2 (1-7)	DUP, Sex, SES
Fuchs & Steinert, 2004[c]	66	Germany	PI	IP	59%	100%	Both	-	DUP
Kohn et al, 2004[c]	80	Germany	PI	IP	73%	100%	Both	3 (N/A)	DUP, Sex, SES
Sharifi et al, 2009	91	Iran	PI, FI, MR	IP	58%	47%	Both	-	DUP
O'Callaghan et al, 2009	142	Ireland	PI, FI	SP	62%	74%	Both	2 (0-8)	DUP
Yamazawa et al, 2004	83	Japan	MR	OP	42%	100%	Referral Source	-	-
Gill, Koh & Jambunathan, 2005	38	Malaysia	PI	IP	58%	76%	First Contact	-	-
Razali & Mohd Yasin, 2008	60	Malaysia	PI, FI	OP	80%	100%	First Contact	-	-
Turner, Smith-Hamel & Mulder, 2006	184	New Zealand	PI, CI	SP	72%	55%	Referral Source	4 (0-42)[e]	Ethnicity
Chong et al, 2005(i)	112	Singapore	PI, FI, MR	PS	57%	100%	Both	-	DUP
Chong et al, 2005(ii)	287	Singapore	PI, FI	SP	55%	33%	Referral Source	-	-
Temmingh & Oosthuizen, 2008	21	South Africa	PI, FI, MR	IP	52%	95%	Both	3 (1-6)	DUP, Sex, Ethnicity
Platz et al, 2006[c]	104	Switzerland	PI, FI	SP	75%	N/A	Both	3 (1-8)	DUP

[a] All patients in sample were African Caribbean; [b] All patients in the sample were African American
[c] Contacts included prodromal period; [d] Samples from two different countries within the same study;
[e] Range presented, median estimated from mean value; N/A = Data not available

Data Source: PI = Patient Interview; FI = Family/Friend Interview; CI = Clinician/Caseworker Interview; MR = Medical Records; Q = Questionnaire

Sample Source: SP = Specialized Treatment Program; PS = Psychiatric Services; CS = Community Services; IP = Inpatient; OP = Outpatient; CA = Catchment Area; CJ = Criminal Justice

Covariates Examined: DUP = Duration of Untreated Psychosis; SES = Socioeconomic Status

Table 2.1 con't. – Characteristics of studies included in the systematic review.

Study	**n**	**Country**	**Pathways Data Source**	**Sample Source**	**% Male**	**% Schiz. Spectrum**	**Care Pathway Contact**	**# Contacts Median (Range)**	**Covariates of Interest**
Bhugra et al, 2000[a,d]	46	Trinidad	PI, FI, MR	PS, CS, CJ	57%	100%	First Contact	-	-
	38	United Kingdom			74%	100%			
Harrison et al, 1989[a]	131	United Kingdom	PI, FI, MR	CA	65%	68%	First Contact	-	Sex, Ethnicity
Cole et al, 1995	93	United Kingdom	PI, FI, MR, Q	CA	54%	62%	First Contact	-	Sex, SES, Ethnicity
Burnett et al, 1999	100	United Kingdom	PI, FI, MR	CA	65%	100%	Referral Source	-	SES, Ethnicity
Garety & Rigg, 2001	21	United Kingdom	CI, MR	PS, CA	76%	100%	Referral Source	-	-
Morgan et al, 2005	462	United Kingdom	PI, FI, MR	CA	58%	74%	Referral Source	-	DUP, Sex, SES, Ethnicity
Cratsley et al, 2008	59	United Kingdom	MR	SP	68%	81%	Referral Source	-	DUP
Compton et al, 2006[b,c]	25	United States	PI, FI, CI, MR	IP	76%	100%	Both	3 (1-7)[e]	DUP
Chien & Compton, 2008	76	United States	PI, FI, CI, MR	IP	78%	100%	Both	2 (1-8)[e]	-

[a] *All patients in sample were African Caribbean;* [b] *All patients in the sample were African American*
[c] *Contacts included prodromal period;* [d] *Samples from two different countries within the same study;*
[e] *Range presented, median estimated from mean value; N/A = Data not available*

Data Source: PI = Patient Interview; FI = Family/Friend Interview; CI = Clinician/Caseworker Interview; MR = Medical Records; Q = Questionnaire

Sample Source: SP = Specialized Treatment Program; PS = Psychiatric Services; CS = Community Services; IP = Inpatient; OP = Outpatient; CA = Catchment Area; CJ = Criminal Justice

Covariates Examined: DUP = Duration of Untreated Psychosis; SES = Socioeconomic Status

First Contact on the Pathway to Care

Twenty studies examined the first contact on the pathway to care, with one study presenting data from two different countries (Bhugra *et al.* 2000), for a total of 21 datasets (Table 2.2, pg. 22).The first contact for the largest proportion of patients was a physician in 13 of 21 studies. Three additional studies found a similar proportion of patients used a physician or emergency services as the first contact, three studies found that the majority (52%-66%) used emergency services, and two found the majority (62%-63%) of patients made first contact with a non-physician.

When we examined the findings by region, all of the eight European studies found that a physician was the first contact for the largest proportion of patients. In contrast, none of the five North American studies found that a physician was the first contact for the largest proportion of patients, with two studies finding the largest proportion of patients used emergency services, and three finding that approximately equal proportions used a physician or emergency services (Table 2.2, pg. 22). We also examined the findings by availability of universal health insurance and by whether the country employs a gatekeeper system for access to specialist services, but did not observe notable trends for either of these factors.

Table 2.2 - Summary of findings from studies examining the first contact on the pathway to care.

Study	n	Country	Physician Contact	Non-Physician Contact	Emergency Contact	DUP (weeks) Median (Range)
Lincoln, Harrigan & McGorry, 1998[b]	62	Australia	52%	26% [c]	23% [d]	23.9 (N/A)
Norman et al, 2004	70[a]	Canada	**44%**	13%	**43%**	21.1 (N/A)
Bechard-Evans et al, 2007	98	Canada	27%	20%	53%	13.1 (0.1-293.7)
Archie et al, 2010	200	Canada	**36%**	25%	**34%**	22.1 (N/A)
Chiang et al, 2005	35	China	23%	63%	14%	17.4 (0-500.6)
Cougnard et al, 2004	86	France	63%	22% [c]	15% [d]	28 (IQR 4 - 104)
Fuchs & Steinert, 2004[b]	66	Germany	58%	8%	35%	68 (N/A)
Kohn et al, 2004[b]	80	Germany	50%	26%	24% [d]	Overall DUP N/A
Sharifi et al, 2009	91	Iran	57%	23%[c]	14%[d]	11 (0.1-888)
O'Callaghan et al, 2009	142	Ireland	60%	22%	8%[d]	Mean = 82 (SD = 152)
Gill, Koh & Jambunathan, 2005	38	Malaysia	16%	18%	66%	12 (1 - 260)
Razali & Mohd Yasin, 2008	60	Malaysia	38%	62%	0%	-
Bhugra et al, 2000(i)	46	Trinidad	98%	2%	0% [d]	-
Chong et al, 2005(i)	112	Singapore	45%	29%	26% [d]	48 (0.4 - 1344)
Temmingh & Oosthuizen, 2008	21	South Africa	57%	19%	24% [d]	18.1 (IQR 0 - 36.8)
Platz et al, 2006[b]	104	Switzerland	78%	15%	7%	Overall DUP N/A
Harrison et al, 1989	131	United Kingdom	76%	10%	11% [d]	-
Cole et al, 1995	93	United Kingdom	43%	35%	22% [d]	-
Bhugra et al, 2000(ii)	38	United Kingdom	50%	26%	24% [d]	-
Compton et al, 2006b	25	United States	**48%**	0%	**52%** [d]	32.9 (0.4 - 337.7)
Chien & Compton, 2008	76	United States	33%	0%	64% [d]	27.7 (0.4 - 590.3)

[a] *Prodromal patients removed from sample;*

[b] *Contacts included prodromal period;*

[c] *Family members included as potential care pathway contacts;*

[d] *Police included as potential care pathway contacts;*

DUP = Duration of Untreated Psychosis; N/A = Data not available; SD = Standard Deviation

Referral Source on the Pathway to Care

Twenty-two studies examined the referral source on the pathway to care (Table 2.3, pg. 24). In contrast to the first contact, the referral source for the largest proportion of patients was emergency services in nine of 22 studies. One additional study found an approximately equal proportion of patients were referred by emergency services and a physician. A physician was the referral source for the largest proportion of patients in eight studies, and a non-physician in four studies.

When we examined the findings by region, six of the eight European studies found that the physician was the source of referral for the largest proportion of patients. In contrast, six of seven North American studies found that emergency services were the referral source for the largest proportion of patients, with the seventh study finding an equal proportion referred by emergency services and a physician. Four of five Asian studies found that the largest proportion of patients used a non-physician as the referral source (Table 2.3, pg. 24). We again examined the findings by both the availability of universal health insurance and the use of a gatekeeper system in the jurisdiction of interest, but did not observe any notable trends.

Table 2.3 - Summary of findings from studies examining the source of referral on the pathway to care.

Study	n	Country	Physician Contact	Non-Physician Contact	Emergency Contact	DUP (weeks) Median (Range)
Addington et al, 2002	86	Canada	36%	12%[a]	52%	27 (0 - 780)
Scholten et al, 2003	134	Canada	39%	16%	46%	19.4 (IQR 7.3-44.8)
Norman et al, 2004	110	Canada	41%	10%	49%	21.1 (N/A)
Addington & Addington, 2006	373	Canada	**46%**	7%	**47%**	Overall DUP N/A
Archie et al, 2010	200	Canada	31%	5%	51%	22.1 (N/A)
Chiang et al, 2005	35	China	23%	48%	29%	17.4 (0-500.6)
Fuchs & Steinert, 2004	66	Germany	50%	38%	12%	68 (N/A)
Kohn et al, 2004	80	Germany	46%	23%	29%[b]	Overall DUP N/A
Sharifi et al, 2009	91	Iran	42%	36%[a]	16%[b]	11 (0.1-888)
O'Callaghan et al, 2009	142	Ireland	73%	0%	27%[b]	Mean = 82 (SD = 152)
Yamazawa et al, 2004	83	Japan	19%	63%	14%[b]	20 (N/A)
Turner, Smith-Hamel & Mulder, 2006	184	New Zealand	13%	7%[a]	80%[b]	4.3 (N/A)
Chong et al, 2005(i)	112	Singapore	21%	44%	35%[b]	48 (0.4 - 1344)
Chong et al, 2005(ii)	287	Singapore	24%	41%[a]	14%[b]	13.3 (26.0) *Mean (SD)*
Temmingh & Oosthuizen, 2008	21	South Africa	76%	19%	5%[b]	18.1 (IQR 0 - 36.8)
Platz et al, 2006	104	Switzerland	80%	10%	11%	Overall DUP N/A
Burnett et al, 1999	100	United Kingdom	57%	5%	36%[b]	-
Garety & Rigg, 2001	21	United Kingdom	N/A	N/A	62%[b]	-
Morgan et al, 2005	462	United Kingdom	40%	8%	52%[b]	9.4 (N/A)
Cratsley et al, 2008	59	United Kingdom	47%	3%	37%[b]	13 (0-182)
Compton et al, 2006	25	United States	20%	4%	76%[b]	32.9 (0.4 - 337.7)
Chien & Compton, 2008	76	United States	12%	0%	78%[b]	27.7 (0.4 - 590.3)

[a] Family members included as potential care pathway contacts; [b] Police included as potential care pathway contacts; DUP = Duration of Untreated Psychosis; N/A = Data not available; SD = Standard Deviation

Determinants of the Pathway to Care

Of the 30 included studies, only nine examined the sex, socioeconomic, or ethnic determinants of the pathways to care of patients with FEP (Table 2.1, pg. 19). Some studies also explored other determinants of the pathway to care. However, these are beyond the scope of this review given our stated objective and the limited number of studies available.

Seven studies explored sex as a determinant of the care pathway (Table 2.1, pg. 19), and three found no association (Cole *et al.* 1995; Cougnard *et al.* 2004b; Kohn *et al.* 2004). A Canadian study found that males were nearly five times more likely to make first contact with the emergency department (Archie *et al.* 2010), and a British study found that males were less likely to be admitted by a general practitioner (Morgan *et al.* 2005a). A study from South Africa found that males were more likely to be admitted involuntarily (Temmingh and Oosthuizen, 2008). Two British studies found evidence that sex may act as an effect modifier in the relationship between ethnicity and compulsory admission; however, the findings were conflicting, with one finding ethnic differences for males only (Morgan *et al.* 2005a), and the second finding ethnic differences only for females (Harrison *et al.* 1989).

Several socioeconomic indicators were examined as determinants of the pathway to care in six studies (Table 2.1, pg. 19). Five studies found no evidence that socioeconomic factors are predictive of the care pathway (Archie *et al.* 2010; Burnett *et al.* 1999; Cole *et al.* 1995; Cougnard *et al.* 2004b; Morgan *et al.* 2005a). Findings from a German study suggest that patients with semi-skilled or no vocational training were more likely to make first contact with police (Kohn *et al.* 2004).

Ethnicity as a determinant of the pathway to care was examined in seven studies (Table 2.1, pg. 19), of which three found no evidence of ethnic differences (Cole *et al.* 1995; Temmingh and Oosthuizen, 2008; Turner *et al.* 2006). Two British studies found that Afro-

Caribbean patients were less likely to be referred by a general practitioner and more likely to have police involvement on their pathway to care (Burnett *et al.* 1999; Morgan *et al.* 2005a), and a third found longer treatment-delays for Afro-Caribbean patients (Harrison *et al.* 1989). A study from Canada found that Asian and patients of other ethnic backgrounds (not including Afro-Canadian) were three to four times more likely to make first contact with emergency services than white patients (Archie *et al.* 2010). Lastly, three of the four studies reporting ethnic differences in the pathway to care also found evidence of differences in compulsory admissions for ethno-racial minority patients (Archie *et al.* 2010; Harrison *et al.* 1989; Morgan *et al.* 2005a).

The Pathway to Care and DUP

Twenty-four studies provided data on the DUP of participants, which varied substantially across studies (Table 2.2, pg. 22; Table 2.3, pg. 24), likely due in part to differences in definition and measurement (Compton *et al.* 2007). The median DUP ranged from 4 weeks for a study from New Zealand (Turner *et al.* 2006) to 68 weeks for a study from Germany (Fuchs and Steinert, 2004) (median across studies=21.6 weeks).

Of the 23 studies that measured DUP, 15 examined a putative association between the pathway to care and DUP (Table 2.1, pg. 19). Ten studies assessed the impact of the first contact, with two finding no significant association (O'Callaghan *et al.* 2010; Sharifi *et al.* 2009), and a third having an insufficient sample to allow conclusions to be drawn (Temmingh and Oosthuizen, 2008). A Canadian study found evidence that patients whose first contact was with a non-physician had a significantly longer DUP (Bechard-Evans *et al.* 2007). Descriptive data from German studies also indicated a longer DUP for patients who made first contact with a non-physician or at a hospital for another complaint (Fuchs and Steinert, 2004), and a shorter

DUP for patients who made first contact with emergency services (Kohn *et al.* 2004). In contrast, an American study found longer treatment delays when first contact was with a general practitioner (Compton *et al.* 2006). Data from France suggest longer delays when first contact is with a private psychiatrist, as compared with a general practitioner or public psychiatrist (Cougnard *et al.* 2004b). Similarly, a study from China also suggests that DUP is longest when the first care pathway contact is a psychiatrist or psychologist (Chiang *et al.* 2005). Finally, a study from Singapore found no difference between making first contact with a traditional or religious healer as compared with those who sought help from another type of care pathway contact (Chong *et al.* 2005).

Five studies assessed the impact of the referral source on the DUP, with two finding no significant association (O'Callaghan *et al.* 2010; Scholten *et al.* 2003). A study from Canada found that patients referred from inpatient units to early intervention services had a significantly shorter DUP, whereas patients referred by community agencies, psychologists or psychiatrists had significantly longer DUP (Addington and Addington, 2006). Similarly, a study from Switzerland found delays in time to referral when the referral source was a psychiatrist, psychologist or non-physician service, as compared with referral by a general practitioner or psychiatric services (Platz *et al.* 2006). Data from the United Kingdom suggests that individuals referred by a home treatment team or the emergency department had the lowest DUP (Cratsley *et al.* 2008).

Lastly, a study from the United Kingdom reversed the direction of the association and looked at the impact of DUP in predicting the type of care pathway contact. This study found that having a long DUP (>66 days) was not predictive of having a general practitioner or criminal justice source of referral (Morgan *et al.* 2005a).

Discussion

The findings from our systematic review on the pathways to care of patients with FEP suggest that the type of contact differs depending on whether the first contact or the referral source is considered. These contact points represent different time-periods in the course of illness, and may suggest a failure to identify previously untreated patients with psychotic symptoms presenting to a general practitioner. This could be because the symptoms are subtle, the assessment contact is too brief, or the presentation of a psychotic disorder is an infrequent event in a general practice. The care pathways also differed by geographic region, likely due to differences in social, cultural, and health service contexts. These regional trends highlight the need for research that is specific to the jurisdiction of interest.

Our findings support prior claims that involuntary and negative pathways to care, such as with police or emergency services, are frequent for patients with FEP (Garety and Rigg, 2001). This is of particular concern given that negative pathways to care may be associated with poor engagement in treatment(Compton, 2005) and greater dissatisfaction with services (Bhugra *et al.* 2004). Qualitative research on help seeking in FEP also indicates that negative experiences with psychiatric services may have an impact on future delays in help-seeking (Monteiro *et al.* 2006). Taken together, these findings suggest that we need to pay greater attention to the potentially deleterious impact of the involvement of police, ambulance and emergency services on the pathway to care.

Contacts with non-physicians tended to be infrequent relative to contacts with physicians and emergency services, except in some specific Asian jurisdictions. Lincoln and colleagues suggest that non-physician contacts may be involved as part of a “parallel help-seeking strategy” (Lincoln *et al.* 1998, pg. 22), which would not be captured by the indices employed by the included studies. Qualitative research on help-seeking in early psychosis indicates that non-physician contacts play an important role in linking the families of patients with psychiatric services (Wong, 2007a; Wong, 2007b), and families may use personal contacts as resources to expedite the help-seeking process (Bergner *et al.* 2008). There is also evidence that patients tend to under-report contact with non-physician services, possibly due to the perception that informal contacts do not warrant equal status on the help-seeking pathway (Lincoln and McGorry, 1995).

The studies that explored the sex, socioeconomic, or ethnic determinants of the pathways to care had conflicting findings, likely reflective of contextual differences across studies. Additionally, the objective of included studies was generally not to explore the socio-demographic determinants of the pathway to care, but rather to use these variables as covariates for other analyses. Of exception, several studies did focus on ethnic differences as the primary objective. The included studies were also limited in their power to explore these determinants, and future research may obtain a better understanding from studies that are designed and powered to examine the socio-demographic determinants of the pathway to care.

There is some evidence to suggest that the pathway to care has an impact on the DUP, however the results were inconsistent across studies, so it is difficult to draw conclusions. It is probable that the type of care pathway contact varyies the length of time between contact and referral into an appropriate treatment program. Indeed, data from Canada suggest that referral delay between the first contact and the initiation of adequate treatment accounts for a substantial proportion of the total DUP (Bechard-Evans *et al.* 2007). There is also evidence that patients who are already receiving mental health care at the time of onset of psychosis have a referral delay that is almost four times that of those who seek care after onset (Norman *et al.* 2004), which is consistent with several of the included studies that found a longer DUP was associated with contact with a psychiatrist and/or psychologist (Addington and Addington, 2006; Chiang *et al.* 2005; Cougnard *et al.* 2004b; Platz *et al.* 2006). This may be due to the difficulties that service providers face in recognizing and responding to the change in symptoms that occur at the onset of psychosis if patients are in treatment for other psychiatric conditions. It is also possible that clinicians have difficulties persuading patients to accept treatment for a different condition.

It is noteworthy that several additional factors have been found to impact the pathway to care in FEP. However, a comprehensive summary of these factors is beyond the scope of this review, and the small number of studies examining such determinants limits drawing any conclusions. Briefly, living alone at the time of onset (Burnett *et al.* 1999; Cole *et al.* 1995) and a lack of family involvement on the pathway to care (Cole *et al.* 1995; Morgan *et al.* 2005a) increased the likelihood of a negative care pathway. Additionally, the presence of definitive psychotic symptoms, as compared with insidious symptoms, impacts the type of care pathway contacts employed (Platz *et al.* 2006), and patients presenting with delusions, hallucinations, depression or suicidal ideation tend to be more likely to have successful treatment contacts (Addington *et al.* 2002). However, the mode of onset of psychosis was not found to impact various indices of the pathway to care (Chien and Compton, 2008). There is also some evidence to suggest that specific diagnostic groups may have a different likelihood of a negative pathway to care (Cougnard *et al.* 2004a; Morgan *et al.* 2005b).

Although we have presented the findings on the determinants of the pathway to care independently, it is probable that there is substantial interaction between various factors. Some investigators have acknowledged this by including interaction terms in their multivariate models, and have found some evidence of an interaction between SES and ethnicity (Burnett *et al.* 1999), and for both sex and age with ethnicity (Morgan *et al.* 2005a). It is also possible that patients entering the treatment system through emergency services may have shorter delays but may be more likely to be admitted involuntarily. Similarly, there may be some overlap between an insidious mode of onset of psychosis and long prodromal period, as the transition from prodromal phase to psychotic phase is usually less dramatic. In general, the limited evidence on such interactions prevents us from speculating on the exact nature of the complex interplay between the various factors. Future studies will need to employ more comprehensive approaches using alternative methodologies to gain further insight into the mode of action of such interactions.

Finally, it is also important to consider the nature of the pathway to care during the prodromal phase of FEP, when the symptoms are first beginning to emerge. Despite this, few studies included in our review examined prodromal contacts. Findings from these studies suggest that individuals are more likely to make contact with physician and non-physician services during the prodrome, and with emergency services after the onset of psychotic symptoms (Addington and Addington, 2006; Norman *et al.* 2004; Platz *et al.* 2006). A more complete understanding of the help-seeking attempts made during the prodromal phase of illness is crucial for secondary prevention and early intervention efforts.

Our findings are limited by the lack of a standard and validated measure of pathways to care (Singh and Grange, 2006), which restricts the comparability of the outcome data across studies. Furthermore, the included studies differed with respect to the definition of the pathway to care, and the inclusion or exclusion of different types of contacts can have an impact on the observed indices of the pathway to care. The trends and conclusions drawn from these data should be interpreted with caution given this heterogeneity in the outcome measure.

Despite these limitations, we are able to conclude that prior research on the pathways to care of patients with FEP has not sufficiently explored whether sex, socioeconomic status or ethnicity are determinants of the care pathways, or the impact of the pathway to care on DUP.

Additional determinants warrant further investigation, and a greater understanding of the complex interactions between individual determinants and of the nature of the pathway to care during the prodrome is needed. Future studies should be designed and powered to examine these determinants of the pathways to care, and investigators should make explicit the definitions of pathways to care employed. Finally, studies that aim to understand the potential impact of negative pathways to care on subsequent engagement and satisfaction with services are needed, and research specific to the jurisdiction of interest is warranted.

Understanding the determinants of the pathways to mental health care and the impact on DUP is crucial for informing the provision of mental health services. Such research is needed to identify disparities in the delivery and uptake of health and social services, the barriers that patients face when seeking help for psychotic symptoms, and inconsistencies in the response of service providers to help-seeking contacts. By increasing access for patients experiencing a first-episode of psychosis, we can potentially improve the outcomes of the disorder, prevent significant disability and delay in achieving social, educational and career milestones, and help to ease the psychological distress experienced by patients and their family members.

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Update to the Literature Review

Following the publication of our systematic review on pathways to care in first-episode psychosis, two additional studies were published that meet criteria for inclusion in the review. A descriptive study from Pakistan found that approximately equal proportions of patients made contact with physician and non-physician services as the first contact (Naqvi *et al.* 2009), which is consistent with other Asian studies from our review. This study did not examine the determinants of the pathway to care. The second study from The Netherlands focused on migration and urbanicity (Boonstra *et al.* 2011), which has not been examined previously. They found that the referral source for the largest proportion of patients was a general practitioner, which is again consistent with other European studies in our review. This study also found that patients referred by a general practitioner had a significantly longer delay than those referred by other medical professionals or by emergency services, and that the delay was longer for patients who were being seen on an ongoing basis at the onset of psychosis (Boonstra *et al.* 2011). The Dutch study also found that immigrant patients were more likely to be referred by emergency services (Boonstra *et al.* 2011).

Of interest, two additional studies have looked at pathways to care among individuals who are at a high risk for psychosis, which would include the putative ‘prodromal’ period for those who transition to psychosis (Phillips *et al.* 1999; Shin *et al.* 2010). These studies suggest that contact with emergency services is rare during this phase of illness, in contrast to the high utilization of these services by patients with active psychosis (Anderson *et al.* 2010). There has been recent interest in the development and implementation of services aimed at identifying patients at risk and intervening at this early stage in an effort to prevent the onset of psychotic illness. Consequently, the pathways to care of this at-risk patient population will likely become of increasing interest as these services accrue a sufficient sample for research purposes.

CHAPTER 3 - OBJECTIVE AND MIXED METHODS DESIGN

As concluded by our systematic review of the literature in Chapter 2, previous research on health services use in first-episode psychosis has not sufficiently determined whether socio-demographic factors are predictive of service utilization patterns, and whether these patterns have implications for subsequent treatment delay and engagement with mental health services. Prior studies generally presented descriptive data, and the primary objective of the studies was not typically to examine the socio-demographic patterns of service use, with the notable exception of ethnicity (Burnett *et al.* 1999; Cole *et al.* 1995; Harrison *et al.* 1989; Morgan *et al.* 2005b). Additionally, prior studies were limited by small sample sizes, likely due to the low-incidence of psychosis (Proctor *et al.* 2004). Few studies have examined patterns of health services use and the impact on subsequent treatment delay for first-episode psychosis in a Canadian context, particularly in Montréal (Anderson *et al.* 2010). The modes and routes by which patients access services are largely dependent on the social, cultural, and health system context, thereby highlighting the need for more Canadian research. To inform the provision of mental health services, we need to gain a better understanding of the sequencing and determinants of the help-seeking behaviour of patients experiencing the symptoms of early psychosis, the response of the health care system to such contacts, and the consequences of the pathway to care.

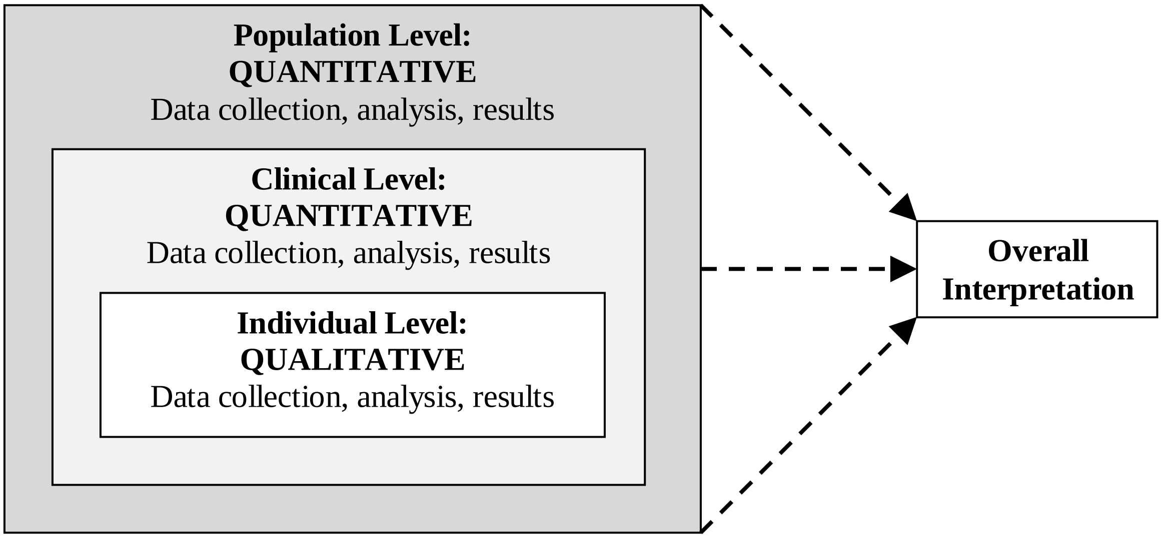
The overall objective of this thesis was to describe the socio-demographic and clinical determinants of the use of health services surrounding a first psychotic episode, and to determine the impact of these patterns on treatment delay and engagement with services. To achieve this objective, we used a mixed methods design, which is characterized by the inclusion of both quantitative and qualitative methods. This is done with the intent that the data will be "…integrated, related, or mixed at some stage of the research process. The underlying logic of mixing is that neither quantitative nor qualitative methods are sufficient in themselves to capture the trends and details of the situation."(Creswell *et al.* 2004, pg.7) The combination of quantitative and qualitative methods in a single study is often based on the rationale that each is associated with a number of strengths and limitations, and the incorporation of both allows for the limitations of one method to be offset by the strengths of the other, and vice versa (Bryman, 2006; Creswell *et al.* 2003; Kroll *et al.* 2005; Stange *et al.* 1994). Additionally, health sciences research is often focused on complex human behaviours, which requires the use of different strategies to provide a comprehensive account of the phenomenon under investigation (Creswell *et al.* 2003; Morse, 2003; Newman *et al.* 2003; Sandelowski, 2000a).

The design that was used in the current study was a multilevel triangulation design, which uses a distinct set of methods to collect different but complementary data at various levels of a phenomenon (Creswell and Plano Clark, 2007). An overall interpretation is formed by integrating the findings from each level. Using this design, we employed quantitative and qualitative methods to examine health services use by patients with first-episode psychosis at the population-, clinical-, and individual-levels (Figure 3.1, pg. 41):

- At the population level (Chapter 4), we used quantitative analyses of an administrative database to estimate the extent to which socio-demographic and clinical indicators are associated with patterns of health services use prior to an index diagnosis of psychosis. We also examined the impact of socio-demographic, clinical, and utilization indicators on subsequent treatment delay, as established by time to diagnosis and time to contact with psychiatric services.

- At the clinical level (Chapter 5), we used quantitative methods to estimate the extent to which socio-demographic and clinical factors are associated with the number and type of care pathway contacts among patients presenting to a specialized first-episode treatment program. We also evaluated the impact of the type of care pathway contact on treatment delay and subsequent withdrawal from services.
- At the individual level (Chapter 6), we used qualitative methods to describe the experiences with mental health services of patients with a first-episode of psychosis, and to identify factors that may have helped or hindered help-seeking efforts.

Integration of the quantitative and qualitative components was done in the thesis discussion (Chapter 7) by triangulating the findings from each study (Creswell and Plano Clark, 2007) The use of these disparate methods and data sources at each level of analysis allowed us to gain a more comprehensive understanding of the patterns of health services use, and its impact on treatment delay and service engagement, for patients experiencing a first-episode of psychosis.



Adapted From: Creswell and Plano Clark, 2007

Figure 3.1- A diagram of the multilevel triangulation design used to examine health services use by patients with a first-episode of psychosis.

CHAPTER 4 - THE POPULATION LEVEL: ADMINISTRATIVE DATABASE ANALYSIS

Our systematic review on the pathways to care in first-episode psychosis in Chapter 2 concluded that prior studies have not sufficiently determined whether socio-demographic or clinical factors impact health services use and treatment delay for first-episode psychosis in a Canadian context. In Manuscripts II and III, we conduct a population-based study using an administrative health and social services database from Montréal, Québec. In Manuscript II, we obtain an estimate of the incidence of first-episode psychosis in Montréal, which is fundamental to the delivery of early intervention services. In Manuscript III, we estimate the extent to which socio-demographic factors and clinical indicators are associated with patterns of mental health services use prior to an index diagnosis of psychosis, and the impact of these factors on subsequent treatment delay.

We are aware of only one study that has used administrative data to examine health services use in first-episode psychosis, however the data were limited to inpatient and outpatient records from psychiatric services and did not include contacts with primary care or non-physician services (Rietdijk *et al.* 2011). Other studies have typically used samples obtained from psychiatric services or specialized treatment programs (Anderson *et al.* 2010), which are unlikely to capture all cases seeking treatment. The population-based information on the incidence of first-episode psychosis and the use of health services by this patient population presented in Manuscripts II and III is crucial for the planning and implementation of early intervention services.

Detailed Methods

Study Design and Source of Data

We obtained access to data from the health and social services database of the *Agence de la Santé & des Services Sociaux* (ASSS) of Montréal, known as the *Banque de Données Jumelées sur les Services de Santé*, which was constructed by the ASSS in 2003. It is based on administrative data from several service providers, particularly the *Régie de l'Assurance Maladie du Québec* (RAMQ), which is the publically funded health insurance plan that provides universal coverage of medical services to nearly all residents of Québec.

The construction of the ASSS database involved linking the data from various service providers using encrypted RAMQ health insurance numbers. It is comprised of six linked datasets:

(1) The RAMQ beneficiary table consists of socio-demographic information, including age, gender, indices of social and material deprivation, and mortality information, where relevant. The vital statistics are obtained from the *Institut de la Statistique du Québec*.

(2) The RAMQ medical services table contains insurance claims for all inpatient and ambulatory health care services provided by physicians working under a fee-for-service remuneration scheme. Approximately 96% of individuals receiving physician services in Montréal do so from a fee-for service physician (Agence de la Santé et des Services Sociaux de Montréal, 2008). This database includes data such as procedure codes, nature and location of the procedure, specialty of the physician, and diagnosis. The procedure codes are based on the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures (Statistics Canada, 1986) and diagnoses are classified according to the International Classification of Diseases, 9th revision (ICD-9) (World Health Organization, 1977).

(3) The RAMQ pharmaceutical table provides data on medications dispensed in community pharmacies for beneficiaries of the pharmacare plan, specifically individuals aged 65 years and over, recipients of social assistance programs, and individuals who do not have access to a private insurance plan. Approximately 30% of individuals aged 14 to 25 years, and approximately 50% of the total population, are covered by this program (Régie de l'Assurance Maladie du Québec, 2007a; Régie de l'Assurance Maladie du Québec, 2007b). This dataset includes information on drug identification and dosage.

(4) The Med-Écho table is a hospital discharge register, containing information on all hospitalizations occurring in the Province of Québec, including acute care, long-term care, and day surgeries. Data are available on length of stay, and primary and secondary diagnoses. The diagnoses for hospitalizations occurring prior to April 2006 are classified according to ICD-9 (World Health Organization, 1977), and the diagnosis for hospitalizations occurring since are classified according to the 10th revision (ICD-10) (World Health Organization, 1992). Each hospitalization is also assigned a diagnosis-related group (DRG), which categorizes patients by diagnosis and resources required for treatment.

(5) The dataset of the CLSC (*Centre Local de Services Communautaires*), which is a province-wide network of sectorized front-line public health and social service clinics. Each CLSC covers an area with an average population of 45,000, and one in four Québec residents use the services provided by the CLSC (Philibert *et al.* 2007). This table includes information on physicians who are not remunerated on a fee-for-service scheme and would not be included in the RAMQ medical services database. It also contains information on contact with non-physician services provided by the CLSC, such as nurses, social workers, psychologists, and psycho-educators. Additionally, there is code indicating

the reason for the visit that corresponds to “Schizophrenia and Other Psychotic Disorders”, as well as other types of mental health and psychosocial problems.

(6) The dataset of the CHSLD (*Centre Hospitalier Soins de Longue Durée*), which provides residential and long-term care services. This table includes information on the type of facility, the length of stay, and the reason for needing residential services, including psychosis.

The ASSS database covers the fiscal years 2000 to 2006 inclusive, and includes all RAMQ beneficiaries residing in Montréal at any point from April 1st 2000 to March 31st 2007. The database includes information on medical services and pharmaceutical claims for these individuals anywhere in the Province of Québec, as well as hospitalizations occurring at a Québec institution. It is important to note that there are no private institutions in the area where patients with a psychotic disorder could otherwise have received treatment.

Case Ascertainment

The sampling frame for the current study was all individuals in the ASSS database between the ages of 14 and 25 years registered with the RAMQ as living in Montréal and using health services at any point during the period from April 1st 2004 through March 31st 2007 (i.e. fiscal years 2004 to 2006, inclusive). Included in the case definition were cases of schizophrenia-spectrum psychosis, which includes individuals with a diagnosis of schizophrenia, schizophreniform disorder, delusional disorder, and paranoia. Cases were identified by the presence of one of the following service contacts in the ASSS database:

a. A physician claim for schizophrenia-spectrum psychosis in the RAMQ medical services table with a corresponding psychiatric procedure code;

b. A CLSC visit record with a cited reason of “Schizophrenia or Other Psychotic Disorders” and a corresponding procedure code for a mental health or emergency visit;
c. A hospitalization discharge abstract with a primary or secondary discharge diagnostic code for schizophrenia-spectrum psychosis.

The RAMQ pharmaceutical table was not included in the case definition because a large number of individuals were taking an antipsychotic medication without a corresponding health services contact for psychosis in the database. A cross tabulation of the specific drugs and dosages suggested that only 12% of these individuals would be taking medication for psychosis (data not shown).

To remove prevalent cases of psychosis, we excluded all individuals who had a prior medical claim, CLSC visit, hospitalization or admission to a long-term care facility for any psychotic disorder, including affective, organic, and substance induced psychoses. We also excluded individuals who had a record of a prior prescription of any antipsychotic medication recorded in the pharmaceutical database. These exclusions are consistent with the clinical definition of FEP used by many early intervention programs, which typically limit enrolment to previously untreated cases (Breitborde *et al.* 2009). The database extends back to the year 2000, therefore the clearance period for excluding prevalent cases ranged from four- to six-years, depending on the year of onset of psychosis. The diagnostic codes and drug classifications that were used to construct our sample are listed in Appendix D through Appendix F.

To assess the impact of our case definition on obtained incidence estimates and observed patterns of service use, we conducted sensitivity analyses that included cases with a history of “Unspecified Psychosis” prior to the index diagnosis of schizophrenia-spectrum psychosis. A large proportion of patients classified initially as “Unspecified Psychosis” are later diagnosed with schizophrenia as the clinical presentation changes or additional information on prior symptomatology becomes available (Schimmelmann *et al.* 2005; Veen *et al.* 2004).

Socio-Demographic Variables

We obtained information on the sex, age at index diagnosis, and CLSC territory of residence for each case from the RAMQ beneficiary table.

Because data on individual-level socioeconomic status is not available in the ASSS database, we used the material and social deprivation index as an ecological measure of socioeconomic disparities (Gamache *et al.* 2010; Pampalon *et al.* 2009a; Pampalon *et al.* 2009b; Pampalon and Raymond, 2000). These indices were developed in the Province of Québec using data from census dissemination areas (DA), and scores are assigned at a high level of geographical resolution, the six-digit residential postal code of each beneficiary. Each DA is assigned a score for both material and social deprivation using data on six socioeconomic indicators from the 2006 census for the population aged 15 years and over. Specifically, material deprivation "...refers to the lack of the goods and conveniences that are part of modern life" (Pampalon *et al.* 2009a, pg.86) and is estimated from three variables: the proportion of the population without a high school diploma, the employment to population ratio, and the average income. Social deprivation "...refers to the fragility of the social network, from the family to the community" (Pampalon *et al.* 2009a, pg.86) and is estimated from an additional three variables: the proportion of the population who live alone, the proportion who are separated, divorced or widowed, and the proportion who are in a single-parent family (Gamache *et al.* 2010). These two dimensions of deprivation have been found to be relatively independent within Québec (r=0.13 for the current sample, data not shown)

(Pampalon and Raymond, 2000). The indicators are constructed for each available census from 1991 to 2006 using principal component analysis, and are age- and sex-standardized (Pampalon and Raymond, 2000). The DAs are grouped into quintiles of equal population size based on the provincial distribution, with the fifth quintile representing the most disadvantaged areas in the province (Pampalon and Raymond, 2000). Deprivation scores can be assigned to approximately 98% of the Québec population, with exclusions based on characteristics of the DA (typically residential facilities or very small population) (Pampalon *et al.* 2009b). An evaluation of the deprivation indices has found that the direction of the findings tend to be consistent with those obtained when individual-level indicators are used, however the deprivation indices may underestimate the socioeconomic disparities between groups (Pampalon *et al.* 2009a). We dichotomized the deprivation indices in the current analyses, and individuals falling into the worst quintile of material or social deprivation were classified as materially deprived or socially deprived, respectively.

We constructed a binary indicator variable based on whether there was evidence of substance abuse preceding the index diagnosis. This was determined by the presence of a medical claim or a hospitalization with a substance abuse diagnostic code, a hospitalization with intoxication listed as the external cause, an admission to a long-term care facility for an addiction problem, or a CLSC visit for addiction or substance abuse problems. Substance abuse and addiction are highly prevalent among patients with first-episode psychosis (Conus *et al.* 2007), and are associated with the modes by which patients access health services (Carr *et al.* 2003).

As an indicator of case severity, we also constructed a binary variable based on whether the individual had a hospital admission for a mental health condition in the week preceding or following the index diagnosis. Although this variable is not an indicator of the severity of psychotic symptoms *per se*, it is likely an indicator of overall case severity. Individuals who are hospitalized for FEP tend to have more severe functional and behavioural disturbance, are more likely considered to be a risk to self or others (Castle *et al.* 1994; Wade *et al.* 2006), and have an increased likelihood of subsequent readmission (Addington *et al.* 2010).

Service Utilization Indicators

For each case, all available data on the use of health or social services for mental health reasons were extracted from the ASSS database. We used the date of the first instance of a psychosis diagnosis as the index episode. A mental health contact was defined as follows:

a. A physician claim in the RAMQ medical services table that occurred in an outpatient or emergency department setting with a psychiatric diagnostic code, a psychiatric procedure code, or ‘psychiatrist’ listed as the specialty code;
b. A visit to the CLSC with either a psychiatric reason cited for the visit, a mental health procedure code, or ‘psychologist’ or ‘psycho-educator’ listed as the specialty code;
c. A hospitalization with a primary diagnosis of a psychiatric condition, a psychiatric code listed as the external cause, or a psychiatric DRG assigned;
d. An admission to a long-term care facility for a psychiatric reason.

Multiple billings with the same date and location in the medical services table, and with the same date and visit type in the CLSC table, were counted as one contact.

We calculated the total contacts in the four years preceding the index diagnosis of psychosis, and the proportion of individuals who contacted each type of service provider. We also constructed several indicators of service use, including whether the patient had contact with primary care (CLSC or general practitioner (GP)) for a mental health reason preceding the index diagnosis, and whether the individual had any contact with emergency services (inpatient units or emergency department (ED)) preceding the index diagnosis. We also extracted information on whether the index diagnosis occurred at an ED visit, as this is a common portal of entry into the health care system for patients with first-episode psychosis (Anderson *et al.* 2010).

Mental health services are sectorized in Montréal, therefore we constructed a binary indicator variable that classifies whether individuals have access to one of five early intervention services which would be expected to treat cases of first-episode psychosis. Individuals were classified based on their residential postal code using catchment area data reported by each of the programs. We attempted to use this variable in our multivariate analyses to explore whether having access to an early psychosis service would impact observed indices of health services use. However, given that the deprivation scores are also assigned using residential postal code, there was too much co-linearity in the data to include both variables. Over 80% of our sample had access to an early intervention services, and our primary objective was to examine socio-demographic determinants of health services use, therefore we opted to exclude this variable from our analyses in favour of the deprivation scores.

Lastly, we calculated two indicators as proxy measures for treatment delay: (1) The time interval from the first mental health contact to the index diagnosis; (2) The time interval from the first mental health contact to contact with a psychiatrist.

Data Analysis

We estimated the crude annual incidence proportion of first-episode SSP, along with the corresponding 95% confidence intervals (CIs) using the Wilson score method without continuity correction (Newcombe, 1998). We also used direct standardization to adjust the estimates for age and sex, and the 95% CIs were calculated using the method described by Rothman and Greenland (Rothman and Greenland, 1998). Using standardized estimates, we estimated risk ratios for the available socio-demographic variables, along with corresponding 95% CIs (Rothman and Greenland, 1998). The denominator data were obtained from the RAMQ and represent the average number of individuals between the ages of 14 and 25 years with valid RAMQ coverage residing in Montréal between 2004 and 2006, inclusive (Régie de l'Assurance Maladie du Québec, 2007b). To obtain an estimate of the population at risk for each stratum of both material and social deprivation, we used the overall frequency of deprivation scores from all individuals in the sampling frame of the ASSS database, and applied this distribution to the denominator data obtained from the RAMQ to estimate the denominator for each deprivation stratum. Incidence estimates were standardized to the 2006 Québec population using the data provided by the creators of the deprivation index (Gamache *et al.* 2010). For the total number of contacts preceding the index diagnosis, we obtained unadjusted estimates of the association with each of the covariates using a simple linear regression model, in which the dependent variable (number of contacts) was log-transformed due to the positively skewed distribution. Simple logistic regression models were used to estimate unadjusted associations between each of the covariates and the following outcomes defined as binary indicators (i) any contact with emergency services preceding the index diagnosis (analysis restricted to those with prior contacts), and (ii) whether the index diagnosis occurred at an ED visit. We then used multivariable linear and logistic regression models to estimate independent associations of the covariates with each of the aforementioned outcomes. All multivariable linear and logistic regression models included the following variables: sex, age at index diagnosis, material deprivation, social deprivation, substance abuse, contact with primary care services, and case severity. Of exception, the model for contact with emergency services (i) was not adjusted for case severity, as the use of inpatient services was used to define both the predictor (hospitalization in the week preceding or following the index diagnosis) and outcome variables (contact with ED or inpatient services).

We explored the possibility of geographic clustering by estimating multilevel models using the GENMOD procedure in SAS 9.2 (SAS Institute Inc., North Carolina, USA) with CLSC territory as the clustering unit. However, we did not find a substantial difference between findings from the multilevel models and those from conventional multiple regression analyses that assumed the independence of the outcomes of individual patients within the same CLSC region (data not shown). Therefore, we present the results of the conventional multiple regression analyses.

We used Cox-proportional hazards models to estimate the independent effects of the aforementioned covariates on (1) time from first contact to index diagnosis, and (2) time from first contact to contact with a psychiatrist. The analyses were restricted to individuals who had contact prior to the index date. Those who did not have the respective outcomes were censored at the end of the observation period (March 31st 2007). Two individuals died during the follow-up period, both from suicide, but this occurred after the outcome of interest. In preliminary analyses, we verified the proportional hazards assumption that the covariate effect remains constant over the entire follow-up period (Cox, 1972). This was done for each covariate by examining the plot of the log of the negative log of the survival function versus the log of time, with deviations from parallel indicating non-proportional hazards. We also tested the interaction of each covariate with time, with significant interactions indicating a violation of the proportional hazards assumption (Ng'andu, 1997). The covariate ‘contact with primary care’ was found to violate the proportional hazards assumption in both models, and the covariate ‘case severity’ was found to violate the proportional hazards assumption in model 2. Therefore, in final analyses we used a flexible extension of the proportional hazards model that does not impose *a priori* assumptions regarding the proportionality of hazards, and instead uses quadratic regression splines to model the time-dependent effects to estimate how the covariate effect (hazard ratio (HR)) changes over time (Abrahamowicz and MacKenzie, 2007). The final models included variables with significant time-dependent effects (i.e. non-proportional hazards), as well as variables that were statistically significant in the conventional Cox-PH model. The latter were represented in the model by the adjusted (constant over time) HRs.

The results are presented as fully adjusted odds ratios (OR) for logistic regression, as HRs for the PH models, and as time-dependent HRs for the flexible non-PH estimates, along with corresponding 95% confidence intervals (CI). The β-coefficients and 95% CIs of the linear regression analysis using a log-transformed outcome variable were converted to exp(β), which can be interpreted as the relative effects on the outcome of interest. The linear and logistic regression models were performed using SAS version 9.2 (SAS Institute Inc., North Carolina, USA), and the flexible PH regression models were done using R version 2.12.1 (R Foundation for Statistical Computing, Vienna, Austria).

Propensity Score Calibration to Correct for Unmeasured Confounding

Our analyses are limited by the availability of information in the administrative database, and we are missing data on several potentially important confounding variables. In an attempt to examine the impact of unmeasured confounding, we used the propensity score calibration method developed by Stürmer and colleagues to correct parameter estimates for multiple unmeasured confounders (Sturmer *et al.* 2005).

A propensity score is the probability that an individual is 'exposed', conditional on a set of observed covariates (Sturmer *et al.* 2005; Sturmer *et al.* 2007). Propensity score calibration uses data available in a separate 'validation sample', which contains information on potential confounders not available in the 'main' study database, to estimate two types of propensity scores. Specifically, (1) an 'error-prone' propensity score uses only those variables that are measured in the main study, whereas (2) a 'gold-standard' propensity score includes additional variables not available in the main study (Sturmer *et al.* 2005). The relationship between these two scores, estimated in the 'validation sample', is then used to calibrate a propensity score estimated in the main study using established regression calibration techniques typically employed for the correction of measurement error (Rosner *et al.* 1990). Finally, in the main study analyses, the effect of the exposure of interest is adjusted using the calibrated propensity score. Variance estimates are also adjusted to account for the uncertainty introduced by measurement error from the validation sample (Sturmer *et al.* 2005).

The propensity score calibration method is preferable to other strategies for dealing with unmeasured confounding, such as analysis of the sensitivity of the results with respect to potential confounders, because it considers the impact of the joint distribution of multiple unmeasured confounders (Sturmer *et al.* 2005). However, the validity of the method is dependent on the assumption that the 'error-prone' propensity score is a surrogate for the 'gold-standard' propensity score, independent of the outcome. In other words, "...surrogacy holds when the direction of confounding of the observed and unobserved variable(s) is the same" (Sturmer *et al.* 2007, pg. 1116). Propensity score calibration may result in overcorrection of parameter estimates, and bias may be exacerbated relative to the uncorrected model if the surrogacy assumption is not met (Sturmer *et al.* 2005; Sturmer *et al.* 2007). Therefore, in the current study it is used as an additional sensitivity analysis to assess the robustness of the results of the primary analyses.

To implement the propensity score calibration method, we used external validation data from the Prevention and Early Intervention for Psychosis Program (PEPP), which is a clinical research program for first-episode psychosis with an extensive database used for evaluating long-term outcomes and estimating treatment delay. The validation sample included 228 individuals with complete data on potential confounders.

The inclusion of each additional covariate increases the likelihood that the surrogacy assumption will be violated (Sturmer *et al.* 2007), therefore we only included variables that have been previously found to predictors of health services use in first-episode psychosis. Our systematic review suggests that ethnicity, living arrangements at the time of onset, and severity of psychotic symptoms may have an impact on observed care pathway indices (Anderson *et al.* 2010). The parameter estimates for each variable in the regression models were calibrated separately using these variables available in the 'validation' sample. Of exception, we did not calibrate sex or age, as their effects were not expected to be confounded by the additional variables. Propensity score calibration addresses unmeasured confounding by including additional variables not available in the main study. It also addresses residual confounding for the substance abuse variable, as the validation sample includes data on substance abuse diagnoses, whereas the study sample only includes individuals who came into contact for a substance use problem.

We assessed the validity of the regression calibrations by examining the correlation between the ‘error-prone’ propensity scores and the corresponding ‘gold-standard’ propensity scores, as weak correlations can lead to poorly calibrated estimates (Sturmer *et al.* 2005). The propensity score calibration was done using the SAS code provided by Stürmer and colleagues (Sturmer *et al.* 2005), and the *%BLINPLUS* macro for regression calibration developed by Spiegelman and colleagues (Logan and Spiegelman D., 2004).

Ethical Issues

The current study involves secondary analysis of administrative data, and approval to access these data for the purposes of this project was obtained from the Research Ethics Board at the Douglas Mental Health University Institute (Appendix G), a health care facility within the McGill Affiliated Health Network. All data were anonymized via health insurance numbers encrypted by the RAMQ, and the database does not contain identifying information such as beneficiary name, date of birth, or address. Furthermore, the database was accessed at the administrative offices of the Agence de la Santé & des Services Sociaux de Montréal, and individualized data were not taken offsite.

Manuscript II: The Incidence of First-Episode Schizophrenia-Spectrum Psychosis in Montréal – An Estimate from Administrative Data

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Abstract

Information on the incidence of first-episode psychosis (FEP) is crucial for the development of services targeting patients in the early stages of illness. We used population-based administrative data from physician billings, hospitalizations, pharmacies, and public health clinics in Montréal to estimate the incidence of first-episode schizophrenia-spectrum psychosis (SSP). All cases of SSP occurring over a three-year period (2004-2006) among individuals aged 14 to 25 years residing in Montréal were identified. We used a four- to six-year clearance period to remove cases with a history of any psychotic disorder or prescription for an antipsychotic medication. We identified 456 cases of SSP, yielding a standardized annual incidence of 82.9 per 100,000 for males (95% CI = 73.7, 92.1), and 32.2 per 100,000 for females (95% CI = 26.7, 37.8). Using ecologic indicators of material and social deprivation, we found a higher incidence proportion of SSP among individuals living in the most deprived areas, relative to those living in the least deprived areas. Clinical samples obtained from psychiatric services are unlikely to capture all cases seeking treatment, therefore population-based administrative data may be a useful tool for studying the frequency of psychotic disorders.

Introduction

There has been a burgeoning interest in research and service delivery focused on the first-episode of psychosis (FEP), and this has occurred for several reasons. Systematic reviews have confirmed that delay in the treatment of a FEP, expressed as the duration of untreated psychosis (DUP), is associated with poor clinical and functional outcomes (Marshall *et al.* 2005; Norman *et al.* 2005; Norman and Malla, 2001; Perkins *et al.* 2005). Additionally, outcome trajectories are typically defined within two years following the first psychotic episode (Harrison *et al.* 2001). Taken together, these findings have sparked substantial efforts in early symptom detection, comprehensive phase specific care during the initial stages of illness, and attempts to shorten the DUP (McGorry *et al.* 2007). Further, FEP samples lack the confounding effects of prolonged treatment and the impact of relapses, which allow for a better understanding of the course of psychotic disorders.

The development and implementation of specialized services targeting patients in the early stages of psychosis requires population-based information on the incidence of FEP. Prior studies have used samples obtained from early intervention programs (Amminger *et al.* 2006; Cassidy *et al.* 2008; Cheng *et al.* 2011) and secondary mental health services(Proctor *et al.* 2004; Reay *et al.* 2010) to estimate incidence; however, it is unlikely that these clinical samples will capture all cases seeking treatment, as patients may not be referred for more specialized care or may be lost to follow-up after initial contact. Other studies have obtained population-based estimates using extensive case ascertainment methods across a defined catchment area (Kirkbride *et al.* 2006; Kirkbride *et al.* 2007a), but such a comprehensive strategy may not be feasible in all jurisdictions. Routinely collected administrative data are an alternative source of population-based estimates of the incidence of FEP, and have additional advantages such as the availability of a larger number of cases and reduced costs. However, the utility of this information needs to be weighed against the limitations of administrative data, such as the lack of diagnostic standardization across professionals and the limited availability of socio-demographic information.

As part of the health insurance program in Canada, each province administers a database for the purposes of hospital and physician billing. Coverage of these services is universal, so nearly all residents of Canada should be included in these databases. Prior research has found that administrative data from publicly funded provincial insurance programs in Canada are useful for the surveillance of psychiatric disorders (Kisely *et al.* 2009), and estimates of disease burden obtained from these data have been found to be consistent with estimates obtained from community surveys (Bulloch *et al.* 2011). Other Canadian studies have used provincial billing data to obtain population-based estimates of the incidence of schizophrenia generally (Goldner *et al.* 2003; Vanasse *et al.* 2011), however we were unable to identify any studies, Canadian or otherwise, that used administrative data to estimate the incidence of FEP specifically. The operational definition of what constitutes the 'first-episode' of a psychotic disorder varies across clinical and research settings (Breitborde *et al.* 2009), but it differs from an incident case of psychotic disorder in that the patient is expected to be in the early stages of illness. As such, it is typically defined based on one of the following three indicators: (i) the first treatment contact for a psychotic disorder; (ii) the requirement for cases to not have received prior treatment with an anti-psychotic agent for longer than a specified period of time; (iii) the duration of psychotic symptoms (Breitborde *et al.* 2009). Although administrative data typically do not contain sufficient information for estimating symptom onset, they do have the potential to be useful for identifying a FEP based on patterns of health service contacts and antipsychotic use.

The objective of the current study was to obtain a population-based estimate of the incidence of first-episode schizophrenia-spectrum psychosis in Montréal using an administrative health and social services database.

Methods

Study Design and Source of Data

We obtained access to data from the *Agence de la Santé & des Services Sociaux* (ASSS) of Montréal. This database covers the years 2000 to 2006, inclusive, and contains linked administrative data from several health and social service providers in Montréal. The ASSS database primarily consists of physician billing claims, pharmaceutical claims and beneficiary information from the *Régie de l'Assurance Maladie du Québec* (RAMQ). The RAMQ is the publicly funded health insurance plan that provides universal coverage of medical services to residents of Québec, and coverage of pharmaceuticals to approximately 50% of the total population (see Table 4.1, pg. 62 for more details). The database also includes data from the hospital discharge register, from front-line public health and social service clinics, and from residential long-term care facilities. The data are linked using encrypted RAMQ insurance numbers. A description of the datasets that comprise the ASSS database is presented in Table 4.1 (pg. 62).

The ASSS database includes all RAMQ beneficiaries residing in Montréal at any point from 2000 to 2006, inclusive. It contains information on medical services, pharmaceutical claims, and hospitalizations obtained by these individuals anywhere in the Province of Québec. It is important to note that there are no private institutions in the area where patients with a psychotic disorder could otherwise have received treatment.

Table 4.1- Description of the individual datasets that comprise the linked database of the Agence de la Santé & des Services Sociaux (ASSS) of Montréal

Source of Data	Description	Variables of Interest
RAMQ Beneficiaries	Socio-demographic information on all RAMQ beneficiaries	Age, sex, ecological indices of social and material deprivation, mortality
RAMQ Medical Services	Fee-for-service physician claims for all inpatient and ambulatory health care services	Procedure codes*, location of the procedure, physician speciality, diagnosis**
RAMQ Pharmaceutical Program	Medications dispensed in the community to individuals ≥65, recipients of social assistance, those without private insurance (30% of beneficiaries 14-25 years)	Drug identification, dosage
Med-Echo	All hospitalizations occurring in the Province of Québec, including acute care, long-term care, and day surgeries	Primary and secondary discharge diagnoses**
CLSC	Contact with providers at sectorized front-line public health and social services clinics	Type of professional, reason for visit, procedure code
CHSLD	Use of residential long-term care facilities	Type of facility, reason for needing residential services

RAMQ - *Régie de l'Assurance Maladie du Québec*; CLSC - *Centre Local de Services Communautaires*; CHLSD - *Centre Hospitalier Soins de Longue Durée*.

**The procedure codes are based on the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures(Statistics Canada, 1986)*

***Diagnoses are classified according to the International Classification of Diseases, 9th revision (ICD-9)(World Health Organization, 1977) prior to April 2006, and are classified according to the 10th revision (ICD-10)(World Health Organization, 1992) since April 2006 (MED-ECHO only).*

Case Ascertainment

The sampling frame consisted of all individuals in the ASSS database between the ages of 14 and 25 years living in Montréal from 2004 to 2006, inclusive. We identified cases of schizophrenia-spectrum psychosis (SSP) during this period by the presence of one of the following service contacts:

a. A physician claim for SSP in the medical services table with a corresponding psychiatric procedure code;
b. A visit to a public health clinic with a cited reason of "Schizophrenia or Other Psychotic Disorders" and a corresponding procedure code for a mental health or emergency visit;
c. A hospitalization with a primary or secondary discharge diagnosis of SSP.

To remove prevalent cases of psychosis, we excluded individuals who had a prior medical claim, clinic visit, hospitalization or admission to a long-term care facility for any psychotic disorder, including affective, organic, and substance-induced psychoses. We also excluded individuals who had a prior prescription of any antipsychotic medication recorded in the pharmaceutical database. These exclusions are consistent with the clinical definition of FEP used by many early intervention programs, which typically limit enrolment to previously untreated cases (Breitborde *et al.* 2009). The database extends back to the year 2000, therefore the clearance period for excluding prevalent cases ranged from four- to six-years, depending on the year of onset of psychosis. Appendix D to Appendix F list the diagnostic codes and drug classifications that were used to construct our sample.

To assess the impact of our case definition on obtained incidence estimates, we conducted sensitivity analyses that included cases with a history of "Unspecified Psychosis" prior to the index diagnosis of SSP. A large proportion of individuals initially diagnosed with "Unspecified Psychosis" are later diagnosed with schizophrenia as the clinical presentation changes or additional information on prior symptomatology becomes available (Schimmelmann *et al.* 2005; Veen *et al.* 2004).

Socio-Demographic Variables

We obtained all available socio-demographic data for our sample, including sex, age at index diagnosis, and an ecologic measure of socioeconomic disparities (Gamache *et al.* 2010). The index of material and social deprivation was developed in Québec using data from census dissemination areas, and scores are assigned based on the residential postal code of each beneficiary. Material deprivation is represented by the proportion of the population without a high school diploma, the employment to population ratio, and average income. Social deprivation is represented by the proportion of the population who live alone, are separated, divorced or widowed, and are in a single-parent family (Gamache *et al.* 2010). The deprivation scores are divided into quintiles based on the distribution across the province, and each individual is assigned a score from one (least deprived) to five (most deprived) for each dimension.

Data Analysis

We estimated the crude annual incidence proportion of first-episode SSP, along with the corresponding 95% confidence intervals (CIs) using the Wilson score method without continuity correction (Newcombe, 1998). We also used direct standardization to adjust the estimates for age and sex, and the 95% CIs were calculated using the method described by Rothman and Greenland (Rothman and Greenland, 1998). Using standardized estimates, we estimated risk ratios for the available socio-demographic variables, along with corresponding 95% CIs (Rothman and Greenland, 1998). The denominator data were obtained from the RAMQ (Régie de l'Assurance Maladie du Québec, 2007b), and represent the average number of individuals between the ages of 14 and 25 years with valid RAMQ coverage residing in Montréal between 2004 and 2006, inclusive. To obtain an estimate of the population at risk for each stratum of both material and social deprivation, we used the overall frequency of deprivation scores from all individuals in the sampling frame of the ASSS database, and applied this distribution to the denominator data obtained from the RAMQ to estimate the denominator for each deprivation stratum. Incidence estimates were standardized to the 2006 Québec population using the data provided by the creators of the deprivation index (Gamache *et al.* 2010).

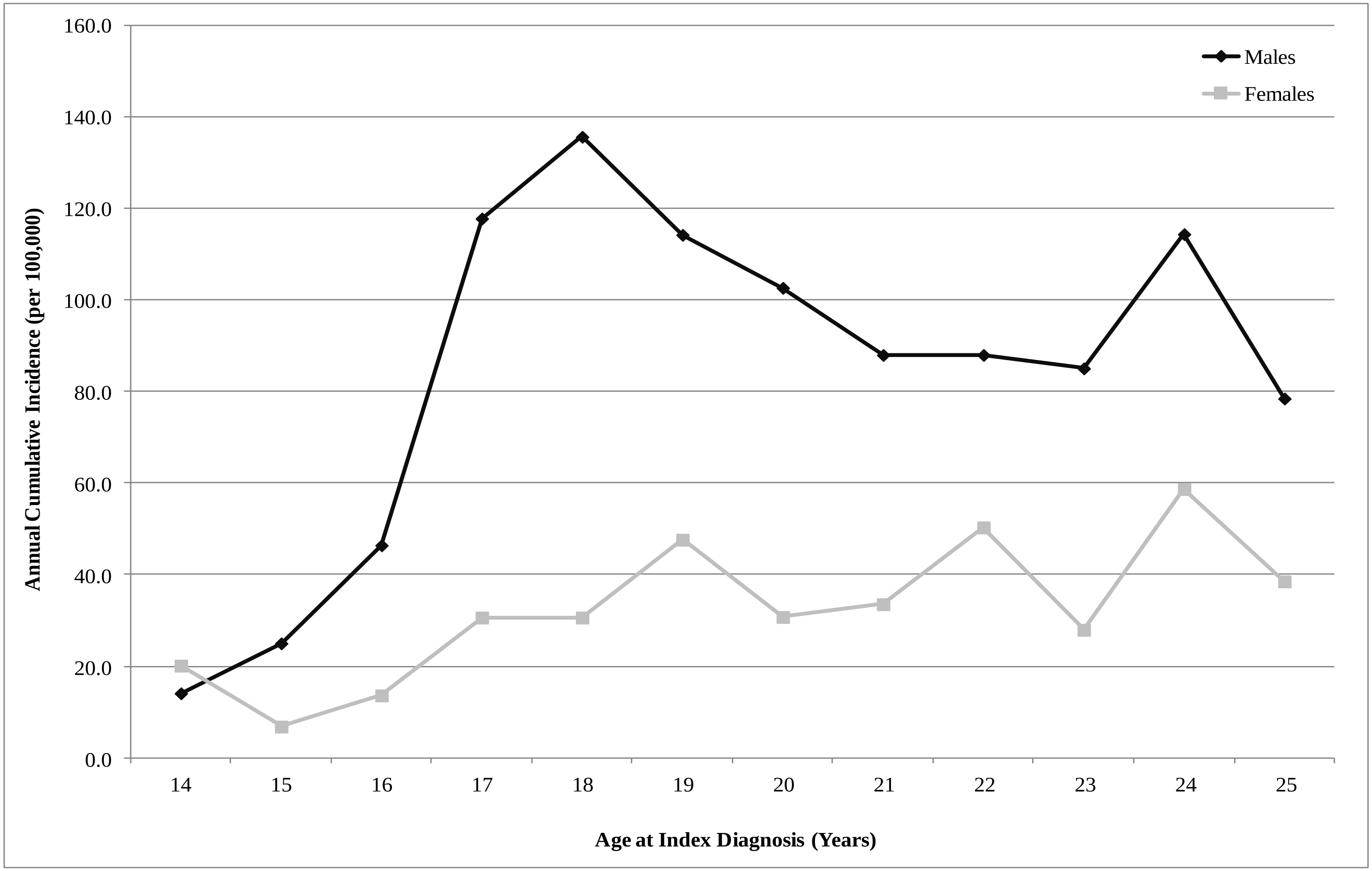
Results

Over the three-year period from 2004 to 2006, the average population registered with RAMQ as living in Montréal for our *a priori* selected age group of 14 to 25 years was approximately 261,500 individuals (127,500 males; 134,000 females). This age group represents nearly 15% of the total population. We identified 456 cases of first-episode schizophrenia-spectrum psychosis (SSP) (323 males; 133 females) within our selected age group. The median age at index diagnosis was 20 years (IQR=18-23) for males and 21 years (IQR=19-24) for females.

Over 25% of cases resided in the areas corresponding to the worst stratum of neighbourhood-level material deprivation, and almost 40% resided in the areas corresponding to the worst stratum of neighbourhood-level social deprivation. Eighty-two percent of cases lived in the catchment area of one of the five specialized FEP programs in Montréal, as determined by residential postal codes. The service contact that yielded the index diagnosis was emergency services (ER or inpatient) for 60% of cases, a community-based physician for 33% of cases, and a non-physician for 7% of cases. The index diagnosis was made by a psychiatrist for 69% of all cases.

The incidence of SSP by age and sex is shown in Figure 4.1 (pg. 67). The incidence for males was more than twice as high as females (RR=2.57; 95%CI = 2.09, 3.16), with a standardized annual incidence of 82.9 per 100,000 per year for males (95%CI = 73.7, 92.1), and 32.2 per 100,000 per year for females (95%CI = 26.7, 37.8) (Table 4.2, pg. 68). The incidence of SSP was significantly higher among individuals living in the most materially deprived areas (RR=1.75; 95%CI = 1.33, 2.30) and among individuals living in the most socially deprived areas (RR=1.84; 95%CI = 1.28, 2.64), as compared with those living in the least deprived areas (Table 4.2, pg. 68).

We conducted sensitivity analyses that included additional cases with a history of "Unspecified Psychosis" prior to the index diagnosis of SSP. Using this case definition, we identified a total of 611 cases (435 males, 176 females). This yields an annual incidence proportion of 113.7 per 100,000 per year for males (95%CI = 103.5, 124.9), and 43.8 per 100,000 per year for females (95%CI = 37.8, 50.7). The risk ratios were attenuated in the sensitivity analysis, but the observed trends were unchanged (Data not shown).



Note: The 95% confidence intervals for stratum-specific estimates were very wide due to the small sample within each stratum and are therefore omitted.

Figure 4.1 - Crude annual incidence estimates of first-episode schizophrenia-spectrum psychosis by age and sex.

Table 4.2- Annual incidence estimates and risk ratios for the sample of cases with first-episode schizophrenia-spectrum psychosis obtained from an administrative database in Montréal, Canada (n=456).

Denominator Population	**Population at Risk**		**n**	**%**	**Crude Incidence***	**95% CI**	**Adjusted Incidence*†**	**95% CI**	**RR†**	**95% CI**
	n	**(%)**								
Females	134,000	51.2	133	29.2	33.1	27.9, 39.2	32.2	26.7, 37.8	*Ref.*	
Males	127,500	48.8	323	70.8	84.4	75.7, 94.2	82.9	73.7, 92.1	2.57	2.09, 3.16
Material Deprivation										
(Least Deprived) 1	71,965	27.5	93	20.4	43.1	35.2, 52.8	42.1	33.4, 50.7	*Ref.*	
2	46,102	17.6	66	14.5	47.7	37.5, 60.7	48.2	36.5, 59.9	1.15	0.83, 1.57
3	42,049	16.1	85	18.6	67.4	54.5, 83.3	67.8	53.3, 82.3	1.61	1.20, 2.17
4	43,357	16.6	84	18.4	64.6	52.2, 79.9	65.0	51.1, 79.0	1.55	1.15, 2.08
(Most Deprived) 5	54,889	21.0	119	26.1	72.3	60.4, 86.4	73.5	60.2, 86.8	1.75	1.33, 2.30
Social Deprivation										
(Least Deprived) 1	35,930	13.7	38	8.3	35.3	25.7, 48.4	35.5	23.7, 47.2	*Ref.*	
2	28,582	10.9	44	9.6	51.3	38.2, 68.9	53.5	37.3, 69.7	1.51	0.96, 2.36
3	36,061	13.8	59	12.9	54.5	42.3, 70.3	55.1	40.8, 69.4	1.55	1.02, 2.37
4	66,133	25.3	134	29.4	67.5	57.0, 80.0	68.0	56.5, 79.5	1.92	1.32, 2.78
(Most Deprived) 5	91,656	35.1	172	37.7	62.6	53.9, 72.6	65.1	55.3, 74.9	1.84	1.28, 2.64

CI = Confidence Interval; RR = Risk Ratio; Ref. = Reference Category;

** Average annual incidence per 100,000 population per year; † Estimates standardized for age and sex;*

NB: Values not summing to 100% are due to missing data

Discussion

To the best of our knowledge, our study is the first to use routinely collected administrative data to estimate the incidence of first-episode schizophrenia-spectrum psychosis (SSP). Our findings are strengthened by the use of data from multiple linked service providers that includes nearly the entire population of Montréal. There are no privately funded health care facilities offering treatment for psychosis in the area, thus allowing comprehensive case ascertainment. The entire population of Québec is required to be registered with the RAMQ.

It is difficult to compare our estimate of the annual incidence of first-episode SSP to those obtained in other jurisdictions due to inconsistencies in the included age range and diagnostic subgroups of psychosis. Several studies have reported estimates for age groups similar to the range used in our study (Cassidy *et al.* 2008; Cheng *et al.* 2011; Kirkbride *et al.* 2006), however the case definitions included all types of psychotic disorders, rather than limiting the sample to SSP as we did in the current analysis. Based on the age-specific estimates reported for these studies (male: 66-80 per 100,000; female: 33-50 per 100,000), and given that SSP usually accounts for approximately 65% of first-episode cases (Kirkbride *et al.* 2006; Reay *et al.* 2010), we suspect that our estimates for males are likely higher than those reported previously, whereas our estimates for females may be lower. The latter may be due to our exclusion of the affective psychoses from our case definition and the restricted age range of our cases, as females account for more than 50% of first-episode psychosis (FEP) cases with affective psychoses, and also tend to be older at first contact (Kirkbride *et al.* 2006).

In a study using administrative data to estimate the prevalence of schizophrenia in British Columbia (Canada), Goldner and colleagues (2003) coined the term ‘contact prevalence’. In the current study we have estimated the ‘contact incidence’ of first-episode SSP. Contact incidence is distinct from treated incidence, as individuals with psychotic disorders may access health services but not subsequently make contact with a psychiatric treatment program. It is also distinguished from true incidence, as not all individuals with psychotic disorders may come in contact with the health care system. Goldner (2003) argues that there will be high levels of concordance between contact incidence and the true incidence of psychosis when there is "…relatively high diagnostic visibility, a policy-based emphasis on provision of services to persons with severe mental disorders, proliferation of assertive community treatment programs, and efforts to increase the early diagnosis and treatment of psychotic disorders." (Goldner *et al.* 2003, pg. 1020)

Although our study is the first to use administrative data to estimate the incidence of first-episode SSP specifically, prior Canadian studies have used provincial insurance data to estimate the incidence of schizophrenia generally. Specifically, Vanasse and colleagues (2011) estimated the annual incidence of schizophrenia in Québec for individuals aged 18 to 24 years to be 203 per 100,000 for males and 76 per 100,000 for females, and estimates from British Columbia range from 66.6 to 119.6 per 100,000 for males, and from 77.1 to 89.9 per 100,000 for females (Bray *et al.* 2006). These discrepant findings are likely due to differences in the case definition employed, as we were attempting to measure the incidence of the first-episode of a schizophrenia-spectrum disorder. As such, we removed all individuals from our sample who had a history of *any* psychotic disorder, including affective, organic and substance-induced psychosis, whereas the aforementioned studies only excluded cases who had a prior diagnosis of schizophrenia (Bray *et al.* 2006; Vanasse *et al.* 2011). We also had access to prescription data for nearly 75% of our sample and were therefore able to remove individuals with a prior history of antipsychotic use, in keeping with clinically relevant case definitions of an incident case of FEP. Additionally, our study used multiple data sources, thereby increasing the likelihood of identifying prevalent cases and improving the sensitivity of our case definition.

Our sample is comprised of approximately 70% males and 30% females, which is the expected sex distribution for samples of SSP (Baldwin *et al.* 2005). However, in contrast to the typical finding of an older age at first contact for females (Kirkbride *et al.* 2006), we did not find a gender difference in the age distribution of our sample. This is likely due to the fact that the distribution has been truncated by design, which will impact the observed median. Indeed, other studies using samples restricted to adolescence and early adulthood have also reported a similar age at first contact between males and females (Cheng *et al.* 2011).

We found evidence of socioeconomic disparities in the incidence of SSP, as a disproportionate number of cases were residing in the most materially and socially deprived areas of the city, and these individuals had a higher incidence proportion than individuals living in the least deprived areas of the city. Neighbourhood-level factors have been previously shown to have an impact on the risk of SSP (Kirkbride *et al.* 2007b), and prior ecological studies have found an association between deprivation indices and the prevalence of psychiatric admissions for psychosis (Allardyce *et al.* 2005; Croudace *et al.* 2000). It is unlikely that the socioeconomic disparities we observed are the result of social drift, due to the young age range of our sample and the high likelihood that these individuals have their parent's address listed on the RAMQ file. However, this finding may be due to the effects of unmeasured confounding from variables that are unavailable in the administrative dataset, such as ethnicity and migration status (Bourque *et al.* 2011).

Our analyses are limited by the restricted time-span of the available data, and there is a possibility of having included some prevalent cases of psychosis if there has been a long duration between episodes. However, the four-year cumulative incidence of relapse in FEP is

75%, and a large proportion of remaining cases never go on to have a second episode (Robinson *et al.* 1999). The aforementioned study by Vanasse and colleagues (2011) conducted in Québec also used provincial insurance data and hospitalizations to assess different algorithms for identifying incident cases of schizophrenia. The algorithm most similar to the current study yields positive-predictive values of 78% to 87% for a four- to six-year clearance period (Vanasse *et al.* 2011). These estimates were based on the full age-spectrum for adult onset schizophrenia and are likely higher for our sample given the young age range of included cases. Therefore, we estimate that only a small proportion of cases may be prevalent.

We are unable to generalize our findings to individuals not covered by RAMQ, including university students who come from out of province and sub-groups of the disadvantaged and homeless population. Additionally, we only included cases of SSP and thus are unable to generalize our findings to other types of FEP, including affective psychoses and substance-induced psychoses. We opted to exclude cases of non-SSP given that there is evidence that cases of non-psychotic affective disorder may be incorrectly coded as an affective psychosis using the ICD-9 classification system (Welham *et al.* 2004). Our initial attempts at case ascertainment support this. Including affective psychoses in the case definition, we obtained incidence estimates that were much higher than expected, with approximately 60% of the sample comprised of patients with affective psychoses, whereas clinical data suggests an expected proportion of approximately 25% to 30% for first-episode samples (Kirkbride *et al.* 2006; Reay *et al.* 2010; Whitty *et al.* 2005).

We also did not assess changes in diagnostic categories over time when selecting our sample. Other studies have evaluated the stability of specific diagnostic categories for first-episode psychosis (Bromet *et al.* 2005; Chaves *et al.* 2006; Jarbin and Von, 2003;

Schimmelmann *et al.* 2005; Veen *et al.* 2004; Whitty *et al.* 2005). Using data from these studies and our definition of SSP, we calculated that the positive-predictive value of a diagnosis of SSP at initial contact ranges from 85% to 97%, and the negative-predictive values range from 64% to 85%. These high positive predictive values indicate that few individuals in our sample are likely to have a non-SSP disorder. The negative predictive values suggest that approximately 15% to 35% of individuals initially diagnosed with a non-SSP psychosis are later found to have SSP, therefore we have likely missed some cases by excluding individuals with a history of any psychosis. Given that non-SSP accounts for a small proportion of total FEP cases (25% to 30%) (Whitty *et al.* 2005), this number is likely to be minimal. We have evaluated diagnostic stability to some extent in our sensitivity analysis by including cases with a history of a diagnosis of "Unspecified Psychosis", however we are unable to fully evaluate the potential impact of this without more extensive validation studies. We may have also included some individuals with subclinical psychotic symptoms who wouldn't meet diagnostic thresholds for entry into an early intervention program.

We could have reduced the likelihood of misclassification by only including individuals with two or more instances of a diagnostic code for psychosis, however we did not want to miss cases who receive a diagnosis of a psychotic disorder and do not return for follow-up. A brief examination of contacts following the index diagnosis indicates that approximately 15% of cases had no contact with mental health services for the duration of the follow-up period, and 36% had no subsequent contact for a SSP disorder. This is likely due to the combined effects of losses to follow-up, censoring at the end of the follow-up period, and misclassified index diagnoses. Additional studies with a longer duration of follow-up would be required to disentangle the effects of these factors.

Finally, our analyses are limited by the availability and accuracy of the data. We may have missed cases who sought treatment outside the province of Québec, and we do not have data on important risk factors for psychosis, such as ethnicity and migration status. The structure of the database also prevents us from calculating more accurate person-time denominators, as individuals are only included in the database for a given year if they had contact with services. Additionally, although many of the ICD-9 diagnostic and procedure codes have been validated in the RAMQ database (Cadieux and Tamblyn, 2008; Tamblyn *et al.* 2000; Wilchesky *et al.* 2004), we are not aware of any studies that have validated the RAMQ diagnostic codes for psychosis specifically, which is a common problem when using administrative data for psychiatric research (Byrne *et al.* 2005). If administrative databases are to be employed for studying FEP, important considerations for future research include the validity of the diagnostic codes for psychosis, the accuracy of defining the first-episode, and diagnostic reliability across different service providers and systems of care.

Despite these limitations, our study has demonstrated the feasibility of using routinely collected administrative data to obtain population-based estimates of the incidence of FEP. By taking a population health services perspective, we may gain additional insights on such topics as the epidemiology of FEP, the patterns of health services utilization, and the use of pharmacotherapy in this patient population. Given that samples obtained from psychiatric services are unlikely to capture all cases seeking treatment, population-based administrative data are an important source of information for research on first-episode psychosis and its impact on population health.

Manuscript III: Patterns of Health Services Use by Patients with First-Episode Schizophrenia-Spectrum Psychosis - The Impact of Primary Care

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Abstract

Objective: To estimate the extent to which socio-demographic factors and clinical indicators are associated with patterns of mental health service use preceding an index diagnosis of a first-episode of psychosis (FEP), and to examine the impact of these factors on treatment delay.

Methods: We used population-based administrative data from physician billings, hospitalizations, and public health clinics in Montréal to examine the use of services prior to a first diagnosis of psychosis. Incident cases of schizophrenia-spectrum psychosis occurring from 2004 through 2006 among individuals aged 14 to 25 years were identified, and mental health contacts in the four years preceding the index diagnosis were analyzed.

Results: Of the 456 cases identified, 32% had no contact with services preceding the index diagnosis. Nearly 50% of cases received the index diagnosis in the emergency department (ED). Individuals who were in contact with primary care services had a reduced likelihood of contact with the ED and inpatient services, but also had a longer time to diagnosis and time to contact with a psychiatrist.

Conclusions: These results support clinical findings that patients with FEP are heavy users of emergency services. Improving access to primary care may reduce the burden on EDs and inpatient units, however primary care providers may need additional training in the symptoms of early psychosis and referral protocols. Given that clinical samples from specialized services are unlikely to capture all cases seeking treatment, population-based administrative data is an important source of information for understanding patterns of health services use in first-episode psychosis.

Introduction

Over the last two decades, there has been a marked increase in the development and implementation of specialized services targeting patients in the early stages of psychosis (McGorry *et al.* 2007). These services are motivated by a common objective, which is to provide timely assessment and comprehensive treatment designed specifically for this phase of illness. Delay in treatment may have clinical implications for many medical conditions, however it is especially deleterious in first-episode psychosis (FEP) given that an extended period from the onset of psychotic symptoms to appropriate psychiatric intervention, known as the duration of untreated psychosis (DUP), has been repeatedly found to be associated with adverse clinical and functional outcomes (Marshall *et al.* 2005; Perkins *et al.* 2005). This evidence has sparked substantial efforts towards early symptom detection, comprehensive care during the initial stages of illness, and attempts to shorten the DUP (McGorry *et al.* 2007).

Treatment delay can be conceptualized as consisting of two phases: (1) a help-seeking phase, encompassing the time between the onset of psychosis and first contact with health services; (2) a referral phase, encompassing the period between first contact with health services and entry into an appropriate treatment program (Bechard-Evans *et al.* 2007; Norman *et al.* 2004). Prior research suggests that non-modifiable patient-level factors may influence the help-seeking component of treatment delay, whereas system-level factors are associated with the referral component of delay (Bechard-Evans *et al.* 2007). Indeed, referral delays may be responsible for a substantial portion of the DUP (Bechard-Evans *et al.* 2007; Brunet *et al.* 2007; Norman *et al.* 2004), and may be an efficacious target for reducing overall DUP.

Given the potential impact of systemic factors on reducing the referral component of delay, it is surprising that few studies to date have used health services administrative data to examine patterns of service use and treatment delay in FEP. Prior studies have sampled patients predominantly from early intervention programs, inpatient facilities, and outpatient psychiatry (Anderson *et al.* 2010). It is unlikely that such a sampling strategy will identify all cases seeking treatment, as patients may not be referred for more specialized care or may be lost to follow-up after initial contact. We are aware of only one study that used administrative data to examine health services use in FEP, however the data were limited to inpatient and outpatient records from psychiatric services and did not include contacts with primary care or non-physician services (Rietdijk *et al.* 2011). The planning and implementation of early intervention services for psychosis would benefit from accurate, population-based information on the patterns of health services use in FEP.

The objective of our study was to estimate the extent to which socio-demographic factors and clinical indicators are associated with patterns of mental health services use prior to an index diagnosis of psychosis, and the impact of these factors on treatment delay. To achieve these objectives, we conducted a population-based study using an administrative health and social services database.

Methods

Study Design and Source of Data

We obtained access to linked administrative data from several health and social service providers in Montréal for the fiscal years 2000 to 2006, inclusive. The database consists primarily of data from the provincial publicly funded health insurance provider, the *Régie de l'Assurance Maladie du Québec* (RAMQ), which covers medical services for all residents of Québec. Also included are data from the hospital discharge register, front-line public health and social services clinics, and the publicly funded pharmaceutical program that covers approximately 50% of the total population (Table 4.1, pg. 62). All RAMQ beneficiaries residing in Montréal are included in the database, and information is available on their use of services anywhere in Québec.

Approval to access these data for the purposes of this project was obtained from the Research Ethics Board at the Douglas Mental Health University Institute in Montréal. All data were anonymized via health insurance numbers encrypted by the RAMQ.

Sampling

We identified cases of schizophrenia-spectrum psychosis (SSP) between the ages of 14 and 25 years diagnosed from 2004 through 2006, inclusive. Included in the case definition were individuals with a diagnosis of schizophrenia, schizophreniform disorder, delusional disorder and paranoia. Cases were identified by the presence of a physician claim, a clinic visit record, or a hospitalization discharge abstract with a diagnostic code for SSP. We used a four- to six- year clearance period to exclude individuals with prior contact for *any* psychotic disorder or who had a record of a prior prescription of an antipsychotic medication. These exclusions are consistent with the clinical definition of FEP used by many early intervention programs, which typically limit enrolment to previously untreated cases. Appendix D through Appendix F list the diagnostic codes and drug classifications that were used to construct our sample, and a detailed description of case ascertainment is reported elsewhere (Anderson *et al.* 2011).

To assess the impact of our case definition on observed patterns of service use, we conducted sensitivity analyses that additionally included cases with a history of "Unspecified

Psychosis” prior to the index diagnosis of SSP. A large proportion of patients classified initially as “Unspecified Psychosis” are later diagnosed with schizophrenia (Malla *et al.* 2002; Veen *et al.* 2004).

Socio-Demographic Variables

We obtained information on the sex and age at index diagnosis, and we used indices of material and social deprivation as ecological measures of socioeconomic disparities (Gamache *et al.* 2010; Pampalon *et al.* 2009a; Pampalon *et al.* 2009b; Pampalon and Raymond, 2000). These indices were developed in Québec using census data and scores are assigned at a high level of geographical resolution, the six-digit postal codes (Gamache *et al.* 2010). Material deprivation is estimated from three variables: the proportion of the population without a high school diploma, the employment to population ratio, and the average income. Social deprivation is estimated from an additional three variables: the proportion of the population who live alone, the proportion who are separated, divorced or widowed, and the proportion who are in a single-parent family (Gamache *et al.* 2010). Deprivation scores are divided into quintiles based on the provincial distribution, and individuals are assigned a score. We dichotomized the indices and individuals falling into the worst quintile of material or social deprivation were classified as materially deprived or socially deprived.

We constructed a binary indicator variable based on whether there was evidence of substance abuse preceding the index diagnosis. This was determined by the presence of a service contact with a corresponding substance abuse diagnostic or external cause code. Substance abuse is associated with the modes by which patients access health services (Carr *et al.* 2003). As an indicator of case severity, we also constructed a binary variable based on whether the individual had a hospital admission in the week preceding or following the index diagnosis. Individuals who are hospitalized for FEP tend to have more severe functional and behavioural disturbances, are more likely to be a risk to self or others (Castle *et al.* 1994; Wade *et al.* 2006), and have an increased likelihood of subsequent readmission (Addington *et al.* 2010).

Service Utilization Indicators

A contact was defined as a mental health visit if there was a psychiatric diagnostic code, procedure code, or external cause code assigned, or if the speciality of the clinician was listed as ‘psychiatrist’, ‘psychologist’, or ‘psychoeducator’. Multiple billings with the same date and location were counted as one contact.

We calculated the total mental health contacts in the four years preceding the index diagnosis of psychosis, and the proportion of individuals who made contact with each type of service provider. We also constructed several indicators of service use, including whether the patient had contact with primary care services (clinic or general practitioner (GP)) for a mental health reason preceding the index diagnosis, whether the individual had any contact with emergency services (inpatient units or emergency department (ED)) preceding the index diagnosis, and whether the index diagnosis occurred at an ED visit.

We calculated two indicators as proxy measures for treatment delay: (1) The time interval from the first mental health contact to the index diagnosis; (2) The time interval from the first mental health contact to contact with a psychiatrist.

Data Analysis

For the total number of contacts, we obtained unadjusted estimates of the association with each of the covariates using a simple linear regression model, in which the dependent variable was log-transformed due to the positively skewed distribution. Simple logistic regression models were used to estimate unadjusted associations between each covariate and the following binary indicators: (i) any contact with emergency services preceding the index diagnosis (analysis restricted to those with prior contacts), and (ii) whether the index diagnosis occurred at an ED visit. We then used multivariable regression models to estimate independent associations of the covariates with each of the aforementioned outcomes. All regression models included the following variables: sex, age, material deprivation, social deprivation, substance abuse, contact with primary care, and case severity. Of exception, the model for contact with emergency services (i) was not adjusted for case severity, as the use of inpatient services was used to define both the predictor (hospitalization in the week preceding or following the index diagnosis) and outcome variables (contact with ED or inpatient services).

We initially used multivariable Cox-proportional hazards (PH) models to estimate the independent effects of the aforementioned covariates on (1) time from first contact to index diagnosis, and (2) time from first contact to contact with a psychiatrist. The analyses were restricted to individuals who had contact prior to the index date. Those who did not have the respective outcomes were censored at the end of the observation period. We verified the PH assumption that the covariate effect remains constant over the entire follow-up period (Cox, 1972). This was done by testing the interaction of each covariate with time (Ng'andu, 1997). The covariate ‘contact with primary care’ was found to violate the PH assumption in both models, and the covariate ‘case severity’ was found to violate the PH assumption in model 2.

Therefore, in final analyses we used a flexible extension of the PH model that does not impose *a priori* assumptions regarding the proportionality of hazards, and instead models the time-dependent effects to estimate how the covariate effect (hazard ratio (HR)) changes over time (Abrahamowicz and MacKenzie, 2007). The final models included variables with significant time-dependent effects (i.e. non-proportional hazards), as well as variables that were statistically significant in the conventional Cox-PH model. The latter were represented in the model by the adjusted (constant over time) HRs.

The results are presented as odds ratios (OR) for logistic regression, as HRs for PH regression, and as time-dependent HRs for the flexible non-PH estimates, along with corresponding 95% confidence intervals (CI). The β-coefficients and 95% CIs of the linear regression analysis using a log-transformed outcome variable were converted to exp(β), which can be interpreted as the relative effects on the outcome of interest. The linear and logistic regression models were performed using SAS version 9.2 (SAS Institute Inc., North Carolina, USA), and the flexible PH regression models were done using R version 2.12.1 (R Foundation for Statistical Computing, Vienna, Austria).

Propensity Score Calibration to Correct for Unmeasured Confounding

To examine the impact of the limited availability of socio-demographic variables, we used propensity score calibration to correct parameter estimates for multiple unmeasured confounders (Sturmer *et al.* 2005).

A propensity score (PS) is the probability that an individual is ‘exposed’, conditional on a set of observed covariates (Sturmer *et al.* 2005; Sturmer *et al.* 2007). PS calibration uses data from a separate ‘validation sample’, which contains information not available in the ‘main’ study database, to estimate two types of PS. Specifically, (1) an ‘error-prone’ PS uses only variables measured in the main study, whereas (2) a 'gold-standard' PS includes additional variables not available in the main study (Sturmer *et al.* 2005). The relationship between these two scores is then used to calibrate a PS estimated in the main study using regression calibration techniques (Rosner *et al.* 1990). Finally, the effect of the exposure of interest in the main study is adjusted using the calibrated PS. Calibration may result in overcorrection of parameter estimates, and bias may be exacerbated if the 'error-prone' PS is not a surrogate for the 'gold-standard' PS, independent of the outcome (Sturmer *et al.* 2005; Sturmer *et al.* 2007). Therefore, it is used as an additional sensitivity analysis to assess the robustness of the results of the primary analyses.

To implement the PS calibration, we used validation data from the Prevention and Early Intervention for Psychosis Program (PEPP), a clinical research program for FEP with an extensive database for evaluating long-term outcomes and estimating treatment delay. The validation sample included 228 patients with complete data on the following potential confounders: ethnicity, living arrangement at onset, and severity of psychotic symptoms. The parameter estimates for each variable in the regression models were calibrated separately. Of exception, we did not calibrate sex or age, as their effects were not expected to be confounded by the additional variables.

We assessed the validity of the calibrations by examining the correlation between the 'error-prone' PS and the corresponding 'gold-standard' PS, as weak correlations can lead to poorly calibrated estimates (Sturmer *et al.* 2005). The PS calibration was done using previously published SAS code (Sturmer *et al.* 2005), and the *%BLINPLUS* macro for regression calibration (Logan and Spiegelman D., 2004).

Results

Description of Sample and Service Contacts

We identified 456 cases of first-episode SSP (323 males; 133 females). The socio-demographic characteristics of cases are presented in Table 4.3 (pg. 86). Nine individuals had missing deprivation scores and were excluded from the multivariate analyses.

The service contact that yielded the index diagnosis was with emergency services (ED or inpatient) for 60% of individuals, a community-based physician for 33%, and a non-physician for 7%. The index diagnosis was made by a psychiatrist in 69% of cases and it occurred in the ED for 48% (Table 4.4, pg. 86). Over 80% of cases (n=377) had access to one of five FEP programs in Montréal as determined by residential postal code.

More than 30% of individuals had no contact with mental health services in the four years preceding the index diagnosis of psychosis. Sixty percent were in contact with primary care (Table 4.4, pg. 86). Figure 4.2 (pg. 88) shows the proportion of individuals making contact with each type of service provider at any point prior to and including the index diagnosis date.

Among individuals who had prior contact with mental health services (n=309), 55% made first contact with a physician (n=170), 19% with a non-physician (n=59), and 26% with emergency services (n=80). The diagnostic trends for service contacts preceding the index diagnosis are shown in Table 4.5 (pg. 87).

Table 4.3- Demographic characteristics of the administrative database sample (n=456).

Variable	**n**	**%**
Males	323	70.8%
Most Materially Deprived	119	26.1%
Most Socially Deprived	172	37.7%
History of Substance Abuse	60	13.2%
Indicator of Severity	165	36.2%

	Mean	**SD**
Age at Index Diagnosis	20.7	3.0

Table 4.4 - Description of mental health services contacts for all individuals in the administrative database sample (n=456).

Variable		**n**	**%**
Index Contact	*Physician*	148	32.5%
	Non-Physician	30	6.6%
	Emergency Services	275	60.3%
Index Diagnosis by Psychiatrist		314	68.9%
Index Diagnosis in ED		218	47.8%
Contact with Primary Care Services		275	60.3%
No Contact Prior to Index Diagnosis		147	32.2%

ED = Emergency Department

Table 4.5 - Most frequently cited diagnoses for all contacts with mental health services preceding the index diagnosis of psychosis in the administrative database study (n=2405).

Diagnosis	n	% of Total
Anxiety, Dissociative & Somatoform Disorders	483	20.1%
Problems with Family Life	323	13.4%
Unspecified/Undiagnosed Non-Psychotic Disorders	282	11.7%
Adaptation Problems	198	8.2%
Stress Reaction, Adjustment Reaction & Emotional Disturbance	158	6.6%
Depressive Disorder	215	8.9%
Personality Disorders	128	5.3%
Other Social Problems	99	4.1%
Substance Abuse or Dependence	80	3.3%
General Symptoms: Sleep, Malaise & Fatigue	64	2.7%

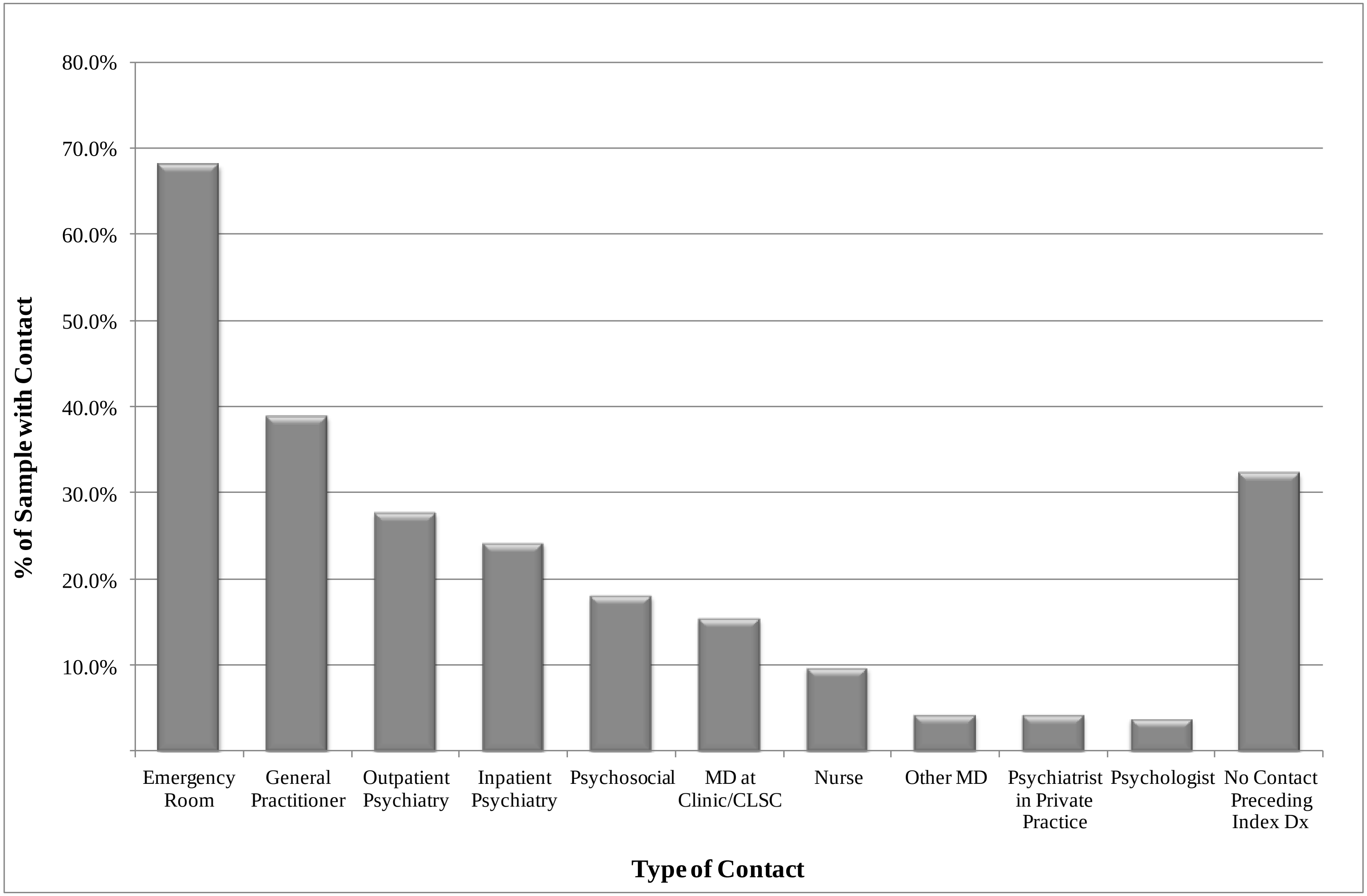

Figure 4.2- The proportion of the total sample of patients with first-episode schizophrenia-spectrum psychosis (n=456) making contact with each type of service provider in the four years prior to and including the index diagnosis of psychosis.

Predictors of Service Utilization

The results of the regression analyses are presented in Table 4.6 (pg. 90). In the four years preceding and including the index diagnosis date, the median number of total contacts was 3 (IQR 2-6). Males had fewer contacts than females (exp(β)=0.76, 0.63-0.90). Individuals who were in contact with primary care services had nearly three times more contacts (exp(β)=2.72, 2.29-3.19), and those with a history of service contact for substance abuse had almost twice as many contacts (exp(β)=1.80, 1.42-2.29).

Seventy-two percent (n=223/309) of cases with prior contact used emergency services at some point in the four years preceding the index diagnosis. Males were less likely to have prior contact with emergency services (OR=0.51, 0.28-0.95). Having a history of substance abuse was associated with an increased likelihood of emergency service contact (OR=7.65, 2.27–25.82), whereas individuals in contact with primary care had much lower odds of prior emergency service contact (OR=0.15, 0.06–0.39).

Forty-eight percent of cases received the index diagnosis of psychosis in the ED. Individuals in contact with primary care were less likely to receive the index diagnosis in the ED (OR=0.36, 0.24-0.54).

Table 4.6 - Results of the univariate and multivariate regression analyses in the administrative database of predictors of service utilization for individuals with first-episode schizophrenia-spectrum psychosis (n=456).

Linear Regression Models		**Sex**		**Age at Diagnosis**		**Material Deprivation**		**Social Deprivation**		**Substance Abuse**		**Use of Primary Care**		**Case Severity**	
		exp(β)	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**
Log of Total Contacts	*Unadjusted*	0.68*	(0.56, 0.84)	0.998	(0.97, 1.03)	0.84	(0.68, 1.04)	0.95	(0.78, 1.16)	1.92*	(1.45, 2.51)	2.75*	(2.32, 3.25)	0.96	(0.79, 1.17)
	Fully Adjusted	0.76*	(0.63, 0.90)	0.98	(0.95, 1.01)	0.94	(0.79, 1.14)	0.97	(0.82, 1.14)	1.80*	(1.42, 2.29)	2.72*	(2.29, 3.19)	1.09	(0.92, 1.30)

Logistic Regression Models		**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
**Emergency Services Contact	*Unadjusted*	0.84	(0.53, 1.34)	0.97	(0.89, 1.05)	0.57	(0.33, 1.00)	1.00	(0.60, 1.68)	7.79*	(2.36, 25.73)	0.15*	(0.06, 0.40)	N/A	N/A
	Fully Adjusted	0.51*	(0.28, 0.95)	0.96	(0.88, 1.05)	0.61	(0.33, 1.12)	0.87	(0.49, 1.54)	7.65*	(2.27, 25.82)	0.15*	(0.06, 0.39)		
Index Diagnosis in ED	*Unadjusted*	1.07	(0.71, 1.60)	1.03	(0.97, 1.10)	0.85	(0.56, 1.30)	1.30	(0.89, 1.90)	1.39	(0.81, 2.41)	0.36*	(0.24, 0.53)	1.47	(1.00, 2.16)
	Fully Adjusted	0.94	(0.61, 1.44)	1.04	(0.97, 1.11)	0.78	(0.50, 1.21)	1.22	(0.82, 1.83)	1.32	(0.75, 2.34)	0.36*	(0.24, 0.54)	1.35	(0.90, 2.03)

Proportional Hazards Models		**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**
** Time to Index Diagnosis	*Unadjusted*	1.56*	(1.22, 2.00)	1.01	(0.97, 1.05)	1.19	(0.91, 1.55)	1.06	(0.84, 1.33)	1.03	(0.77, 1.39)	0.42*†	(0.28, 0.61)	1.14	(0.90, 1.44)
	Fully Adjusted	1.55*	(1.19, 2.02)	1.02	(0.98, 1.06)	1.17	(0.89, 1.54)	0.97	(0.76, 1.24)	1.06	(0.78, 1.45)	0.42*†	(0.29, 0.62)	1.06	(0.83, 1.36)
**Time to Contact with Psychiatrist	*Unadjusted*	1.35*	(1.04, 1.74)	0.96*	(0.92, 1.00)	0.96	(0.73, 1.26)	1.21	(0.95, 1.54)	1.14	(0.84, 1.55)	0.31*†	(0.22, 0.44)	1.02†	(0.74, 1.41)
	Fully Adjusted	1.15	(0.88, 1.51)	0.95*	(0.91, 0.99)	0.96	(0.72, 1.28)	1.16	(0.90, 1.49)	1.06	(0.77, 1.47)	0.32*†	(0.23, 0.45)	0.94†	(0.67, 1.30)

*N/A = Variable not included in model; * Statistically significant based on 95% confidence intervals; ** Sample only included individuals with prior contacts (n=309); † Variable had non-proportional hazards;*

CI = Confidence Intervals; OR = Odds Ratio; HR = Hazard Ratio; ED = Emergency Department

Predictors of Treatment Delay

Among those with prior contact, the median time from first contact to index diagnosis was 595 days (IQR=73-1127). The results of the Cox-PH model suggested that males had a shorter time to diagnosis (HR=1.55, 1.19-2.02), whereas individuals in contact with primary care had a longer time to diagnosis (HR=0.42, 0.29-0.62). None of the other covariates had significant time-dependent or non-linear effects, therefore the final flexible PH model included sex and primary care. This model indicates that patients in contact with primary care have a longer time to index diagnosis in the initial months after first contact (HR=0.32, 0.20-0.53), but the effect weakens over time and disappears by two-years (Figure 4.3, pg. 92).

The median time from first contact with services to contact with a psychiatrist was 219 days (IQR=5-920). The results from the Cox-PH model suggest that both increasing age (HR=0.95, 0.91-0.99) and contact with primary care (HR=0.32, 0.23-0.45) were associated with a longer time to contact with a psychiatrist. In addition, case severity was found to have significant time-dependent effects, although it was non-significant in the conventional PH model. Therefore, the final flexible PH model included age, contact with primary care, and case severity. This model indicates that patients in contact with primary care have a longer time to contact with a psychiatrist in the initial months after first contact (HR=0.20, 0.13-0.32), but the effect weakens over time and disappears by six months (Figure 4.4, pg. 93). This model also shows that case severity is not associated with time to contact with a psychiatrist in the two years after the first contact, however in the third year it becomes strongly associated with a shorter time to contact among those who have not yet had contact with a psychiatrist (HR=2.08, 1.25-3.49) (Figure 4.5, pg. 94). The fact that severity has no short-term predictive ability explains why its effect in the conventional Cox-PH model, constrained to be constant over time, was not statistically significant (HR=0.94, 0.67-1.30).

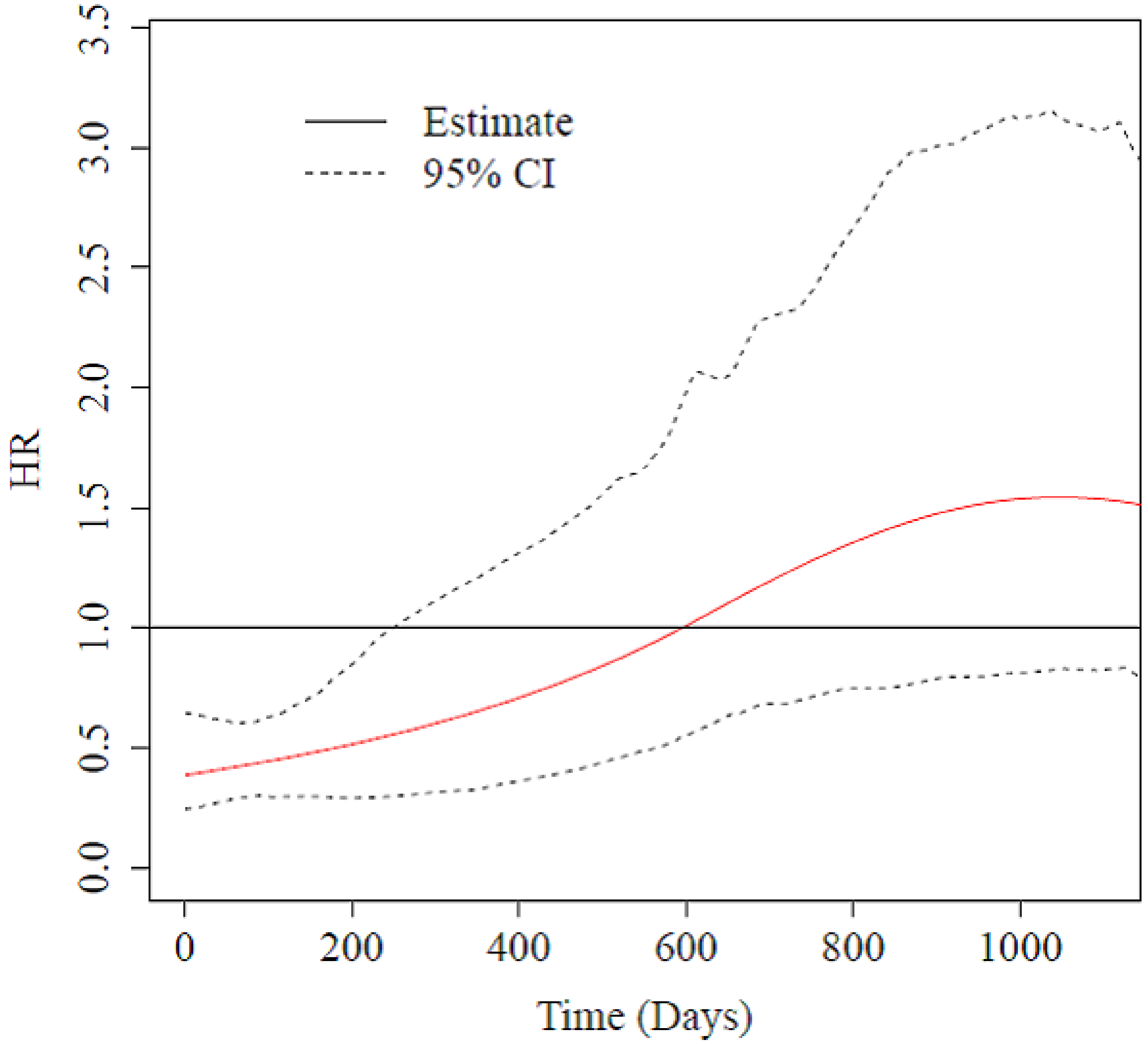

Figure 4.3 - Results of the flexible extension of the proportional hazards model of the time-dependent effects of contact with primary care on time from first contact to index diagnosis, among patients with first-episode schizophrenia-spectrum psychosis.

The horizontal line at HR=1 corresponds to no association. Thus, if the point estimate (solid curve) is below 1, this indicates that contact with primary care is associated with a longer time to index diagnosis, and if the estimate is above 1 then it is associated with a shorter time to index diagnosis.

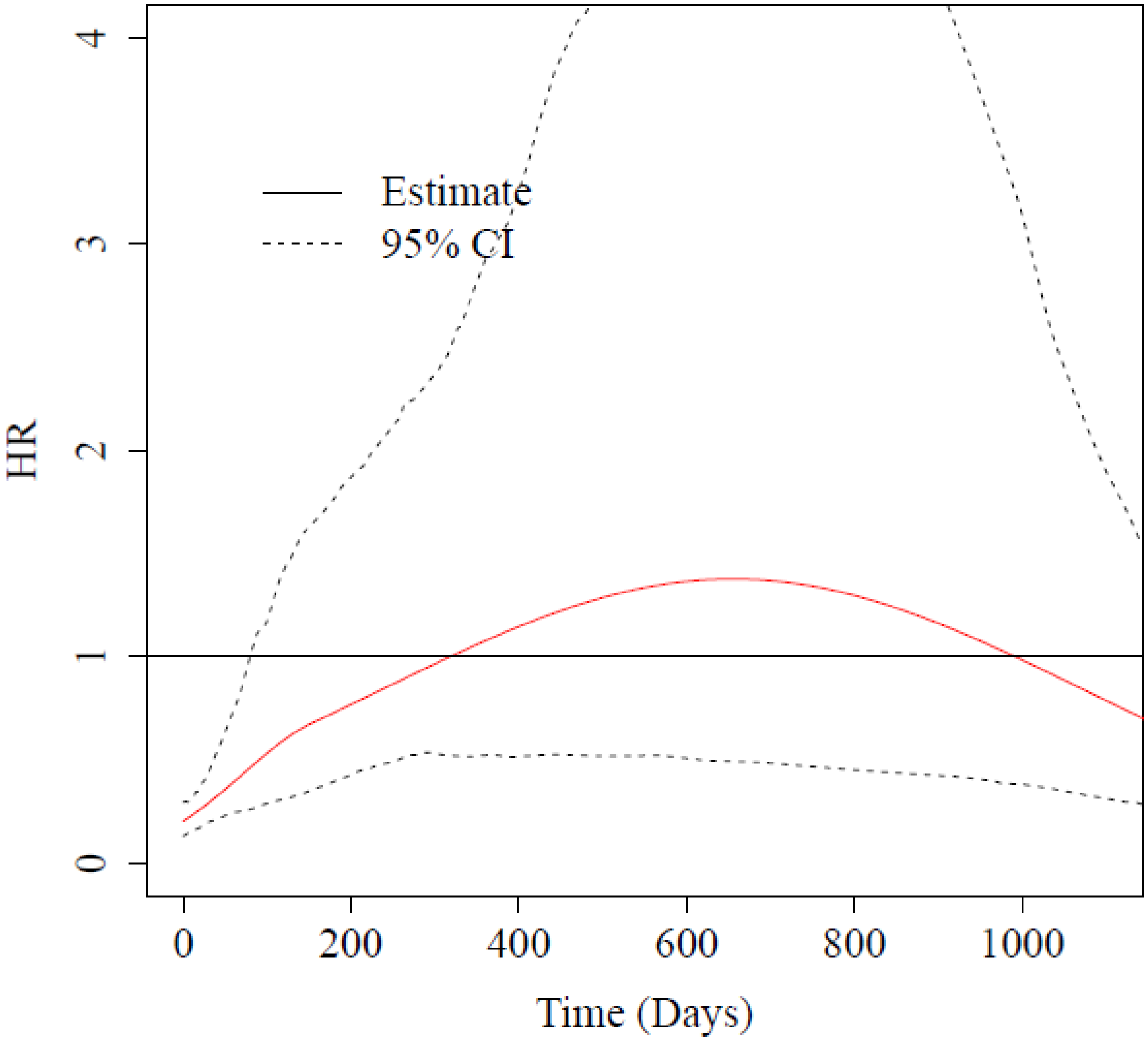

Figure 4.4 - Results of the flexible extension of the proportional hazards model of the time-dependent effects of contact with primary care services on time from first contact to contact with a psychiatrist, among patients with first-episode schizophrenia-spectrum psychosis.

The horizontal line at HR=1 corresponds to no association. Thus, if the point estimate (solid curve) is below 1, this indicates that contact with primary care is associated with a longer time to contact with a psychiatrist, and if the estimate is above 1 then it is associated with a shorter time to contact with a psychiatrist.

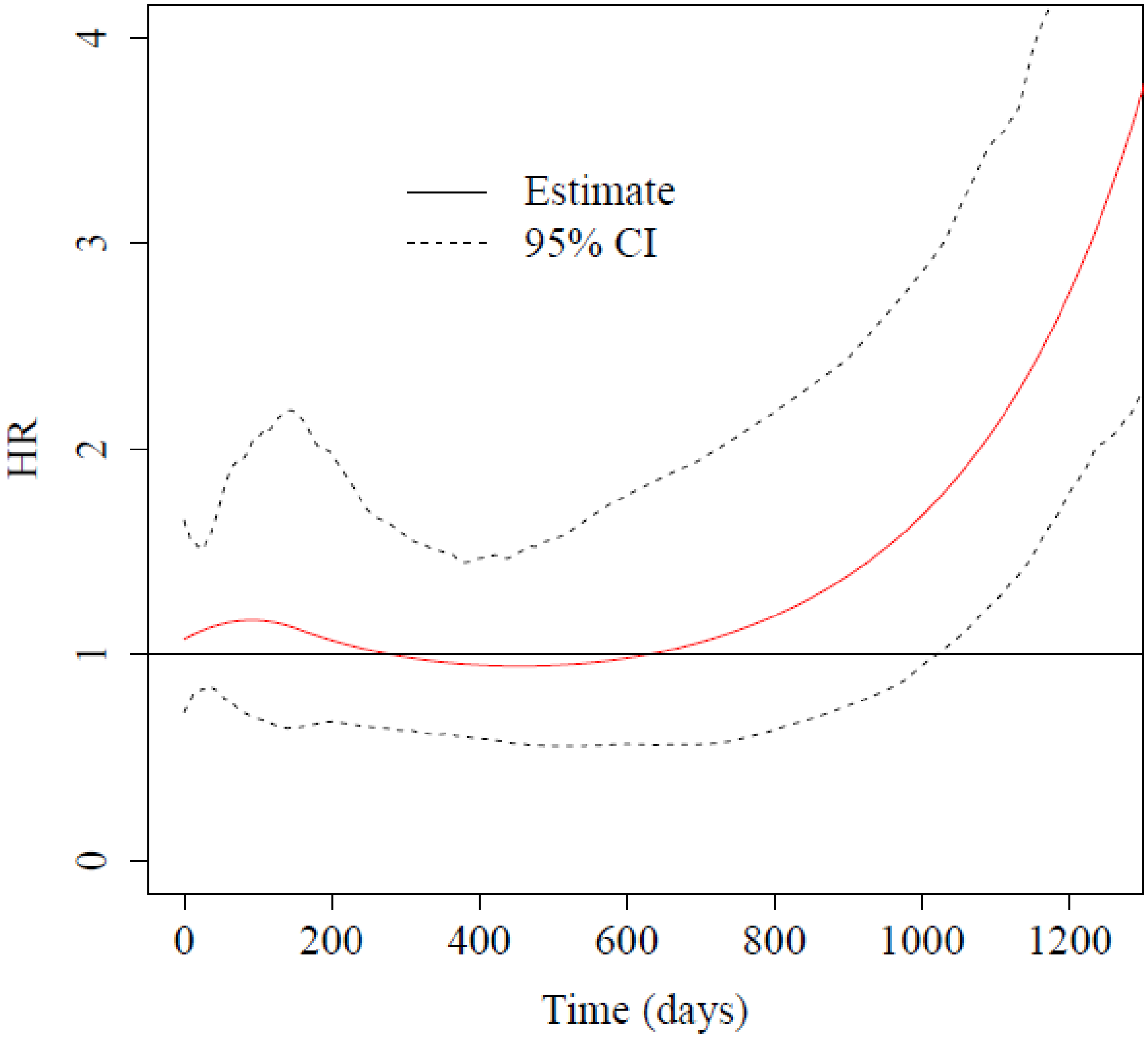

Figure 4.5 - Results of the flexible extension of the proportional hazards model of the time-dependent effects of severity on time from first contact to contact with a psychiatrist, among patients with first-episode schizophrenia-spectrum psychosis.

The horizontal line at HR=1 corresponds to no association. Thus, if the point estimate (solid curve) is below 1, this indicates that severity is associated with a longer time to contact with a psychiatrist, and if the estimate is above 1 then it is associated with a shorter time to contact with a psychiatrist.

Sensitivity Analysis

We conducted sensitivity analyses that also included cases with a history of "Unspecified Psychosis" prior to the index diagnosis of SSP, and we identified an additional 155 cases, for a total of 611 (435 male, 176 female). The association between case severity and an increased likelihood of ED index diagnosis became statistically significant in the sensitivity analysis (OR=1.55, 1.10-2.18), however none of the other findings from the primary analyses changed materially (data not shown).

Propensity Score Calibration

Table 4.7 (pg. 96) compares the socio-demographic characteristics of the study sample with the validation sample. The correlation between the error-prone PSs and the gold-standard PSs was moderate to very strong (social deprivation=0.65; case severity=0.75; material deprivation=0.80; contact with primary care=0.87; substance abuse=0.92). Calibration using the PSs from the validation study attenuated the parameter estimates slightly but did not change the conclusions drawn from the fully adjusted models (Table 4.8, pg. 97). Of exception, the positive association between case severity and a greater number of contacts was marginally significant (exp(β)=1.28, 1.02-1.62).

Table 4.7 - Comparison of demographic characteristics of the main sample and the validation sample used for propensity score calibration in the administrative database analysis.

Variable		**Study Sample (n=456)**		**Validation Sample (n=228)**	
		n	**%**	**n**	**%**
Males		323	70.8%	154	67.5%
Most Materially Deprived		119	26.1%	58	25.4%
Most Socially Deprived		172	37.7%	85	37.3%
History of Substance Abuse		60	13.2%	134	58.8%
Contact with Primary Care		275	60.3%	72	31.6%
Indicator of Severity		165	36.2%	112	49.1%
Living Alone at Onset		N/A		74	32.5%
Ethnicity	*White*	N/A		147	64.5%
	Black			28	12.3%
	Asian			31	13.6%
	Other			22	9.6%
BPRS	*I (Most Severe)*	N/A		49	21.5%
	II			56	24.6%
	III			59	25.9%
	IV (Least Severe)			64	28.1%

	Mean	**SD**	**Mean**	**SD**
Age at Index Diagnosis	20.7	3.0	23.0	4.0

N/A - *Variable not available in main dataset; BPRS = Brief Psychiatric Rating Scale*

Table 4.8 - Comparison of regression parameters from the fully adjusted model, the error-prone propensity score model, and the calibrated propensity score models in the administrative database analysis.

		Material Deprivation		**Social Deprivation**		**Substance Abuse**		**Use of Primary Care**		**Case Severity**	
Linear Regression Models		**exp(β)**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**
Log of Total Contacts	*Fully Adjusted*	0.84	(0.68, 1.04)	0.95	(0.78, 1.16)	1.92*	(1.45, 2.51)	2.75*	(2.32, 3.25)	0.96	(0.79, 1.17)
	PS Uncorrected	0.94	(0.79, 1.14)	0.97	(0.82, 1.14)	1.80*	(1.42, 2.29)	2.72*	(2.29, 3.19)	1.09	(0.92, 1.30)
	PS Corrected	1.11	(0.85, 1.42)	0.98	(0.79, 1.20)	1.75*	(1.31, 2.32)	2.69*	(2.27, 3.22)	1.28*	(1.02, 1.62)
Logistic Regression Models		**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
** Emergency Services Contact	*Fully Adjusted*	0.61	(0.33, 1.12)	0.87	(0.49, 1.54)	7.65*	(2.27, 25.82)	0.15*	(0.06, 0.39)	N/A	N/A
	PS Uncorrected	0.72	(0.39, 1.32)	0.74	(0.42, 1.28)	6.35*	(1.90, 21.23)	0.17*	(0.06, 0.43)		
	PS Corrected	0.95	(0.48, 1.86)	0.65	(0.37, 1.17)	5.83*	(1.73, 19.67)	0.17*	(0.07, 0.45)		
Index Diagnosis in ER	*Fully Adjusted*	0.78	(0.50, 1.21)	1.22	(0.82, 1.83)	1.32	(0.75, 2.34)	0.36*	(0.24, 0.54)	1.35	(0.90, 2.03)
	PS Uncorrected	0.79	(0.51, 1.21)	1.21	(0.82, 1.78)	1.28	(0.74, 2.23)	0.37*	(0.25, 0.54)	1.34	(0.90, 2.00)
	PS Corrected	0.72	(0.46, 1.13)	1.15	(0.77, 1.72)	1.24	(0.70, 2.18)	0.37*	(0.25, 0.55)	1.11	(0.71, 1.73)
Proportional Hazards Models		**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**
**Time to Index Diagnosis	*Fully Adjusted*	1.17	(0.89, 1.54)	0.97	(0.76, 1.24)	1.06	(0.78, 1.45)	0.42*†	(0.29, 0.62)	1.06	(0.83, 1.36)
	PS Uncorrected	1.14	(0.87, 1.50)	1.00	(0.78, 1.27)	1.00	(0.74, 1.36)	0.68*†	(0.52, 0.89)	1.07	(0.84, 1.36)
	PS Corrected	1.11	(0.83, 1.47)	0.98	(0.76, 1.26)	0.99	(0.72, 1.35)	0.69*†	(0.52, 0.91)	0.99	(0.76, 1.29)
**Time to Contact with a Psychiatrist	*Fully Adjusted*	0.96	(0.72, 1.28)	1.16	(0.90, 1.49)	1.06	(0.77, 1.47)	0.32*†	(0.23, 0.45)	0.94†	(0.67, 1.30)
	PS Uncorrected	0.95	(0.72, 1.26)	1.18	(0.92, 1.51)	1.03	(0.75, 1.41)	0.42*†	(0.32, 0.56)	1.23†	(0.96, 1.57)
	PS Corrected	0.94	(0.70, 1.26)	1.17	(0.90, 1.51)	1.00	(0.72, 1.38)	0.43*†	(0.33, 0.58)	1.11†	(0.84, 1.46)

*N/A = Variable not included in model; * Statistically significant based on 95% confidence intervals; ** Sample only included individuals with prior contacts (n=309); † Variable had non-proportional hazards;*

CI = Confidence Intervals; OR = Odds Ratio; PS = Propensity Score; ER = Emergency Room;

Discussion

The findings from our analysis of a population-based administrative database suggest that many patients with a first-episode of SSP have no contact with mental health services prior to the index diagnosis of psychosis, and emergency services tend to be a common portal of entry into the health care system. Having a history of contact with services for substance abuse and being in contact with primary care services impacted patterns of service use across multiple indicators.

Our study uses novel methods to examine the patterns of health service use in FEP, as it is one of the first to use routinely collected administrative data, and it includes contact with both primary care and non-physician services. We also used sophisticated statistical techniques to model non-proportional hazards and to examine the impact of unmeasured confounding. Our findings are strengthened by the use of data from multiple linked service providers that includes nearly the entire population of Montréal. There are no privately funded hospital facilities offering treatment for psychosis in the area, thus allowing comprehensive case ascertainment. Our results are also strengthened by the use of a first-episode sample, as we are more likely to capture both frequent and infrequent users of services, in contrast to samples that include prevalent cases, where the probability of being sampled is proportional to service use (Mojtabai *et al.* 2009).

Our case definition limits the generalizability of our findings. We restricted the age range to 14 to 25 years to increase the likelihood that the index diagnosis represents the first-episode. We also only included cases of SSP and thus are unable to generalize our findings to other types of psychotic disorders. We have missed individuals not covered by RAMQ, and have also likely missed cases of SSP by excluding individuals with a history of "Unspecified Psychosis" prior to the index diagnosis. A large proportion of these patients are later diagnosed with schizophrenia as the clinical presentation changes or additional information becomes available (Malla *et al.* 2002; Veen *et al.* 2004). We assessed the potential impact of this in our sensitivity analysis, with little effect on our overall findings. Our analyses are also limited by the availability of the information in the database. We do not have information on contacts with agencies not included in the dataset, such as complementary and alternative medical practitioners and psychologists working in private practice. Given that these services are not covered by provincial health insurance, we have likely captured the majority of contacts with mental health services. We also do not have data on contacts with police and the criminal justice system, which tend to be frequent in this patient population (Anderson *et al.* 2010). Finally, we are missing data on several important confounding factors, including ethnicity, living arrangements at onset, and severity of psychotic symptoms. We again attempted to control for this using propensity score calibration, which allowed us to adjust the regression coefficients for variables not available in the administrative dataset; however, we are unable to estimate the independent effects of these important covariates. Even with propensity score calibration, it is unlikely that all potential confounders were included, or measured with sufficient accuracy, so residual confounding likely remains.

It is important to note that we do not have information on the timing of psychosis onset, therefore we are unable to discern contacts for active psychosis from contacts that occurred during the prodrome to psychosis or for a co-morbid mental health problem. Common symptoms of the psychosis prodrome include depressed mood, anxiety, sleep disturbance, social withdrawal, odd behavior, suspiciousness, deterioration in functioning, and irritability (Yung and McGorry, 1996). The diagnostic codes assigned to visits preceding the index diagnosis are reflective of this heterogeneous pattern of symptomatology that characterizes the prodrome to psychosis, and are consistent with a prior study of prodromal help-seeking that also used administrative data (Rietdijk *et al.* 2011). Despite this lack of knowledge regarding the timing of onset, the patterns of health services use we observed are remarkably similar to those obtained using structured interviews with clinical samples. We found that 55% of individuals had their first mental health contact with a physician, whereas 61% received their index diagnosis via the ED or inpatient services. The differential frequency of emergency service use for these different time points are consistent with our systematic review on health services use in FEP (Anderson *et al.* 2010), and we speculate that it is partially due to missed opportunities for identifying previously untreated patients with psychotic symptoms. This finding likely also reflects a progression in the severity of psychotic symptoms, from insidious prodromal symptoms to more overt positive symptoms. Indeed, the long lag time between first contact and index diagnosis suggests that these contacts occurred primarily during the pre-psychotic 'prodromal' period.

Contact with emergency services was common in our sample, which is again consistent with findings from clinical samples (Anderson *et al.* 2010). Nearly half of our sample received the index diagnosis of psychosis in the ED. This estimate is almost twice as high as recent estimates from Québec, which found only 27% of incident cases of schizophrenia were diagnosed in the ED (Vanasse *et al.* 2011). However, our sample was restricted to adolescent cases, and younger patients with SSP have been found to use emergency services more frequently (Jin *et al.* 2003). This trend is concerning, as prior research suggests that contact with police, ambulance, and the ED may be associated with poor engagement with treatment (Compton, 2005), greater dissatisfaction with services received (Bhugra *et al.* 2004), and delays in subsequent help-seeking (Monteiro *et al.* 2006). It is possible that contact with emergency services is reflective of a lack of access to GPs or non-emergency psychiatric services. It may also be an indicator of more severe symptomatology, a more acute presentation, or the presence of disturbing behaviour. Prior research from Montréal suggests that it is unlikely that patients with FEP are using emergency services as a last resort, as these patients do not have a longer DUP or a greater number of help-seeking contacts (Bechard-Evans *et al.* 2007).

Our findings suggest that improving access to primary care may decrease the burden of FEP patients in the emergency room and inpatient units, provided that primary care providers have the practical knowledge for case recognition and the health service context allows for rapid access to specialized treatment. However, we speculate that GPs and other front line health care workers may need additional training in the recognition of the symptoms of early psychosis and protocols for referral to specialized care. Patients who were in contact with primary care had a greater number of contacts and longer treatment delay. Prior research has found that individuals who were receiving ongoing care at the onset of psychosis had a longer referral delay than individuals who sought care after onset (Boonstra *et al.* 2011; Norman *et al.* 2004). Taken together, these findings may be suggestive of delayed recognition of the symptoms of early psychosis or attempts made by the GP to manage the psychotic symptoms. They may also indicate that primary care providers are lacking the necessary linkages to facilitate referral to more specialized services.

We did not find evidence of socioeconomic disparities across the service utilization indicators that we employed. There is evidence that socioeconomic gradients in health service use exist for non-psychotic mental health problems, but not for psychotic disorders (Steele *et al.* 2006). We only have ecological indicators of socioeconomic status available in the administrative database, and such indicators tend to underestimate the disparities between groups when compared to individual-level data, although the direction of the findings tend to be the same (Pampalon *et al.* 2009a). Consequently, we have likely underestimated the impact of material and social deprivation on patterns of service use. Alternatively, the ecological deprivation indicators we used may not be the most suitable choice for the age-rage of our sample due to factors such as transient residence, the impact of the disease process on educational and occupational attainment, and ties to the family of origin. Prior research from Canada suggests that under universal health care where cost and availability are lesser issues, education is more strongly associated with patterns of mental health services use than other indicators of socioeconomic status, likely due to its impact on acceptability barriers (Steele *et al.* 2007).

The proportion of individuals in our sample with a history of service contact for substance abuse is markedly lower than estimates from clinical samples, which typically find approximately 45% of patients with FEP have substance abuse problems (Rabinowitz *et al.* 1998). Our measure is likely an indicator of severe substance abuse requiring contact with services, and is consistent with the proportion of FEP patients reported to have moderate to severe substance abuse (Rabinowitz *et al.* 1998). We have attempted to correct this residual confounding with propensity score calibration, with little impact on our findings.

Our study raises several questions that are worthy of further investigation. Research involving GPs and other primary care clinicians would be beneficial to understand the reasons behind the lengthy referral delay associated with these providers. Additional research is also needed to elucidate the relationship of socioeconomic disparities with patterns of service utilization for this adolescent and young adult patient population. If administrative databases are to continue to be employed for studying FEP, psychometric research to establish the validity and reliability of these data is needed. Important considerations include the validity of the diagnostic and procedure codes for psychosis, the accuracy of defining the first-episode, and diagnostic reliability across different service providers and systems of care. Given that hospital-based samples are unlikely to capture all cases seeking treatment, population-based administrative data is an important source of information for understanding patterns of health services use and treatment delay in first-episode psychosis.

CHAPTER 5 - THE CLINICAL LEVEL: PATHWAYS TO CARE ANALYSIS

As described in our systematic review of the literature in Chapter 2, prior studies have not sufficiently determined whether socio-demographic or clinical factors impact the pathways to care and treatment delay for first-episode psychosis. We examined this at the population-level in Chapter 4 and found that system-level factors, such as having access to primary care services, were stronger determinants of patterns of health services use than socio-demographic factors. In Manuscript IV, we use a richer clinical dataset from a specialized early intervention program for first-episode psychosis in Montréal to examine this at the clinical-level. We estimate the extent to which socio-demographic factors and clinical indicators are associated with the number and type of care pathway contacts, and with referral delay. We also evaluate the impact of negative pathways to care on subsequent engagement with services.

This manuscript is an important contribution to the current literature, as few studies to date have explored the determinants of the pathway to care, especially in a Canadian context, and ours is the first to examine the impact of the pathway to care on subsequent engagement with mental health services. Knowledge regarding the modes and routes by which patients obtain specialized care, and the implications of these help-seeking experiences for service disengagement, is fundamental to maximizing the benefits obtained from early intervention efforts.

Detailed Methods

Study Population

We obtained data from the Prevention and Early Intervention for Psychoses Program (PEPP) at the Douglas Mental Health University Institute in Montréal. PEPP is a specialized early intervention clinical research program for first-episode psychosis, servicing a defined catchment area of over 290,000 inhabitants. This two-year program is focused on early detection and comprehensive care during the early stages of psychotic illness, and includes assertive case management, psycho-social interventions, antipsychotic medication, family based interventions, monitoring of symptoms and functioning, and continuity of care and follow-up (Malla *et al.* 2003). PEPP has an extensive database for evaluating long-term outcomes and estimating treatment delay.

Patients are eligible for admission into PEPP if they are between the ages of 14 and 30 years, have a confirmed diagnosis of an affective or non-affective psychotic disorder, and are treatment naïve, defined as having received less than 30 consecutive days of antipsychotic therapy. Individuals are excluded from the program if they have a history of organic mental disorder, epilepsy, pervasive developmental disorders, or intellectual disability (IQ<70). Patients are also excluded if forensic services are involved, such that they have outstanding charges for a serious offence for which they are likely to receive sentencing. Patients with a substance abuse disorder are included provided that their primary diagnosis is a psychotic disorder. All diagnoses are confirmed by a senior psychiatrist using the Structured Clinical Interview for the DSM-IV (SCID) (First *et al.* 1996). All patients admitted to the program between January 2003 and October 2010 who had complete data on the outcomes of interest were included in the current analyses.

The PEPP program was an ideal source of participants for this study because the clinical services and research program are fully integrated. As such, standardized assessment protocols are conducted with each individual at regular intervals throughout the two-year program, resulting in a comprehensive source of data on various risk factors, clinical indices, symptomatology, and outcome measures. Additionally, PEPP uses an open referral system, and patients are referred to the program from a variety of different sources, including general practitioners, mental health professionals, emergency departments, school counsellors, religious agencies, and family and friends. Since physician referral is not a requisite condition for entry into the program, this enabled a detailed assessment of the non-medical points of contact and sources of referral on the pathway to care.

Data Collection

Data were collected using the *Course of Onset and Relapse Schedule* (CORS), which is a standardized semi-structured interview developed by PEPP investigators in London (Ontario) and Montréal (Norman *et al.* 2004). The interview is conducted by a trained evaluator, usually within the first three months following admission to the program, and it takes approximately two hours to complete. The interview seeks to construct a timeline of the patient's life to gather information on symptom onset, duration of untreated psychosis, help seeking and referral delay, and the pathways into mental health care. This timeline is then presented to the PEPP research team and a senior clinical research psychiatrist, and a consensus is reached on various clinical and service use indicators. A detailed description of measures relevant to the current study follows.

Baseline Measures

We obtained information on sex and the age at time of entry into the PEPP program. We used age as a continuous variable in the current analyses. Patients' living circumstances at onset was used as a proxy for social support. We dichotomized this variable as 'living with others' versus 'living alone'.

We had information available on the socioeconomic status (SES) of the parents, as well as the educational attainment of the patient. However, parental SES had a very large amount of missing data (>45%), and patient education is of questionable validity as an indicator of SES for our sample given that many individuals are still in school, and the disease process may have impacted educational attainment. Therefore, we opted to use the material and social deprivation index as an ecological measure of socioeconomic disparities (Gamache *et al.* 2010; Pampalon *et al.* 2009a; Pampalon *et al.* 2009b; Pampalon and Raymond, 2000). This index was developed in the Province of Québec using data from census dissemination areas (DA), and scores are assigned based on the six-digit residential postal code of each individual. Each DA is assigned a score for both material and social deprivation using data on six socioeconomic indicators from the 2006 census for the population aged 15 years and over (for further details, see Chapter 4 – Socio-demographic Variables). Specifically, material deprivation "...refers to the lack of the goods and conveniences that are part of modern life" (Pampalon *et al.* 2009a, pg. 86) and is represented in the index by the proportion of the population without a high school diploma, the employment to population ratio, and average income. Social deprivation "...refers to the fragility of the social network, from the family to the community" (Pampalon *et al.* 2009a, pg. 86) and is represented in the index by the proportion of the population who live alone, who are separated, divorced or widowed, and who are in a single-parent family (Gamache *et al.* 2010). We dichotomized the deprivation indices for the purposes of the current analyses, and individuals falling into the worst quintile of material or social deprivation were classified as materially deprived and socially deprived, respectively.

We asked patients to classify their ethnic background using the Statistics Canada divisions for population group (Statistics Canada, 2011), and we categorized these as follows: (1) 'White', which includes individuals of European descent; (2) 'Black', which includes people of African, Haitian, Jamaican or Somali background; (3) 'Asian', which is comprised of people of Arabic/West Asian, Chinese, Filipino, Japanese, Korean, South Asian, or South East Asian ancestry; (4) 'Other population groups', including Aboriginal Peoples, Latin Americans and individuals of mixed descent. These categories are taken from a similar Canadian study on pathways to care, which reported ethnic differences across these groups (Archie *et al.* 2010).

The diagnosis of each patient is established using the Structured Clinical Interview for the DSM-IV (SCID) (First *et al.* 1996). The interview is conducted by an evaluator who is trained in the use of the instrument, and the diagnosis is reviewed and a consensus reached by the PEPP research team and a senior clinical research psychiatrist. The specific aspect of the diagnosis that was of interest is whether the patient had a lifetime substance abuse disorder, and this variable was dichotomized in the current analysis. Substance abuse and addiction are highly prevalent among patients with FEP (Conus *et al.* 2007), and have been found to impact pathways to care (Etheridge *et al.* 2004; Morgan *et al.* 2005a; Morgan *et al.* 2005b).

The severity of psychotic symptoms is measured as part of the baseline assessment at PEPP using the expanded *Brief Psychiatric Rating Scale* (BPRS-E) (Ventura *et al.* 2000). The BPRS-E consists of 24 items rated on a 7-point Likert scale representing increasing levels of severity (1 = symptom absent; 7 = extremely severe). Prior analysis of the BPRS-E among patients with early psychosis reveals a four-factor structure, consisting of positive symptoms, negative symptoms, affective symptoms, and mania (Dingemans *et al.* 1995; Kopelowicz *et al.* 2008; Ventura *et al.* 2000). It has been shown to have good internal consistency (α = 0.64 – 0.76) (Dingemans *et al.* 1995), high inter-rater reliability (ICC = 0.87) (Bell *et al.* 1992), and demonstrated predictive validity (Bell *et al.* 1992). The total score for the BPRS-E is calculated by summing the scores from all items (range 24-168), and we divided the scores into quartiles to aid the interpretability of the findings.

Retrospective Measures

The 'duration of untreated illness' (DUI) is the period from the onset of the first psychiatric symptoms to the initiation of adequate antipsychotic treatment for a period of one month, and the 'duration of untreated psychosis' (DUP) is the period from the onset of psychotic symptoms to the initiation of adequate antipsychotic treatment for a period of one month (Malla *et al.* 2002). Information on symptom onset and duration is obtained from the CORS interview, and the DUI and DUP are established by consensus of the PEPP research team. High levels of inter-rater reliability have been obtained for these measures (ICC = 0.86 to 0.93 for PEPP Montreal, unpublished data). The DUI was used as a proxy for mode of onset, with shorter DUIs suggesting an acute rather than insidious onset. Of exception, in one model we replaced DUI with the length of the 'prodrome' to psychosis (details below), which is the period of psychiatric symptoms that immediately precede and are continuous with the onset of psychotic symptoms. Both variables were used as a continuous measure with log-transformation due to the positively skewed distribution.

The patient's level of functioning prior to psychosis onset was assessed using the Premorbid Adjustment Scale (PAS) (Cannon-Spoor *et al.* 1982). This instrument evaluates the degree to which the patient achieved social, developmental and educational milestones prior to the onset of psychosis. It is based on interviews with the patient's family members and is administered by a symptom evaluator at the baseline assessment. The PAS consists of 26 items and covers four developmental periods: childhood (up to age 11), early adolescence (ages 12-15), late adolescence (ages 16-18) and adulthood (over age of 19) (Cannon-Spoor *et al.* 1982). The PAS score is assigned based on an ordinal scale ranging from zero to six (ex. 0 = excellent student; 6 = failing all courses), and the total is divided by the number of items to yield a final score between 0 (best) and 1(worst). The PAS has been previously shown to have good levels of internal consistency (α=0.72-0.79) and inter-rater reliability (r = 0.74-0.85) (Cannon-Spoor *et al.* 1982), and has demonstrated predictive and concurrent validity (Brill *et al.* 2008). It is also able to distinguish between individuals with schizophrenia and the general population (Cannon-Spoor *et al.* 1982). Using the method described by Haas and Sweeney (1992) the PAS scores were used to classify individuals into one of three trajectories of premorbid adjustment: deteriorating, stable poor, and stable good. A deteriorating pattern of premorbid adjustment is defined as a pattern of progressive decline in PAS scores across the developmental periods, as evidenced by a difference of two or more points. The remaining patients are classified as stable poor if their scores fall below the group median, and are classified as stable good if the scores fall above the group median (Haas and Sweeney, 1992). Pre-morbid adjustment is included as a covariate in the analyses because the levels of functioning exhibited by the patient prior to the onset of psychotic symptoms may have an impact on the length of time that psychotic symptoms go unrecognized by family members and the social resources available to the patient at the time of help seeking.

Data on each patient's pathway to care were obtained from the pathways to care portion of the CORS interview (Appendix H). This portion of the interview seeks to identify the type and sequence of care pathway contacts from whom the patient or family member sought help during the period from the onset of psychiatric symptoms to entry into the PEPP program. In contrast to other measures of pathways to care in the literature (Anderson *et al.* 2010), family members and police are not care pathway contacts, but individuals who initiate help seeking on behalf of the patient.

Within the context of the current study, the term 'care pathway contact' will refer to the specific individual, agency or service provider with whom the patient came into contact on his or her pathway to mental health care. The 'prodromal contact' refers to the service provider from whom the patient or family member first sought help after the onset of psychiatric symptoms, but before the symptoms of active psychosis began. The 'first contact' refers to the service provider from whom the patient or family member first sought help after the onset of psychotic symptoms. The 'referral source' denotes the care pathway contact from whom the patient or family member sought help immediately prior to entry into PEPP, such that this contact suggested or arranged for the patient to be screened for program eligibility. Each care pathway contact was categorized into one of three groups: (a.) Physician – includes general practitioners, psychiatrists, or outpatient mental health services; (b.) Non-Physician – includes private psychologists, counsellors, social workers, religious agencies, or self referral; (c.) Emergency – refers to emergency departments, crisis teams, or inpatient units.

We calculated the proportion of patients seeking help from each type of care pathway contact for the prodromal contact, the first contact, and the referral source. The prodromal contact was dichotomized based on whether there was any contact during the prodrome, and the first contact and referral source were dichotomized based on whether the contact was with emergency services. We also calculated the total number of contacts between the onset of psychotic symptoms and entry into PEPP, which has good inter-rater reliability (ICC=0.86 for PEPP Montréal, unpublished data). In the current analyses, we dichotomized the total number of contacts as ‘0-2 contacts’ or ‘>2 contacts’ due to the restricted range of data which limited the utility of this variable as a continuous measure. We also constructed a binary indicator based on whether the patient was in contact with primary care services, defined as contact with a general practitioner in private practice or in a public health clinic. Finally, we obtained data on whether there was police or ambulance involvement on the pathway to care, which was extracted from the timeline constructed during the CORS interview. This variable was dichotomized based on whether there was any contact.

Lastly, we calculated the referral delay, defined as the time from the first contact with mental health services to PEPP referral (Bechard-Evans *et al.* 2007).

Prospective Measures

We used the time to withdrawal from PEPP as a measure of service disengagement. Patients were considered disengaged if there was no contact for a continuous period of three months. Time to disengagement was calculated as the number of months from program entry to the first month of no contact. Individuals who were incarcerated or were admitted to a detoxification program during follow-up were considered to have disengaged. Those who moved out of the PEPP catchment area or were referred to alternate services were censored, as we did not have information on subsequent engagement with services. Patients who completed the program were censored at 24 months, and current patients were censored at the end of the follow-up period (June 2011).

Multiple Imputation for Missing Data

We were missing data for several of the covariates of interest in the current analyses. The proportion of missing data for each variable ranged from 2% to 30%, and the case-wise proportion of missing data was 42%. Thus, the use of complete case analysis would substantially reduce the power of our analyses and potentially bias our findings (Greenland and Finkle, 1995). To circumvent this, we used multiple imputation to deal with missing data in our analyses.

Multiple imputation is a well validated approach for estimating missing values. It replaces missing data points by random selection from a set of plausible values that are based on the distribution of variables with missing observations, conditional on the observed data. This is done multiple times to create several datasets with complete observations, which are then analyzed in parallel and synthesized to compute summary parameter estimates that account for the uncertainty introduced by the imputation process (Greenland and Finkle, 1995). The approach assumes that data are missing at random (MAR), such that the pattern of missing data is predictable from other observed covariates in the dataset (Rubin, 1987). Although it is impracticable to judge whether the MAR assumption holds, simulations have demonstrated that the parameter estimates and standard errors are relatively robust to deviations from the MAR assumption, provided that there is not a large proportion of data missing for a given variable (<25%), and a only a modest correlation between the variable and the cause of the missing data (Collins *et al.* 2001).

In the current analysis, we observed an arbitrary pattern of missing data (Table 5.1, pg. 116), so we used a two step imputation procedure (Berglund, 2011). Firstly, we used a Markov Chain Monte Carlo (MCMC) method to impute enough data to produce a monotone pattern. We then performed multiple imputation using PROC MI in SAS 9.2 (SAS Institute Inc., North Carolina, USA) with the logistic regression method (seed=8957089, burn-in iterations=200, iterations=100). We conducted ten imputations, as the use of additional imputations beyond this yields negligible gains in relative efficiency (Berglund, 2011). We then analyzed the data using standard analysis techniques described below, and the results were synthesized using PROC MIANALYZE.

We imputed data for the following independent variables (% missing): diagnostic category (1.5%), length of prodrome (2.4%), DUI (4.0%), material deprivation (4.3%), social deprivation (4.3%), ethnic group (4.6%), co-morbid substance abuse (5.9%), symptom severity (7.4%), living arrangements at onset (17.9%), and premorbid adjustment (27.2%). The large amount of missing data for premorbid adjustment was likely due to the fact that this measure is based on interviews with family members (Cannon-Spoor *et al.* 1982). We additionally included age, sex, contact with primary care services, prodrome contact, first contact, referral source, contact with police and ambulance, total contacts, referral delay, and disengagement from PEPP in the imputation model. We did not impute data for missing outcome variables.

Table 5.1 - The arbitrary pattern of missing data observed in the pathway to care analysis.

Number of Cases (n=324)	Variable									
	Baseline Diagnosis	**Prodrome Length**	**DUI**	**Material Deprivation**	**Social Deprivation**	**Ethnic Group**	**Substance Abuse**	**BPRS**	**Live Alone**	**PAS Course**
189	-	-	-	-	-	-	-	-	-	-
35	-	-	-	-	-	-	-	-	-	X
8	-	-	-	-	-	-	-	-	X	-
21	-	-	-	-	-	-	-	-	X	X
11	-	-	-	-	-	-	-	X	-	-
5	-	-	-	-	-	-	-	X	-	X
2	-	-	-	-	-	-	-	X	X	-
1	-	-	-	-	-	-	-	X	X	X
2	-	-	-	-	-	-	X	-	-	-
2	-	-	-	-	-	-	X	-	-	X
3	-	-	-	-	-	-	X	-	X	-
1	-	-	-	-	-	-	X	-	X	X
6	-	-	-	-	-	X	-	-	-	-
3	-	-	-	-	-	X	-	-	-	X
2	-	-	-	-	-	X	-	-	X	-
2	-	-	-	-	-	X	-	-	X	X
7	-	-	-	X	X	-	-	-	-	-
1	-	-	-	X	X	-	-	-	-	X
1	-	-	-	X	X	-	-	-	X	-
1	-	-	-	X	X	-	-	-	X	X
1	-	-	-	X	X	-	-	X	-	-
1	-	-	-	X	X	-	X	-	X	-
1	-	-	-	X	X	-	X	-	X	X
1	-	-	X	-	-	-	-	-	-	-
3	-	-	X	-	-	-	-	-	X	X
1	-	-	X	-	-	-	-	X	X	X
1	-	-	X	-	-	-	X	-	-	X
1	-	X	-	-	-	-	-	-	-	X
1	-	X	-	-	-	-	X	-	X	X
2	-	X	X	-	-	-	-	-	X	X
1	-	X	X	-	-	-	X	X	X	X
1	-	X	X	-	-	X	X	-	X	X
1	-	X	X	X	X	X	-	-	X	X
1	X	-	-	-	-	-	X	-	-	X
2	X	-	-	-	-	-	X	-	X	-
1	X	-	X	-	-	-	X	X	X	X
1	X	X	X	-	-	-	X	X	X	X
Total	5	8	13	14	14	15	19	24	58	88

DUI = Duration of Untreated Illness; BPRS = Brief Psychiatric Rating Scale; PAS = Premorbid Adjustment Score;

Data Analysis

Simple logistic regression was used to estimate unadjusted associations between each covariate and the following outcomes defined as binary indicators: (i) contact during the prodrome; (ii) first contact with emergency services; (iii) referral source emergency service; (iv) more than 2 total contacts; and (v) whether the patient had contact with police or ambulance services. For referral delay, we obtained unadjusted estimates of the association with each of the covariates using a simple linear regression model, in which the dependent variable was log-transformed due to the positively skewed distribution. We then used multivariable regression models to estimate independent associations of the covariates with each of the aforementioned outcomes. All multivariable models included the following covariates: sex, age, material deprivation, social deprivation, ethnic group, living arrangements at onset, co-morbid substance abuse, DUI, symptom severity, pre-morbid adjustment, and contact with primary care services. Of exception, model i did not include DUI because this measure includes both the length of the prodrome and the DUP, and the latter would occur after the outcome of interest. Rather, we included the length of the prodrome as a covariate, and this variable was also log-transformed due to the positively skewed distribution.

We used Cox-proportional hazards (PH) models to estimate the independent effects of indicators of negative pathways to care on disengagement from PEPP. In preliminary analyses, we verified the PH assumption that the covariate effect remains constant during the entire follow-up period (Cox, 1972). This was done for each of the covariates by examining the plot of the log of the negative log of the survival function versus the log of time, with deviations from parallel indicating non-proportional hazards. We also tested the interaction of each covariate with time, and significant interactions indicate a violation of the PH assumption (Ng'andu, 1997). The covariate ‘age at entry’ was found to violate the PH assumption.

Therefore, in final analyses we used extended Cox regression models that allowed for time-dependent covariates, and added time-dependent interactions between age and follow-up time (Ata and Sözer, 2007). The multivariate model included sex, age, material deprivation, social deprivation, ethnic group, living arrangements at onset, co-morbid substance abuse, DUI, symptom severity, whether there was contact with police or ambulance on the pathway to care, and the total number of care pathway contacts.

The results are presented as odds ratios (OR) for logistic regression and as hazard ratios (HR) for the PH models, along with corresponding 95% confidence intervals (CI). The β-coefficients and 95% CIs of the linear regression analysis using a log-transformed outcome variable were converted to exp(β), which can be interpreted as the relative effects on the outcome of interest. Additionally, the findings did not change materially between the unadjusted and fully adjusted models. Therefore, we present the results of the fully adjusted models from the imputed dataset. All analyses were performed using SAS version 9.2.

Ethical Issues

As part of the standard intake procedure at PEPP, all patients are asked to provide voluntary and informed consent for the use of their data for research purposes. We obtained approval to access these data for the current project from the Research Ethics Board at the Douglas Mental Health University Institute (Appendix G), a health care facility within the McGill Affiliated Health Network. All data were anonymized to ensure the confidentiality and privacy of the patients involved, and data were stored on a password protected computer.

Manuscript IV: The Social and Clinical Determinants of the Pathway to Care and the Impact on Service Disengagement in First-Episode Psychosis

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This manuscript is under review.

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Abstract

Although there have been numerous studies on pathways to care in first-episode psychosis (FEP), few have examined the determinants of the pathway to care and its impact on subsequent engagement with mental health services. Using a sample of FEP patients from an early intervention (EI) program in Montréal, we estimated the association of several socio-demographic and clinical factors with the pathway to care and treatment delay. We also assessed the impact of the pathway to care on time to disengagement from EI services. Our findings suggest that few socio-demographic or clinical factors determine pathways to care in a Canadian context. Rather, service-level factors, such as having access to a primary care provider, have a stronger impact on patterns of health service use across multiple indicators. Patients who were in contact with primary care had a reduced likelihood of negative pathways to care, but also had longer referral delays to EI services. Socio-demographic and clinical factors were more relevant for predicting subsequent engagement with EI services, and indicators of negative pathways to care were not associated with service disengagement. Topics that warrant additional investigation include the influence of negative pathways to care on the quality of service engagement, reported satisfaction with services, and propensity for future help-seeking.

Introduction

Many individuals suffering from a psychiatric disorder do not receive medical care for their symptoms, and when care is received it is often only after several years (Wang *et al.* 2007). This divergence between the burden of illness and the likelihood of obtaining treatment has led to an interest in the modes and routes by which patients with mental health problems access help, known as the pathways to care. The care pathways encompass not only the help-seeking behaviour of the patient and family, but also the accessibility of mental health services and the identification of and response to symptoms by each contact on the pathway to care (Singh and Grange, 2006). As such, pathways to care are likely to be influenced by social, cultural and system-level factors.

Numerous studies have examined the pathways to care of patients with a first-episode of psychosis (FEP) specifically (Anderson *et al.* 2010). This concept is of particular importance in FEP, as it is well established that an extended period between the onset of psychotic symptoms and the initiation of antipsychotic treatment, known as the duration of untreated psychosis (DUP), is associated with poor clinical and functional outcomes (Marshall *et al.* 2005; Norman *et al.* 2005; Norman and Malla, 2001; Perkins *et al.* 2005). The DUP can be conceptualized as consisting of two phases: (1) the time between psychosis onset and first contact with health services, known as help-seeking delay; (2) the time between first contact and entry into an appropriate treatment program, known as referral delay (Bechard-Evans *et al.* 2007). Both help-seeking and referral delays impact the DUP, and there is evidence that referral delays are responsible for a substantial portion (Bechard-Evans *et al.* 2007; Brunet *et al.* 2007; Norman *et al.* 2004).

We recently conducted a systematic review on the pathways to care of patients with FEP (Anderson *et al.* 2010). Our findings suggest that there is insufficient evidence on the impact of socio-demographic factors on observed patterns of service utilization, and on whether these patterns have implications for treatment delay and subsequent engagement with mental health services. Prior studies have generally presented descriptive data, and the primary objective was not to examine the socio-demographic predictors of service use, with the notable exception of ethnicity (Burnett *et al.* 1999; Cole *et al.* 1995; Harrison *et al.* 1989; Morgan *et al.* 2005b). Further research is needed to better understand the patterns and determinants of health services use in FEP, and the impact of these patterns on referral delay and service engagement, in order to better inform the provision of mental health services.

The objectives of the present study were: (1) To estimate the extent to which socio-demographic factors and clinical indicators are associated with the pathway to care and referral delay among patients presenting to a specialized early intervention (EI) program for FEP; (2) To evaluate the impact of indices of negative pathways to care on subsequent engagement with services.

Methods

Study Population

We obtained data from the Prevention and Early Intervention for Psychoses Program (PEPP) in Montréal. PEPP is a specialized clinical research program for FEP, with an extensive database for evaluating long-term outcomes and estimating treatment delay. Patients are eligible for PEPP if they are aged 14 to 30 years, have a diagnosis of affective or non-affective psychosis, and have received less than 30 consecutive days of antipsychotic therapy. Individuals are excluded if they have a history of organic mental disorder, epilepsy, pervasive developmental disorders, or intellectual disability (IQ≤70). Patients are also excluded if forensic services are involved, such that they have outstanding charges for a serious offence for which they are likely to receive sentencing. All patients admitted to PEPP between January 2003 and October 2010 with complete data on the outcomes of interest were included in the current analysis.

All PEPP patients are asked to provide informed consent for the use of their data for research purposes. We obtained approval to access these data for the current project from the Research Ethics Board at the Douglas Mental Health University Institute, a health care facility within the McGill Affiliated Health Network.

Data Collection

Data were collected using the *Course of Onset and Relapse Schedule* (CORS), which is a standardized semi-structured interview developed by PEPP investigators in London (Ontario) and Montréal (Norman *et al.* 2004). The interview constructs a timeline of the patient's life to gather information on symptom onset, DUP, help seeking and referral delay, and the pathways into mental health care. All measures from CORS are derived via consensus between the research team and a senior clinical research psychiatrist following presentation of the CORS timeline. A detailed description of the measures relevant to the current study follows.

Baseline Measures

We obtained information on sex and age at program entry. Age was used as a continuous variable in the analyses. Patients' living circumstances at onset was used as a proxy for social support, and we dichotomized this variable as 'living with others' versus 'living alone'.

We used the material and social deprivation index as an ecological measure of socioeconomic disparities (Gamache *et al.* 2010). It was developed in Québec using census data, and scores are assigned by residential postal code. Material deprivation includes the proportion of the population without a high school diploma, the employment to population ratio, and average income. Social deprivation includes the proportion of the population who live alone, are separated, divorced or widowed, and are in a single-parent family (Gamache *et al.* 2010). We dichotomized the indices, and individuals falling into the worst quintile of material or social deprivation were classified as materially deprived or socially deprived, respectively.

We asked patients to classify their ethnic background using the Statistics Canada definitions of population group (Statistics Canada, 2011), and we categorized these as follows: (1) 'White', which includes individuals of European descent; (2) 'Black', which includes people of African, Haitian, Jamaican or Somali background; (3) 'Asian', which is comprised of people of Arabic/West Asian, Chinese, Filipino, Japanese, Korean, South Asian, or South East Asian ancestry; (4) 'Other population groups', including Aboriginal Peoples, Latin Americans and individuals of mixed descent. These categories are taken from a similar Canadian study on pathways to care, which reported ethnic differences across these groups (Archie *et al.* 2010).

Diagnoses are established using the Structured Clinical Interview for the DSM-IV (SCID) (First *et al.* 1996). The specific aspect of the diagnosis that was of interest is whether the patient had a lifetime substance abuse disorder.

We assessed the severity of psychotic symptoms using the expanded *Brief Psychiatric Rating Scale* (BPRS-E) (Ventura *et al.* 2000). The BPRS-E consists of 24 items rated on a 7-

point Likert scale representing increasing levels of severity (1 = symptom absent; 7 = extremely severe). It has been shown to have good internal consistency (α=0.64–0.76) (Dingemans *et al.* 1995), high inter-rater reliability (ICC=0.87) (Bell *et al.* 1992), and demonstrated predictive validity (Bell *et al.* 1992). The total score is calculated by summing all items, and we divided the scores into quartiles to aid the interpretability of the findings.

Retrospective Measures

The 'duration of untreated illness' (DUI) is the period from the onset of psychiatric symptoms to the initiation of adequate antipsychotic treatment, and the 'duration of untreated psychosis' (DUP) is the period from the onset of psychotic symptoms to the initiation of adequate antipsychotic treatment (Malla *et al.* 2002). High levels of inter-rater reliability have been obtained for these measures (ICC=0.86-0.93 for PEPP Montréal). The DUI was used as a proxy for mode of onset, with shorter DUIs suggesting acute onset. Of exception, in one model we replaced DUI with the length of the 'prodrome' to psychosis (details below), which is the period of psychiatric symptoms that immediately precede and are continuous with the onset of psychotic symptoms. Both variables were used as a continuous measure with log-transformation due to the positively skewed distribution.

The patient's level of functioning prior to psychosis onset was assessed using the Premorbid Adjustment Scale (PAS) (Cannon-Spoor *et al.* 1982). This instrument evaluates the achievement of social, developmental and educational milestones, and consists of 26 items across four developmental periods (Cannon-Spoor *et al.* 1982). It has been previously shown to have good internal consistency (α=0.72-0.79) and inter-rater reliability (r = 0.74-0.85) (Cannon-Spoor *et al.* 1982), and has demonstrated predictive and concurrent validity (Brill *et al.* 2008). PAS scores are assigned using an ordinal scale ranging from zero to six, and the total is divided by the number of items to yield a final score between 0 (best) and 1(worst). The scores were used to classify individuals into one of three trajectories: (1) Deteriorating - a progressive decline in scores (≥2 points) across developmental periods; (2) Stable Poor - scores fall below the group median; (3) Stable Good - scores fall above the group median (Haas and Sweeney, 1992).

Data on pathways to care were obtained by identifying the type and sequence of contacts that the patient or family member sought help from during the period from the onset of psychiatric symptoms to entry into PEPP. Each care pathway contact was categorized into one of three groups: (a.) Physician – includes general practitioners, psychiatrists, or outpatient mental health services; (b.) Non-Physician – includes private psychologists, counsellors, social workers, religious agencies, or self referral (referral source only); (c.) Emergency – refers to emergency departments, crisis teams, or inpatient units.

We calculated the proportion of patients seeking help from each type of contact for the prodromal contact, the first contact, and the referral source. The prodromal contact was dichotomized based on whether there was any contact, and the first contact and referral source were dichotomized based on whether the contact was with emergency services. We calculated the total contacts between the onset of psychotic symptoms and entry into PEPP, which has good inter-rater reliability (ICC=0.86 for PEPP Montréal). This variable was dichotomized as '0-2 contacts' or '>2 contacts'. We also constructed two binary variables based on whether the patient was in contact with primary care (general practitioner (GP) in private practice or clinic) and whether there was police or ambulance involvement.

Lastly, we calculated the referral delay, defined as the time from the first contact with mental health services to PEPP referral (Bechard-Evans *et al.* 2007).

Prospective Measures

We used the time to withdrawal from PEPP as a measure of service disengagement. Patients were considered disengaged if there was no contact for a continuous period of three months. Time to disengagement was calculated as the number of months from program entry to the first month of no contact. Individuals who were incarcerated or were admitted to a detoxification program during follow-up were considered to have disengaged. Those who moved out of the PEPP catchment area or were referred to alternate services were censored, as we did not have information on subsequent engagement with services. Patients who completed the program were censored at 24 months, and current patients were censored at the end of the follow-up period (June 2011).

Multiple Imputation for Missing Data

We used multiple imputation for missing data in our analyses (Greenland and Finkle, 1995), as the proportion of missing data for each variable ranged from 2% to 30%, and the case-wise proportion was 42%. Multiple imputation replaces missing data points by random selection from a set of plausible values that are based on the distribution of variables with missing observations, conditional on the observed data. This is done multiple times to create several datasets with complete observations, which are then analyzed in parallel and synthesized to compute summary parameter estimates that account for uncertainty introduced by the imputation process (Greenland and Finkle, 1995).

We observed an arbitrary pattern of missing data, so we used a two-step imputation procedure (Berglund, 2011). Firstly, we used a Markov Chain Monte Carlo (MCMC) method to impute enough data to produce a monotone pattern. We then performed multiple imputation using PROC MI in SAS 9.2 (SAS Institute Inc., North Carolina, USA) with the logistic regression method. We conducted ten imputations, analyzed the data using the techniques described below, and synthesized the results using PROC MIANALYZE.

We imputed data for the following independent variables (% missing): diagnostic category (1.5%), length of prodrome (2.4%), DUI (4.0%), material deprivation (4.3%), social deprivation (4.3%), ethnic group (4.6%), co-morbid substance abuse (5.9%), symptom severity (7.4%), living arrangements at onset (17.9%), and premorbid adjustment (27.2%). We additionally included age, sex, and all pathway to care indicators in the imputation model. We did not impute data for missing outcome variables.

Data Analysis

Simple logistic regression was used to estimate unadjusted associations between each covariate and the following binary indicators: (i) prodromal contact; (ii) first contact; (iii) referral source; (iv) >2 contacts; and (v) contact with police or ambulance. For referral delay, we obtained unadjusted estimates of the association with each of the covariates using a simple linear regression model, in which the dependent variable was log-transformed due to the positively skewed distribution. We then used multivariable regression models to estimate independent associations of the covariates with each outcome. All models included sex, age, material deprivation, social deprivation, ethnic group, living arrangements, substance abuse, DUI, symptom severity, pre-morbid adjustment, and contact with primary care. Of exception, model i did not include DUI because this measure includes both the length of the prodrome and the DUP, and the latter would occur after the outcome of interest. Rather, we included the length of the prodrome as a covariate.

We used Cox-proportional hazards (PH) models to estimate the independent effects of indicators of negative pathways to care on disengagement from PEPP. In preliminary analyses, we verified the PH assumption that the covariate effect remains constant during the follow-up period (Cox, 1972). This was done by testing the interaction of each covariate with time, and significant interactions indicate a violation of the PH assumption (Ng'andu, 1997). The covariate ‘age at entry’ was found to violate the PH assumption, therefore we used extended Cox regression models that allowed for time-dependent interactions between age at entry and follow-up time (Ata and Sözer, 2007). The multivariate model included sex, age, material deprivation, social deprivation, ethnic group, living arrangements, substance abuse, DUI, symptom severity, contact with police or ambulance, and >2 contacts.

Results are presented as odds ratios (OR) for logistic regression and hazard ratios (HR) for PH regression, with 95% confidence intervals (CI). The β-coefficients and 95% CIs of the linear regression analysis using a log-transformed outcome variable were converted to exp(β), which can be interpreted as the relative effects on the outcome of interest. We compared the results of the analyses of imputed data with the complete case analyses to assess the robustness of the findings to missing data. Although some of the associations in the complete case analysis failed to reach statistical significance due to the reduced sample size (data not shown), the magnitude and direction of the associations were not substantially different. Therefore, we present the results of the fully adjusted models from the imputed dataset. All analyses were performed using SAS 9.2.

Results

In total, 342 eligible patients were admitted to the PEPP program between January 2003 and October 2010. Seven refused participation in the interview and eleven were missing data on the outcomes of interest, for a final sample of 324 patients (226 males; 98 females). The socio-demographic characteristics are presented in Table 5.2 (pg. 133), and the results of all regression analyses are presented in Table 5.3 through Table 5.5 (pp. 134-136).

More than 70% of the sample was diagnosed with a schizophrenia-spectrum psychosis, and over half had a lifetime substance abuse diagnosis. The median DUI was 194.4 weeks (IQR=66.4-437.4), and the median DUP was 16.4 weeks (5.6-51.4). One third of patients had a stable poor pattern of premorbid adjustment, and a quarter demonstrated a deteriorating pattern. Nearly half were in inpatient care at the time of entry into the program.

Only 26% of patients had contact with mental health services during the prodrome. Of those, 38% had first contact with a physician, 40% with a non-physician, and 22% with emergency services. The likelihood of prodromal contact increased with increasing prodrome length (OR=1.61, 1.33-1.94). Individuals who were in contact with primary care were more likely to have contact during the prodrome (OR=2.70, 1.48-4.96).

The first contact after the onset of psychosis was a physician for 20% of patients, a non-physician for 15%, and emergency services for 62%. The referral source to PEPP was a physician for 11% of patients, a non-physician for 15%, and emergency services for 74%. Individuals who were in contact with primary care were less likely to have first contact with emergency services (OR=0.07, 0.04-0.14) or to be referred by emergency services (OR=0.42, 0.24-0.74).

Between the onset of psychosis and contact with the PEPP program, the median number of contacts was 3 (IQR=2-4). Individuals in contact with primary care had an increased likelihood of having more than two contacts (OR=3.50, 1.95-6.30). Asian patients were less likely to have more than two contacts (OR=0.47, 0.22-0.98).

Over 45% of patients had contact with police or ambulance at some point on the pathway to care. The likelihood of contact with these services increased with increasing length of DUI (OR=1.21, 1.02-1.43). Being in contact with primary care reduced the likelihood of contact with police or ambulance (OR=0.47, 0.27-0.82).

The median time between the first contact after psychosis onset and referral to the PEPP program was one week (IQR=0.3-9.5). Patients in contact with primary care had a referral delay that was more than twice as long as those who were not in contact with primary care ($\exp(\beta)$=2.31, 1.36-3.92).

Nearly 28% of patients (n=89) disengaged from PEPP prior to completing the 24 month program, and the median time to dropout was 5 months among those who disengaged (IQR=1-11). Older age was associated with an increased risk of disengagement (HR=1.10, 1.02-1.19). Black patients also had an increased risk of disengagement, as compared with white patients (HR=2.10, 1.19-3.70). Individuals living alone had a reduced likelihood of service disengagement (HR=0.46, 0.21-1.00), although this finding was only marginally statistically significant.

Table 5.2 - Characteristics of the clinical sample of patients with first-episode psychosis (n=324).

Variable		n	% of Total	Distribution
Sex	Male	226	69.8%	69.8%
	Female	98	30.2%	30.2%
	Missing	0	0.0%	-
Low Material Deprivation	Yes	84	25.9%	27.1%
	No	226	69.8%	72.9%
	Missing	14	4.3%	-
Low Social Deprivation	Yes	119	36.7%	38.4%
	No	191	59.0%	61.6%
	Missing	14	4.3%	-
Living Arrangements at Onset	Alone	55	17.0%	20.7%
	With Others	211	65.1%	79.3%
	Missing	58	17.9%	-
Ethnic Group	White	196	60.5%	63.4%
	Black	42	13.0%	13.6%
	Asian	40	12.3%	12.9%
	Other	31	9.6%	10.0%
	Missing	15	4.6%	-
Diagnostic Category	Schizophrenia-Spectrum	231	71.3%	72.4%
	Other Psychosis	88	27.2%	27.6%
	Missing	5	1.5%	-
Comorbid Substance Abuse	Yes	176	54.3%	57.7%
	No	129	39.8%	42.3%
	Missing	19	5.9%	-
Premorbid Adjustment	Stable Good	99	30.6%	41.9%
	Stable Poor	79	24.4%	33.5%
	Deteriorating	58	17.9%	24.6%
	Missing	88	27.2%	-
Quartile of BPRS-E	Quartile I (Most Severe)	75	23.1%	25.0%
	Quartile II	72	22.2%	24.0%
	Quartile III	73	22.5%	24.3%
	Quartile IV (Least Severe)	80	24.7%	26.7%
	Missing	24	7.4%	-
		Median	**IQR**	**Missing (%)**
Age at Entry		22.6	19.8 - 25.9	0 (0%)
Duration of Untreated Illness (weeks)		194.4	66.4 - 437.4	13 (4.0%)
Length of Prodrome (weeks)		30.3	6.2 - 99.0	8 (2.5%)
Duration of Untreated Psychosis (weeks)		16.4	5.6 - 51.4	9 (2.8%)
Time from First Contact to PEPP Referral (weeks)		1.0	0.29-9.5	0 (0%)

BPRS-E = Brief Psychiatric Rating Scale (Expanded); IQR = Interquartile Range

Table 5.3 - Results of the univariate and multivariate logistic regression of predictors of contact in the prodrome, first contact with emergency services, and referral source emergency services, for individuals with first-episode psychosis from a clinical sample (n=324).

Predictor Variables	**Value**	**Outcome Variables**											
		Prodromal Contact				**First Contact**				**Referral Source**			
		Unadjusted		**Fully Adjusted**		**Unadjusted**		**Fully Adjusted**		**Unadjusted**		**Fully Adjusted**	
		OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex	*Female*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Male	0.59	0.35, 0.99	0.53	0.28, 1.01	0.77	0.47, 1.26	0.64	0.34, 1.19	0.64	0.36, 1.12	0.59	0.31, 1.12
Age	*N/A*	0.96	0.90, 1.02	0.94	0.87, 1.02	1.03	0.97, 1.09	1.00	0.93, 1.07	1.05	0.99, 1.12	1.07	0.99, 1.15
Material Deprivation	*Other*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Worst Quintile	1.08	0.62, 1.91	1.51	0.77, 2.94	1.58	0.93, 2.69	1.45	0.76, 2.75	1.34	0.74, 2.41	1.30	0.69, 2.45
Social Deprivation	*Other*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Worst Quintile	0.96	0.57, 1.62	0.88	0.49, 1.58	0.94	0.59, 1.51	1.03	0.58, 1.81	1.00	0.59, 1.67	1.04	0.59, 1.83
Ethnic Group	*White*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Black	0.82	0.39, 1.73	0.90	0.38, 2.13	1.14	0.58, 2.22	1.22	0.54, 2.73	2.55	1.01, 6.44	2.15	0.82, 5.62
	Asian	1.18	0.57, 2.46	1.09	0.47, 2.54	0.86	0.43, 1.71	1.22	0.51, 2.89	0.78	0.38, 1.63	0.77	0.35, 1.67
	Other	1.12	0.48, 2.60	1.49	0.53, 4.13	0.96	0.44, 2.10	0.92	0.36, 2.32	1.32	0.54, 3.24	1.41	0.54, 3.68
Living Arrangements	*With Others*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Alone	1.29	0.68, 2.46	1.30	0.60, 2.82	1.13	0.62, 2.07	1.21	0.59, 2.52	0.68	0.35, 1.34	0.58	0.28, 1.22
DUI*	*N/A*	1.56	1.32, 1.84	1.61	1.33, 1.94	0.90	0.77, 1.05	0.90	0.74, 1.09	0.91	0.77, 1.08	0.89	0.73, 1.10
Substance Abuse	*No*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Yes	1.07	0.64, 1.80	1.04	0.56, 1.95	1.30	0.81, 2.09	1.52	0.81, 2.86	0.76	0.45, 1.30	0.83	0.45, 1.52
Symptom Severity	*I (Least)*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	II	0.95	0.46, 1.95	0.84	0.36, 1.93	0.79	0.41, 1.51	0.64	0.29, 1.41	1.86	0.91, 3.79	1.91	0.89, 4.09
	III	1.00	0.49, 2.05	1.04	0.46, 2.37	1.06	0.54, 2.09	0.97	0.41, 2.30	1.68	0.82, 3.41	1.85	0.87, 3.94
	IV (Most)	1.19	0.59, 2.41	1.36	0.57, 3.21	1.01	0.53, 1.96	0.87	0.39, 1.96	1.54	0.77, 3.10	1.60	0.74, 3.42
Premorbid Adjustment	*Stable Good*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Stable Poor	1.18	0.59, 2.35	1.03	0.45, 2.39	0.89	0.49, 1.61	1.12	0.51, 2.45	0.98	0.52, 1.87	1.17	0.55, 2.48
	Deteriorating	1.03	0.50, 2.11	0.98	0.41, 2.37	0.66	0.37, 1.17	0.52	0.25, 1.09	0.79	0.42, 1.49	0.84	0.40, 1.78
Contact with Primary Care	*No*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Yes	3.15	1.85, 5.37	2.70	1.48, 4.96	0.09	0.05, 0.16	0.07	0.04, 0.14	0.40	0.23, 0.68	0.42	0.24, 0.74

** Length of prodrome used in lieu of DUI in prodromal contact model; NB: Statistically significant results highlighted*

CI = Confidence Intervals; OR = Odds Ratio; Ref. = Reference Category; N/A = Not Applicable; DUI = Duration of Untreated Illness

Table 5.4 - Results of the univariate and multivariate regression of predictors of total contacts (logistic), police/ambulance contact (logistic), and referral delay (proportion hazards), for individuals with first-episode psychosis from a clinical sample (n=324).

Predictor Variables	**Value**	**Outcome Variables**											
		>2 Total Contacts				**Contact with Police/Ambulance**				**Referral Delay**			
		Unadjusted		**Fully Adjusted**		**Unadjusted**		**Fully Adjusted**		**Unadjusted**		**Fully Adjusted**	
		OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**exp(β)**	**95% CI**	**exp(β)**	**95% CI**
Sex	*Female*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Male	0.92	0.57, 1.49	0.90	0.53, 1.54	0.75	0.47, 1.20	0.73	0.43, 1.25	1.24	0.75, 2.07	1.25	0.74, 2.10
Age	*N/A*	0.96	0.91, 1.01	0.96	0.90, 1.02	1.04	0.98, 1.10	1.01	0.95, 1.08	0.98	0.92, 1.04	0.99	0.93, 1.05
Material Deprivation	*Other*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Worst Quintile	0.77	0.47, 1.26	0.83	0.48, 1.42	1.57	0.95, 2.62	1.51	0.88, 2.58	0.88	0.52, 1.51	0.95	0.56, 1.62
Social Deprivation	*Other*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Worst Quintile	0.67	0.43, 1.06	0.62	0.38, 1.01	1.06	0.67, 1.68	1.01	0.61, 1.65	0.98	0.60, 1.60	0.97	0.60, 1.57
Ethnic Group	*White*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Black	0.90	0.47, 1.75	0.93	0.45, 1.90	1.73	0.88, 3.44	1.98	0.87, 4.50	0.70	1.06, 1.39	0.63	0.32, 1.25
	Asian	0.59	0.30, 1.16	0.47	0.22, 0.98	1.05	0.48, 2.27	1.05	0.43, 2.57	0.79	0.39, 1.60	0.69	0.34, 1.41
	Other	0.70	0.33, 1.51	0.64	0.28, 1.46	0.85	0.37, 1.92	0.74	0.27, 2.01	0.86	0.38, 1.95	0.86	0.38, 1.95
Living Arrangements	*With Others*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Alone	0.88	0.49, 1.57	0.84	0.43, 1.64	1.51	0.83, 2.76	1.45	0.73, 2.89	0.71	0.38, 1.33	0.66	0.34, 1.27
DUI	*N/A*	1.10	0.96, 1.28	1.11	0.94, 1.30	1.19	1.02, 1.39	1.21	1.02, 1.43	*Not Included*		*Not Included*	
Substance Abuse	*No*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Yes	1.25	0.78, 1.99	1.20	0.69, 2.07	1.37	0.87, 2.18	1.45	0.85, 2.46	1.06	0.65, 1.74	0.98	0.59, 1.64
Symptom Severity	*I (Least)*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	II	1.37	0.72, 2.60	1.43	0.72, 2.84	1.44	0.76, 2.75	1.44	0.72, 2.87	1.46	0.74, 2.87	1.60	0.82, 3.11
	III	1.61	0.84, 3.08	1.64	0.82, 3.29	1.58	0.83, 3.00	1.42	0.71, 2.84	1.91	0.97, 3.79	2.03	1.03, 3.99
	IV (Most)	1.83	0.95, 3.51	1.92	0.94, 3.93	1.59	0.84, 3.00	1.52	0.76, 3.05	1.39	0.70, 2.75	1.51	0.76, 3.02
Premorbid Adjustment	*Stable Good*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Stable Poor	0.95	0.52, 1.73	0.78	0.40, 1.50	0.81	0.45, 1.47	0.81	0.42, 1.55	0.98	0.50, 1.93	0.86	0.44, 1.68
	Deteriorating	0.83	0.43, 1.62	0.89	0.44, 1.81	0.80	0.41, 1.57	0.71	0.34, 1.48	1.07	0.53, 2.15	1.09	0.56, 2.14
Contact with Primary Care	*No*	*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*		*Ref.*	
	Yes	3.22	1.86, 5.57	3.50	1.95, 6.30	0.49	0.29, 0.83	0.47	0.27, 0.82	2.25	1.33, 3.80	2.31	1.36, 3.92

NB: Statistically significant results highlighted

CI = Confidence Intervals; OR = Odds Ratio; HR = Hazard Ratio; Ref. = Reference Category; N/A = Not Applicable; DUI = Duration of Untreated Illness

Table 5.5 - Results of the univariate and multivariate proportional hazards regression of predictors of service disengagement for individuals with first-episode psychosis from a clinical sample (n=324).

Predictor Variables	**Value**	**Outcome Variable**			
		Service Disengagement			
		Unadjusted		**Fully Adjusted**	
		HR	**95% CI**	**HR**	**95% CI**
Sex	*Female*	*Ref.*		*Ref.*	
	Male	1.28	0.80, 2.05	1.17	0.71, 1.92
Age	*N/A*	1.03	0.97, 1.08	1.10	1.02, 1.19
Material Deprivation	*Other*	*Ref.*		*Ref.*	
	Worst Quintile	1.15	0.72, 1.84	1.28	0.79, 2.07
Social Deprivation	*Other*	*Ref.*		*Ref.*	
	Worst Quintile	0.71	0.45, 1.12	0.72	0.45, 1.14
Ethnic Group	*White*	*Ref.*		*Ref.*	
	Black	2.00	1.17, 3.42	2.10	1.19, 3.70
	Asian	1.19	0.63, 2.28	1.21	0.61, 2.38
	Other	1.18	0.58, 2.43	1.19	0.56, 2.50
Living Arrangements	*With Others*	*Ref.*		*Ref.*	
	Alone	0.43	0.20, 0.90	0.46	0.21, 1.00
DUI	*N/A*	0.95	0.83, 1.09	0.97	0.84, 1.11
Substance Abuse	*No*	*Ref.*		*Ref.*	
	Yes	1.05	0.68, 1.63	1.10	0.68, 1.78
Symptom Severity	*I (Least)*	*Ref.*		*Ref.*	
	II	0.57	0.31, 1.05	0.56	0.30, 1.07
	III	0.77	0.42, 1.39	0.76	0.41, 1.38
	IV (Most)	0.57	0.31, 1.06	0.54	0.29, 1.03
Police/Ambulance Contact	*No*	*Ref.*		*Ref.*	
	Yes	0.80	0.52, 1.22	0.81	0.52, 1.26
Total Contacts	*0-2 Contacts*	*Ref.*		*Ref.*	
	>2 Contacts	1.16	0.77, 1.77	1.27	0.83, 1.96

NB: Statistically significant results highlighted

CI = Confidence Intervals; HR= Hazard Ratio; Ref. = Reference Category; N/A = Not Applicable; DUI = Duration of Untreated Illness

Discussion

The findings from our analyses suggest that few socio-demographic or clinical factors are predictive of the pathway to care in FEP in a Canadian context. Rather, service-level factors, such as having access to a primary care provider, may have a stronger impact on patterns of health services use across multiple indicators. In contrast, socio-demographic and clinical factors were more relevant for predicting service disengagement, and negative pathways to care did not have an effect on subsequent engagement with EI services in our sample. Few studies to date have explored the determinants of the pathway to care, and ours is the first to examine the impact of the pathway to care on subsequent engagement with services. Our results are strengthened by the use of validated methods to minimize the pernicious effects of missing data, thereby ensuring our study is adequately powered to achieve its objectives.

The patterns of service use observed in the current study are consistent with the findings of our systematic review on pathways to care in FEP (Anderson *et al.* 2010). In both studies, we observed a progression from the use of outpatient physician and non-physician services to the use of more acute types of services, such as inpatient care and the emergency department. However, most of the socio-demographic factors we employed were not significantly predictive of the pathway to care. Indeed, our systematic review found inconsistent results across studies, and it is likely that the impact of these determinants differ depending on the social, cultural and health system context. Only one prior study has examined the socio-demographic predictors of the pathway to care in FEP in a Canadian context (Archie *et al.* 2010). In contrast to our study, Archie and colleagues found that males were nearly five times more likely to make first contact with the ED, and Asian and patients of other ethnic backgrounds (not including Afro-Canadian) were three to four times more likely to make first contact with the ED (Archie *et al.* 2010). This study was conducted at four sites in the province of Ontario and included a large metropolitan centre (Toronto) with a high proportion of South and East Asians. The discrepant findings may be reflective of differences in provincial health care systems, availability of services, or social and cultural composition of the cities. Of exception, we did find that individuals of Asian ethnicity had fewer contacts on the pathway to care. This is consistent with prior Canadian research, which found that Asian immigrants have lower rates of mental health service use (Tiwari and Wang, 2008).

Only one quarter of patients in our sample sought help in the prodrome to psychosis, and the first prodromal contact was most frequently with physician or non-physician services, which has been reported previously (Norman *et al.* 2004). To our knowledge, only one study to date has investigated help-seeking during the prodrome specifically (Rietdijk *et al.* 2011), although several studies on help-seeking in FEP include prodromal contacts as part of the pathway to care (Compton *et al.* 2006; Fuchs and Steinert, 2004; Kohn *et al.* 2004; Lincoln *et al.* 1998; Platz *et al.* 2006). Rietdijk and colleagues (2011) analyzed a large case registry and found that women were more likely to seek help from secondary services during the prodrome than men. Additionally, two studies have looked at help-seeking by individuals at high risk for developing a psychotic disorder, which would include the prodromal period for those who transition to psychosis, and these studies also report more frequent use of physician and non-physician services (Phillips *et al.* 1999; Shin *et al.* 2010). Characterizing the patterns and predictors of help-seeking during the prodromal phase of psychotic illness could be a worthwhile avenue for future research.

We found that contact with emergency services was frequent, which is consistent among FEP samples across most jurisdictions (Anderson *et al.* 2010). Ethnicity as a predictor of emergency service contact is the most extensively studied determinant of the pathway to care, however we did not find ethnic differences in our sample. Ethnic differences have been reported in a Canadian context (Archie *et al.* 2010), and a study by Jarvis and colleagues (2005) in Montréal found that patients of Afro-Canadian descent with psychotic disorders were three times more likely to be brought to the ED by police or ambulance. The discrepancy between our findings and the latter study may be explained by the fact that Jarvis and colleagues looked at psychotic disorders generally, rather than FEP specifically, and there is evidence to suggest that ethnic differences in service utilization occur only after the first contact (Burnett *et al.* 1999; Cole *et al.* 1995). This may be due to negative experiences with services received, stigma from within ethnic communities, and a loss of social support due to such stigma (Cole *et al.* 1995). We may also have missed ethnic differences as a result of the indicators employed in the current study, given that others have found ethnicity to be predictive of an increased risk of compulsory admission (Archie *et al.* 2010; Harrison *et al.* 1989; Morgan *et al.* 2005a) and contact with police (Burnett *et al.* 1999; McGovern and Cope, 1991; Morgan *et al.* 2005a), and a decreased likelihood of GP referral (Burnett *et al.* 1999; Morgan *et al.* 2005b). There is also evidence that social support may be a better predictor of negative pathways to care (Burnett *et al.* 1999; Cole *et al.* 1995), and that observed ethnic differences may be mediated by indicators of social support and isolation (Burnett *et al.* 1999).

The frequent use of emergency services that we observed may be due to a lack of alternative options. Although the health care system in Canada is publically funded, GPs are not obligated to provide services, many individuals do not have a family physician, and a referral from a GP is required to access many specialized services. Our findings suggest that improving access to primary care for patients with FEP may decrease the likelihood of contact with emergency services, including inpatient units, EDs, crisis teams, police, and ambulance. A study from the United Kingdom also found that GP involvement is associated with a reduced likelihood of compulsory admission and contact with police (Cole *et al.* 1995). However, we did find that patients who were in contact with primary care had a greater number of contacts and a longer referral delay, which may indicate that GPs and other primary care providers need additional training in the recognition of early psychosis and protocols for referral to specialized care. Prior research has found that patients who were receiving professional care at the onset of psychosis had a longer referral delay (Boonstra *et al.* 2011; Norman *et al.* 2004). Additionally, there is evidence that patients with insidious and non-specific symptoms, such as anxiety and depression, are more likely to contact GPs (Platz *et al.* 2006), and family members of FEP patients report that GPs may misattribute symptoms to conditions other than a psychotic disorder or administer inappropriate treatment regimens (Etheridge *et al.* 2004). System-level factors are likely also implicated, such as local availability of specialized services, collaboration between different levels of care, and establishment of linkages to facilitate referral.

Nearly 30% of patients disengaged from PEPP over the two-year follow-up, which is comparable with other estimates from EI services (Conus *et al.* 2010; Schimmelmann *et al.* 2006; Turner *et al.* 2007). We found that patients of black ethnicity had more than twice the risk of disengagement. Ethnicity has been reported as a risk factor for disengagement from health services among psychiatric patients generally (O'Brien *et al.* 2009). We also found that living away from family was associated with a reduced risk of service disengagement after controlling for the effects of age, which is in contrast to what has been reported previously (Conus *et al.* 2010; Schimmelmann *et al.* 2006). It is possible that clinicians may use more assertive follow-up for patients who do not have a support system in place, thereby reducing the risk of disengagement. Alternatively, patients who have a strong network of social support may perceive that they are less in need of services, leading to subsequent disengagement. The complex mechanisms by which family involvement impacts on engagement warrants further examination as a potential target for improving adherence with EI programs.

We did not find that the pathway to care had an impact on subsequent engagement with EI services. A descriptive case series hypothesized that negative pathways to care may be associated with service engagement (Compton, 2005), however we were unable to find evidence of this in our analyses. It is possible that this may be due to the nature of EI services, which focus on providing a positive treatment experience through the use of case management, a lack of exclusive emphasis on medication, and a strong orientation toward psychosocial recovery. An alternative explanation is that we used program drop-out as a proxy for service engagement, rather than measuring the quality of engagement. There may be important components of engagement that are associated with negative pathways to care, such as acceptance of treatment, therapeutic alliance with clinicians, and satisfaction with services (O'Brien *et al.* 2009). Indeed, prior studies suggest that contact with emergency services may have an impact on reported satisfaction (Bhugra *et al.* 2004) and propensity to seek help in the future (Monteiro *et al.* 2006). Given the nature of the data, we were also unable to discriminate between those who had contact with the police and those who had contact with an ambulance, and this distinction may be important for disengagement. Patients with forensic involvement are ineligible for the PEPP program, and we are consequently missing those who have the most negative pathways to care in our selected sample. Contact with police may impact subsequent engagement if there is criminal justice involvement, such that pending legal charges or arrests may render medication compliance and outpatient appointments difficult to maintain (Compton, 2005). Individuals with a forensic history are also twice as likely to disengage from services (Conus *et al.* 2010), suggesting that contact with police specifically on the pathway to care may be more detrimental than contact with emergency services generally.

The pathways to care we observed may not be representative of all FEP patients, as our sample has been successful at obtaining specialized services, and utilization patterns may differ for individuals who do not obtain specialized treatment or are currently under the care of other health and social service providers. Our analyses are also limited by the available data. Many of the variables of interest were measured retrospectively, and thus are subject to recall errors and biases. There is substantial heterogeneity within the categories of ethnicity that we employed, which may not accurately capture ethnic differences in the pathways to care. Additionally, we used living arrangements at onset as a proxy for social support, but this variable is too crude to capture the extent and quality of the patient's social support network. We also used ecological indicators of socioeconomic status, which tend to underestimate the disparities between groups when compared to individual-level data (Pampalon *et al.* 2009a). It is unlikely that all potential confounders were included, or measured with sufficient accuracy, so residual confounding may remain.

Our findings on the predictors of service disengagement are only applicable to disengagement from EI services within two-years. Other factors may be important predictors of short- or long-term disengagement, or of dropout from other treatment settings. We also do not know whether PEPP clinicians used the same procedure to follow-up all patients in the event of non-attendance, and there may be systematic differences by factors such as severity of illness, co-morbid substance abuse, or lack of social support.

In summary, improving access to primary care may reduce the burden of FEP patients on EDs and inpatient units, however primary care providers need additional training in the recognition of the symptoms of early psychosis and protocols for referral to specialized care. Patients with FEP are heavy users of emergency services, and few socio-demographic or clinical factors were predictive of pathways to care. Although contact with emergency services did not have an impact on disengagement from an EI program, further research is needed on the impact of these negative pathways to care on factors such as the quality of service engagement, satisfaction with services received, and propensity for future help-seeking.

CHAPTER 6 - THE INDIVIDUAL LEVEL: QUALITATIVE ANALYSIS

In Chapters 4 and 5, we used quantitative methods to examine the patterns of health services use prior to a first-episode of psychosis at the population- and clinical-levels. In both sets of analyses, we describe a complex pattern of help seeking that has implications for subsequent treatment delay. To obtain a deeper understanding of the help-seeking experiences of patients with early psychosis, we use qualitative methods in Manuscript V to describe the experiences of patients on the pathway to care, and to identify factors that may help or hinder the help-seeking process.

Studies using qualitative methods make an important contribution to the burgeoning body of literature on first-episode psychosis, as it "…allows us to pursue essential questions regarding the subjective experience of psychosis and the complex social settings in which young people and their families live their lives."(Boydell *et al.* 2010, pg. 8). This manuscript helps to fill a gap in the current knowledge on pathways to care in first-episode psychosis, as relatively few studies have used a qualitative research paradigm or have been done from the perspective of the person experiencing the psychotic episode. This in-depth knowledge of the help-seeking experiences of patients is useful for identifying where delays may occur and factors that may act as barriers to help-seeking for patients on their pathway to early intervention services.

Detailed Methods

Qualitative Approach

We used a qualitative descriptive approach, which is defined as "…a distinct method of naturalistic inquiry that uses low inference interpretation to present the facts using everyday language." (Sullivan-Bolyai *et al.* 2005, pg. 128) This approach is used when the goal of the study is to produce a comprehensive summary of the phenomenon under investigation. It aims to provide an accurate account that would be recognizable to those experiencing the event, known as descriptive validity, and to detail the meanings that participants ascribe to the event, known as interpretive validity (Sandelowski, 2000b).

All description is influenced by the perceptions of the describer, such that some level of interpretation is required to produce a description of the phenomenon. However, the qualitative descriptive approach requires less inference and interpretation as compared with other qualitative approaches, such as ethnography, phenomenology, or grounded theory, because the researcher is not obliged to position the findings within a philosophical or conceptual framework (Sandelowski, 2000b). As such, the description that is produced is a low inference interpretation of the events, such that the research remains at the 'surface' of the data, while still capturing the relevant aspects of the experience (Milne and Oberle, 2005). Additionally, a qualitative descriptive approach differs from quantitative description in that the findings are not constrained by variables selected *a priori* for measurement, and conclusions are not based on frequency counts and descriptive statistics (Sandelowski, 2000b).

A qualitative descriptive approach was chosen for the current study for several reasons: (1) It is particularly suited to mixed methods designs (Neergaard *et al.* 2009; Sullivan-Bolyai *et al.* 2005), especially given the lack of a requisite philosophical or conceptual framework that has traditionally made it difficult to combine qualitative and quantitative methods (Stange *et al.* 1994); (2) It is useful for research involving vulnerable populations, such as individuals with mental illness, as qualitative description avoids the high levels of interpretation and theory development associated with other qualitative methods, thereby more accurately reflecting the direct experience of the participant (Sullivan-Bolyai *et al.* 2005); (3) It is appropriate to use when the primary language of the participant is not English, as attempting to translate highly interpretive or theorized concepts increases the likelihood of an inaccurate representation of the findings (Sullivan-Bolyai *et al.* 2005); (4) It is especially relevant in health services research, as it produces a straightforward account of the event that is of relevance to practitioners, administrators, and policy makers, thus improving the potential utility and uptake of the findings (Sandelowski, 2000b; Sullivan-Bolyai *et al.* 2005).

Sampling and Recruitment

We recruited participants from the Prevention and Early Intervention for Psychoses Program (PEPP) at the Douglas Mental Health University Institute in Montréal, a specialized early intervention clinical research program for first-episode psychosis (for further details, please refer to Chapter 5 – Study Population). PEPP uses an open referral system, and patients are referred to the program from a variety of different sources, including general practitioners, mental health professionals, emergency departments, school counselors, religious agencies, and family and friends. Since physician referral is not a requisite condition for entry into the program, this enabled a detailed assessment of the non-medical points of contact and sources of referral on the pathway to care.

Qualitative research uses sampling strategies that aim to select “information-rich cases” (Patton, 1990, pg. 169). Patients in months three through twelve of the PEPP program who were deemed to be clinically stable and sufficiently talkative for an interview were approached with a request to participate. The study was presented to the patient by a staff member following a regularly scheduled session. For all interested patients, we followed-up within one week to confirm participation and schedule an interview.

Recruitment continued until the data had reached theoretical saturation, which is the point at which new data supports existing findings but does not add any additional insights (Morse, 1995). The term “theoretical” is used to describe saturation, as an investigator can never be truly confident that saturation has been reached. It is also difficult to achieve saturation in a qualitative descriptive design, as the objective of the research is to capture individual experiences and explore commonalities and differences across them (Milne and Oberle, 2005). Thus, we opted to conclude data collection when no new primary themes emerged, and the data on the primary themes had sufficient depth and breadth to allow for a comprehensive understanding of the phenomenon of interest (Sandelowski, 1995).

Data Collection

When using a qualitative descriptive approach, data collection efforts are “…typically directed toward discovering the *who*, *what*, and *where* of events or experiences, or their basic nature and shape”(Sandelowski, 2000b, pg. 338). We used a combination of unstructured and semi-structured in-depth interviews, which involved an open-ended, conversational technique that focused on the participants’ help-seeking experience (Miller and Crabtree, 1999). We chose this method of data collection because our objective was to obtain a complete account of each participant's experiences seeking mental health services, and the sequence of these narratives would be disrupted in a focus group interview. Additionally, PEPP clients regularly participate in clinical interviews, making the use of a research interview a familiar and comfortable form of data collection.

The unstructured portion of the interview involved asking each participant to describe their experiences seeking help for their symptoms of psychosis, up to the time of entry to the PEPP program. The semi-structured portion of the interview involved questions developed *a priori* based on a prior qualitative study on help-seeking in early psychosis (Boydell *et al.* 2006a). Although this guided the course of the interview (Appendix I & Appendix J), the interviewer also had the flexibility to probe specific areas of interest. The questions elicited the participants' description of their process of obtaining mental health care, including reasons for help-seeking, knowledge of how and where to access services, perceptions of existing services and views on improving access. The interview guide also remained flexible to help ensure that the narratives were participant-driven. Probes were used by the interviewer to clarify information and to obtain more in-depth descriptions of some topics to improve the richness of the data. Additionally, the interviewer took brief field notes throughout the interview to gather information on contextual and non-verbal information that would help inform participant meaning.

All interviews were held at a time and location that was convenient for the participants, typically at the PEPP program unless otherwise requested by the participant. The interviews were audio taped with permission, however if the participant refused (n=1), the interviewer made detailed notes on responses. All participants were given $20 as compensation for their time and contribution to the study.

Data Management and Analysis

Content analysis is the recommended technique for qualitative descriptive studies, as it is a less-interpretive form of analysis that is focused on summarizing interview content using data-derived codes or themes (Hsieh and Shannon, 2005; Sandelowski, 2000b). We used conventional content analysis, which involves reducing the data into smaller segments, or codes, based on the concepts that are represented, and then grouping the material based on shared concepts (Hsieh and Shannon, 2005). The codes are data-driven, in that they are obtained "… from the data rather than being superimposed on them" (Milne and Oberle, 2005, pg. 417). Additionally, the codes are refined and modified over the course of the analytical process as new insights are gained that require a reexamination of the data.

In the current study, we transcribed all interview transcripts verbatim, and excerpts of the French interviews relevant to the study objectives were translated into English. The interviewer reviewed all transcripts while listening to the audio-recording to ensure accuracy and for the inclusion of nonverbal data. We used the software program NVivo 8.0 (QSR International®, Victoria Australia) to facilitate data management and analysis.

Two members of the research team reviewed the transcripts independently to gain a sense of the content and recurring themes. This initial coding scheme was used to identify segments of text pertaining to each code, the segment of text was highlighted in NVivo, and the most relevant code was applied to the text segment. As this process continued, new insights were gained that were added to the emerging coding scheme. Upon completion of this first-level of coding, the segments were sorted to consolidate all of the data related to a specific code, which allowed for the data to be organized into meaningful themes (Hsieh and Shannon, 2005). Each of the main themes was based on numerous excerpts across multiple interviews, and we present several quotations that are representative of these excerpts.

Criteria for Quality and Verification

Lincoln and Guba (1985) propose criterion for evaluating the rigor of a qualitative study that parallel those commonly used to assess quantitative studies. These include credibility (internal validity), transferability (external validity), and dependability (reliability).

We employed several strategies in an attempt to maintain the rigor of the study. Credibility is achieved when the description and interpretation of the phenomenon are presented in such a way that it can be recognized by others (Lincoln and Guba, 1985). This was achieved through the use of rich descriptive quotes from the participants. Data triangulation was also used to increase the credibility of the findings (Creswell, 1998), which involved corroborating the findings from the quantitative and qualitative analyses (Chapter 7). Transferability is the degree that results are applicable in different contexts (Lincoln and Guba, 1985). An overview of the PEPP program was presented so that assessments of transferability could be made, and limitations to transferability are highlighted in the discussion. Dependability is achieved when another researcher can proceed through the decision-making process of the study and arrive at a consistent conclusion (Lincoln and Guba, 1985). This was enhanced by the involvement of two researchers in the collection and analysis of data.

Ethical Issues

Ethics approval was obtained from the Douglas Mental Health University Institute in Montréal, a health care facility within the McGill Affiliated Health Network (Appendix G). All participants provided written consent for both the interview and audio taping (Appendix K & Appendix L), and were informed of their rights to refuse participation or stop the interview at any time. Original audio recordings and full transcripts were destroyed upon completion of the study.

Manuscript V: "There's too many steps before you get to where you need to be" – A Qualitative Description of the Help-Seeking Experiences of Patients with First-Episode Psychosis

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Abstract

Background: There has been substantial research on pathways to care in first-episode psychosis (FEP), however few studies have used a qualitative research paradigm or have been done from the perspective of the person experiencing the psychotic episode.

Objective: We sought to describe the experiences of patients with FEP on their pathway to care, and to identify factors that help or hinder help-seeking efforts.

Methods: Using a qualitative descriptive approach, we conducted semi-structured interviews with sixteen patients recruited from an early intervention program. Data were analyzed using content analysis to organize the findings into themes.

Findings: Participants described the crucial role of significant others in initiating contact with services, and both self-stigma and a pervasive lack of knowledge regarding the symptoms of psychosis and availability of services emerged as barriers to help-seeking. Participants typically described a complex series of contacts along the pathway to care which resulted in feelings of being misunderstood and losing control, but many individuals identified unexpected benefits of their experience.

Conclusions: Our findings suggest a shift in the philosophy and orientation of service delivery towards the creation of services that address these concerns and are relevant to the young people who utilize them.

Introduction

The patterns of health services use by patients experiencing a first-episode of psychosis (FEP) are complex, and often involve a diverse range of service providers. There is some evidence to suggest that these pathways to care can have an impact on the length of time that psychotic symptoms go untreated (Anderson *et al.* 2010), known as the duration of untreated psychosis (DUP), which is an important determinant of clinical and functional outcomes (Marshall *et al.* 2005; Perkins *et al.* 2005). Gaining an in-depth understanding of the pathways to care for patients with FEP is crucial for informing the provision of early intervention services, which focus on case detection, attempts to shorten the DUP, and comprehensive care during the initial stages of illness (McGorry *et al.* 2007).

Although there have been numerous studies on pathways to care in FEP, the bulk of prior research has been done using a quantitative research paradigm (Anderson *et al.* 2010). It is important to also consider the subjective experiences of patients, family members and service providers. A recent review of qualitative research in FEP identified eight studies that looked at the help-seeking experiences of individuals suffering from the symptoms of early psychosis (Boydell *et al.* 2010). Of those, only two studies examined help-seeking from the perspective of the patients themselves (Boydell *et al.* 2006b; Judge *et al.* 2008), and an additional study published since the review examined the experiences of both patients and caregivers (Cadario *et al.* 2011). The remaining qualitative studies on pathways to care in FEP have been done from the perspectives of family members and caregivers (Boydell *et al.* 2010). It is well established that family members play a pivotal role in the pathway to care for many patients (Lincoln *et al.* 1998), however the personal narratives of those experiencing psychotic symptoms should also contribute to the discourse for a deeper understanding of the dynamic processes that impact help-seeking attempts.

In the current study, we sought to describe the experiences of patients with FEP on the pathway to care, and to identify factors that may help or hinder the help-seeking process.

Methods

We used a qualitative descriptive approach, which is defined as "…a distinct method of naturalistic inquiry that uses low inference interpretation to present the facts using everyday language."(Sullivan-Bolyai *et al.* 2005, pg. 128). It is used when the objective is to produce a comprehensive summary of the phenomenon that is recognizable to those who experienced it (Sandelowski, 2000b). The description produced is a low inference interpretation of the events, such that the research remains at the 'surface' of the data, while still capturing the relevant aspects of the experience (Milne and Oberle, 2005). This approach was chosen because it is useful for research involving vulnerable populations and those whose primary language is not English, and it is relevant in health services research for improving the potential utility and uptake of the findings (Sandelowski, 2000b; Sullivan-Bolyai *et al.* 2005).

We recruited participants from the Prevention and Early Intervention for Psychoses Program (PEPP) at the Douglas Mental Health University Institute in Montréal. The PEPP program is specialized for the early assessment and treatment of FEP, focused on case detection and comprehensive care during the initial stages of illness. Eligible patients include those between the ages of 14 and 30 years with a primary diagnosis of an affective or non-affective psychotic disorder who have received less than 30 consecutive days of antipsychotic medication. PEPP uses an open referral system, and referrals come from a variety of medical and non-medical sources.

Qualitative research uses sampling strategies that aim to select “information-rich cases” (Patton, 1990, pg. 169). Patients in month three through twelve of the PEPP program who were deemed to be clinically stable and sufficiently talkative for an interview were approached with a request to participate. The study was presented to the patient by a staff member following a regularly scheduled session. For all interested patients, we followed-up within one week to confirm participation and schedule an interview.

Recruitment continued until the data had reached theoretical saturation, which is the point at which new data supports existing findings but does not add any additional insights (Morse, 1995). Saturation is often difficult to achieve in a qualitative descriptive design, as the objective of the research is to capture individual experiences and explore commonalities and differences across them (Milne and Oberle, 2005). Thus, we opted to conclude data collection when no new primary themes emerged and the data on the primary themes had sufficient depth and breadth to allow for a comprehensive understanding of the phenomenon of interest (Sandelowski, 1995).

We used a combination of unstructured and semi-structured in-depth interviews, which involved an open-ended, conversational technique that focused on the participants’ help-seeking experience (Miller and Crabtree, 1999). The unstructured portion of the interview involved asking each participant to describe their experiences seeking help for their psychotic symptoms. The semi-structured portion of the interview involved questions developed *a priori* based on a separate qualitative study on help-seeking in early psychosis (Boydell *et al.* 2006a). The topics probed in this portion of the interview are presented in Table 6.1 (pg. 158), however these were often mentioned spontaneously during the unstructured narrative. The interview guide remained flexible to allow the data to be participant-driven.

Ethics approval was obtained from the Douglas Mental Health University Institute, a health care facility within the McGill Affiliated Health Network. All participants provided written consent and were informed of their right to refuse participation or stop the interview at any time. All interviews were held at a time and location that was convenient for the participants, typically at the PEPP program unless otherwise requested. The interviews were audio taped with the permission of the participant, however if he/she refused (n=1) the interviewer made detailed notes on responses. All participants were given $20 as compensation for their time and contribution.

Content analysis is the recommended technique for qualitative descriptive studies, as it is less-interpretive relative to other types of qualitative analysis, and is focused on summarizing interview content using data-derived codes or themes (Hsieh and Shannon, 2005; Sandelowski, 2000b). We transcribed all interviews verbatim, and excerpts of the French interviews relevant to our study objectives were translated into English. The interviewer reviewed all transcripts while listening to the audio-recording to ensure accuracy and for the inclusion of nonverbal data. We used the software program NVivo 8.0 (QSR International®, Victoria Australia) to facilitate data management and analysis.

Two members of the research team reviewed the transcripts independently to gain a sense of the content and recurring themes. This initial coding scheme was used to identify segments of text pertaining to each code, the segment of text was highlighted in NVivo, and the most relevant code was applied to the text segment. As this process continued, new insights were gained that were added to the emerging coding scheme. Upon completion of this first-level of coding, the segments were sorted to consolidate all of the data related to a specific code, which allowed for the data to be organized into themes (Hsieh and Shannon, 2005). Each of the main themes was based on numerous excerpts across multiple interviews, and we present several quotations that are representative of these excerpts.

Table 6.1 - Topics probed by the semi-structured questions in the qualitative interview.

Topics:
- People who you told about symptoms
- Individuals involved in the help-seeking process
- How the involvement of others impacted the process
- One word to describe your help-seeking experience
- Things that made help-seeking easier
- Factors that made help-seeking more difficult
- How has the experience had an impact on you
- Suggestions or advice to make the help-seeking process easier

Findings

Twenty-seven individuals were approached with information on our study, and six refused. We contacted the remaining 21 individuals: one had dropped out of PEPP, one had entered a residential detoxification program, and three could not be reached. Sixteen interviews were conducted, ten in English and six in French. The interviews ranged in duration from 15 to 75 minutes (median = 20 minutes).

The interview participants had a median age of 22.5 years (IQR=20-24), and 12 of the 16 participants were male. Eight participants had obtained education beyond high school, 12 were born in Canada, and five were a visible minority. Seven participants could speak both English and French, six spoke English only, and three spoke French only. At the time of the interview, the median number of months since program entry was 5.5 (IQR=4-11).

Participants typically described a complex series of contacts that eventually culminated in admission to the PEPP program. Family members were involved in the pathway to care for ten individuals. Participants had a median of two total contacts prior to PEPP (maximum five), and five had contact with services during the prodrome to psychosis. Thirteen participants had contact with the emergency department, and five had contact with police or ambulance services. Seven participants were admitted to inpatient care at the time of entry to the PEPP program.

When describing their experiences seeking help for their symptoms of psychosis, five primary themes emerged from the participants' responses: (A) The importance of a help-seeker for initiating service contact; (B) Lack of knowledge regarding the symptoms of psychosis and availability of services; (C) Self-stigma as a barrier to help-seeking; (D) Feelings of misunderstanding and loss of control throughout the help-seeking process; and (E) Unexpected benefits of the experience. Each theme was described by the majority of interview participants, and is illustrated below with representative quotes from the interviews.

A. Role of the Help-Seeker

Nearly all participants highlighted the important role of a significant other in initiating the help-seeking process. For most participants, this significant other was a family member, usually a parent.

> "…If I was alone I don't know what to do and like…if I'd been alone I'd be in rehab or something, right? So, like, I really don't know what to do and it really, like fucked up my life. But the good thing I have the support from them, 'cause uh, like the care-ness [sic] that I have from them, because I have people who care for me, and they want me to have a better life."
>
> *Participant #2*

> "For myself, it [the help-seeking process] seemed to unravel without any thought or intention. Whatever, the care was there and it was given when needed. But as far as seeking it out as an individual, I likely wouldn't have. So I think the important thing for me was that I had people around me to stimulate that…"
>
> *Participant #4*

For individuals who did not have family involvement on the pathway to care, there was still an important individual, such as a school counselor or the police, who was the impetus to the help-seeking process.

> "…the human resource manager. She gave me the list of numbers for this type of problem. It seems like there are a lot of people who have, like, pressure at work and they will turn to this type of organization."
>
> *Participant #6*

> "If there was no psychoeducator in my school, I don't know where I might have ended up."
>
> *Participant #13*

> "I started getting scared. And then at one point, I got too scared so I called the cops, and the cops came and they said 'We talked to your neighbor and we're taking you to the hospital.'"
>
> *Participant #16 (Translated)*

B. Lack of Knowledge

Eleven participants made reference to their lack of knowledge about FEP. Some participants described not knowing about the symptoms of psychosis, or that the symptoms they were experiencing could be medically treated.

> "I guess the biggest thing would be to get more information out about what psychotic symptoms are. Because, you know…I was having symptoms for eight months before I sought any help…I didn't know that this was a condition that, you know, you could seek medical treatment for. For me it was just, you know, a state of facts."
>
> *Participant #5*

> “Well, I was hearing voices, but I didn’t know that it was a disease…And I realized that this is something that started years ago…So then, I didn’t hear voices, but I was still quite depressed at the time. So, bit by bit, it added up, and then I started hearing voices. But I didn’t know that I had such a big problem that I needed help.”
>
> *Participant #7 (Translated)*

> “Public awareness, more than anything else… Like, you see a lot of stuff for depression and social anxiety. But for people like me, I would have liked to hear ‘Are you paranoid for no reason? Well maybe you should seek counseling or a meeting and we can decide if you actually need help or not.’…Like, I didn’t know how to deal with it. I didn’t even know what it was.”
>
> *Participant #12*

Participants also described a lack of knowledge about the availability of services or how to access them.

> “For people, really, to know that it exists, people who are there for them…that they be able to talk to people who will listen to them and give them solutions. So it’s important that we really draw attention to that. For those who have problems. Especially us, in fact, we come from [foreign country]. We haven’t lived in this system, like you…We don’t necessarily know that there are people there, who are even paid by the government for this.”
>
> *Participant #7 (Translated)*

> “It’s because there’s not, you know, there’s the Douglas in Verdun [Hospital with PEPP program], but not every city has one, and you have to know where it is. That’s it with psychiatrist hospitals, there aren’t many.”
>
> *Participant #14 (Translated)*

C. Self-Stigma

Twelve participants made comments related to the shame and stigma surrounding mental illness when discussing their experiences with seeking help for their psychotic symptoms. Although none of the participants described a situation where they were directly stigmatized, many used words and descriptions that indicated they had internalized society's stigma against individuals with mental illnesses.

> "I wasn't in denial that I was sick, but I was kind of angry that I was sick, and I wasn't comfortable being in the office, well being in the little area the first time I was seeing the psychiatrist, you know. I wasn't in denial, but there were times I wanted to say 'Fuck man, I'm a normal person I'm not sick.' "
>
> *Participant #3*

> "And she was like 'I have an idea for you. I'm going to make a phone call to the Douglas Hospital and I'm going to get you help because I can't give you the help that you need.' So I said, I was like oh shit, the Douglas Hospital…that's for retards, you know? It's for people who are like really sick, you know?"
>
> *Participant #8*

> "Because I didn't want to [to the Douglas Hospital]. Because I thought that only crazy people go here."
>
> *Participant #13*

These preconceptions sometimes resulted in a fear of seeking help for their symptoms.

> "I don't know if I should do this…I'm scared, I'm petrified of that place. Of going into the asylum."
>
> *Participant #8*

> "I could have gone to detox, but I let it drop. And I continued taking drugs, and I was scared, and I continued to be scared. I was afraid to go and do…how can I say this? Telling my story. I was afraid of that. I don't know. And then, I said 'No, I'm just going to drop it.' "
>
> *Participant #10 (Translated)*

> "… yes I wanted to ask for help… People would tell me especially 'you know, don't go to the hospital, don't take medication, it won't be good, and you won't get your son, blah blah blah.' And now, I think, you know, if it's not going well, it's not going well. I have no choice."
>
> *Participant #16 (Translated)*

D. Feeling Misunderstood and Loss of Control

When describing their experiences seeking help for their symptoms of psychosis, many individuals described feeling misunderstood by service providers. Individuals often felt that the fear and paranoia they felt as a result of their psychotic symptoms was dismissed or not taken seriously, and would have appreciated a more empathic response from service providers.

> "It was difficult, and I felt misunderstood throughout the whole process…. I think the biggest thing was the idea of misunderstanding between myself 'the patient' and those trying to treat me… And sadly in the long run of it, I may have started to curb my responses to what I knew was wanted to be heard of me. Or, you know, what was an expected or desired answer, as opposed to the intimate truth, you know?"
>
> *Participant #4*

> "Yeah, even at the hospital, no one really listened to me…they diagnosed me with a disease and everything, but no one said 'Ah okay, yeah, it's true, it's possible.' …They listen and they judge you".
>
> *Participant #10 (Translated)*

> "I think less focus should have been made on if I was on drugs or not, and what the symptoms actually were. When somebody is hearing stuff and, you know, going through all this stuff, even if they were on drugs you should probably get them some help anyways. It was one thing I noticed the entire process that really bothered me, of like you're guilty before you're proven innocent …you're a drug addict before you're crazy. It was a little bit of a double standard, you know? We're trying to get you help, but you'd better not be on drugs."
>
> *Participant #12*

Many participants also described the loss of control that came along with the experience.

> “It was almost the release of any self-will. And just doing what I was asked to do, instead of doing what I felt I’d prefer, you know?... I almost felt like I was a young kid again, being broken, like a dog, being trained to pee outside or something.”
>
> *Participant #4*

> “From a legal standpoint, I didn’t know my rights. I didn’t know… how they could have the right to keep me like that. You know, if I wanted to leave, did I have the right? At one point, they took away my privileges. I thought about calling a lawyer, but didn’t, you know…”
>
> *Participant #14 (Translated)*

> “I don’t like the idea of forced medication and stuff. I don’t think that’s like a good thing to do. They threatened me with that when I wasn’t going along with the program…so I started doing it and stuff. That I didn’t like.”
>
> *Participant #15*

E. Unexpected Benefits

Although there were many challenges throughout the help-seeking process, more than half of the participants described unexpected benefits of the experience. For some, it brought them closer to their family and friends.

> “I have a fortunate situation of having a pretty caring, loving family on all ends, immediate and external. So I’m sure it strengthened it in some sense, but for the most part, it maintained our love and support of each other in whatever situation we may be in.”
>
> *Participant #4*

> "I guess there's still the baseline where they're still my parents or my family and they'll do, you know, whatever they can so far as they're able to, you know, make sure that I'm healthy. And they'll support me and all the rest of it. I guess what is a little bit more clear to me are partly the limits of that. I mean, as much as they're willing to do, you know, they can't do everything…On the other hand, you know, it is much more clear to me that there's a lot that they would do. A lot more than I probably know."
>
> *Participant #5*

> "…if this were to happen again, I would seriously like for those people to do the same thing. If I had a relapse or whatever. Because it's proof, proof of unconditional love."
>
> *Participant #11 (Translated)*

Others described the sense of community that they found by meeting other people who were going through similar experiences.

> "Then I put myself in the Douglas Hospital. That's when I got to meet the whole staff and everybody, and I stayed for a month. And that was the best time of my life…I was with the patients, you know?...And they were dealing with problems that were real. In the real life, outside, people hide it. They pretend like it doesn't exist, you know? …And like, they [the other patients] knew what loneliness was."
>
> *Participant #8*

> "I was talking about this with another girl, who was there with me, and we've kept in touch…it's something that stays with you. You know, you meet all kinds of people who are also psychotic."
>
> *Participant #14 (Translated)*

We also asked all participants for advice on how to make it easier for people who are experiencing psychotic symptoms to access help. Their responses are summarized in Table 6.2 (pg. 166).

Table 6.2 - Advice provided by interview participants on how to make it easier for people with first-episode psychosis to access help.

Education
- Inform the public about the symptoms of psychosis
- Integrate information about mental illness into the education system
- Reduce the shame and stigma associated with psychosis
- Continue research on first-episode psychosis to identify people at highest risk
Delivery of Services
- Reduce wait times
- Crowded waiting rooms are challenging for those with paranoia or social anxiety
- Improve communication between providers so patients aren't forced to continually recount their stories
- Reduce length of inpatient stay
- Limit the use of force or coercion
- Provide diversions and activities during time in hospital
- Make an effort to validate the patient’s experiences and not be dismissive of delusions or hallucinations
Early Intervention Services
- Increase the visibility of early intervention services
- Emphasize the non-medication aspects of EI services and the interdisciplinary approach
- Provide individualized treatment
- Create opportunities for patients to connect with other people going through the same thing
Personal Strategies
- Keep busy
- Pray
- Talk to others about the symptoms you are experiencing
- Share your experiences with others
- Listen to your doctor

Discussion

Our qualitative description of help-seeking for FEP focused on the experiences as reported by the patients themselves, a perspective which has been lacking in qualitative research on pathways to care (Boydell *et al.* 2010). Participants described the crucial role of significant others in initiating contact with services, and self-stigma and a pervasive lack of knowledge regarding the symptoms of psychosis and availability of services were barriers to help-seeking. Participants typically described a complex series of contacts along the pathway to care which resulted in feelings of being misunderstood and losing control, but many individuals identified unexpected benefits of their experience.

Nearly all participants mentioned a key individual who initiated or facilitated help-seeking on their behalf, which is consistent with quantitative research on pathways to care in FEP (Singh and Grange, 2006). For most individuals, this help-seeker was a family member, usually a parent. Prior qualitative studies have also found that family members play a pivotal role in both seeking help and maintaining contact with services (Boydell *et al.* 2006b; Lester *et al.* 2011; Wong, 2007a). Although important, this involvement takes its toll on family members, and the process is fraught with frustration (Corcoran *et al.* 2007; Gladstone *et al.* 2007) and emotional distress (Cadario *et al.* 2011). The involvement of parents in particular often results in a return to more dependent forms of the parent-child relationship, such as young-people returning to the parental home and parents resuming care-giving tasks that had been previously relinquished (Lester *et al.* 2011; McCann *et al.* 2011b; Sin *et al.* 2005). Family members also report feeling restricted in their ability to assume this care giving role, given that many patients with FEP have reached the age of majority and are autonomous adults (Bergner *et al.* 2008). Despite these challenges, many participants in the current study mentioned that the help-seeking experience brought them closer to their families and emphasized the lengths that their loved ones will go to for them. This sentiment has been previously reported in the qualitative literature (Lester *et al.* 2011), and is echoed in interviews with family members of FEP patients who are involved in the pathway to care (McCann *et al.* 2011b).

Although family members were the primary help-seekers for many of the participants in our study, it is important to also acknowledge the essential role that non-related help-seekers played in the pathway to care of some individuals (Boydell *et al.* 2006b). When lacking in social support or unable to turn to family for help, patients turned to other individuals, such as school counselors and work colleagues. These individuals were pivotal in directing patients to services, sometimes even accompanying them. It is important to identify and support these key contact points in the care pathway, as patients who lack family involvement have an increased likelihood of involuntary and negative pathways to care (Burnett *et al.* 1999; Cole *et al.* 1995).

Prior qualitative research on help-seeking in FEP found that patients often ignored the signs and symptoms of psychosis, and engaged in strategies to hide the symptoms from others in their social network (Boydell *et al.* 2006b). Although this was not described by the participants in our study, there was a pervasive lack of recognition that these symptoms were associated with a mental disorder and could be treated. This finding was also reported by Judge and colleagues (2008) who found that patients were usually the first to notice changes in themselves, but did not necessarily associate them with a need for care or services. This lack of knowledge and recognition of the signs of early psychosis is echoed in the literature on help-seeking by family members, who often misattribute the symptoms to emotional issues, behaviour problems, or substance use, and believe that the problem will resolve on its own (Boydell *et al.* 2010). The failure to recognize early psychotic symptoms as manifestations of a mental illness are a common barrier to accessing treatment (Judge *et al.* 2008) and may contribute to treatment delay (Cadario *et al.* 2011). Among participants in our study, there was also uncertainty about which services to turn to and how to access them once the symptoms were recognized as a mental health problem. This finding is again consistent with studies on help-seeking by family members (Etheridge *et al.* 2004; McCann *et al.* 2011a). Participants in our study emphasized the importance of educating people about the signs of psychosis and availability of services, and several individuals used examples of local public awareness campaigns for other mental health conditions.

The words and phrases participants in our study used to describe their psychotic disorder indicates that many have internalized society's stigmatizing attitudes toward people with mental illness, and this may have acted as a barrier to help-seeking efforts. This type of self-stigma has been reported previously among adolescents taking psychotropic medication, as reflected in the terms used to describe their illness, their self-image, and secrecy among peers for fear of being ostracized or teased for taking medication (Kranke *et al.* 2011). The self-stigma construct in adolescents was also found to differ from adult self-stigma models, likely due to greater concerns regarding peer acceptance and a developing sense of self (Kranke *et al.* 2011). The labels that young people use when describing mental health problems are predictive of a preference for specific types of care pathway contacts (Wright *et al.* 2011), and a fear of stigma is a barrier to help-seeking by FEP patients(Judge *et al.* 2008) and their family members (Cadario *et al.* 2011; Etheridge *et al.* 2004; Franz *et al.* 2010).

Participants in our study had several recommendations for facilitating help-seeking for patients who are experiencing psychotic symptoms. They emphasized the importance of public education and stigma reduction campaigns. The visibility of available services could be increased, and the non-physician and non-pharmacological aspects of the program should be emphasized to avoid deterring patients who may be averse to seeking ‘psychiatric’ treatment. They also identified several aspects of service delivery that were barriers to help-seeking, such as being forced to wait in a crowded room with strangers for long periods of time while experiencing symptoms of social anxiety or paranoia, and having to continually recount intimate or embarrassing details to strangers over the course of multiple service contacts to access help. Finally, participants mentioned the importance of being able to talk to others about what they were experiencing, and meeting others who were going through similar experiences was one of the unexpected benefits of the help-seeking experience. Taken together, these findings suggest a shift in the philosophy and orientation of service delivery towards the creation of services that address these concerns and are relevant to the young people who utilize them.

The findings from our qualitative study on the help-seeking experiences of patients with FEP are limited by several factors. Those who agreed to participate may have different views and opinions on the process of seeking health care. Additionally, patients at PEPP have been successful at obtaining specialized services, and the experiences they described may differ from individuals who are currently under the care of routine health and social service providers. By recruiting patients from PEPP, we also limited our sample to individuals who are engaged with services, and the experiences of non-engaged patients may differ. We only conducted a single interview, which restricted the number of topics that could be discussed and makes the findings vulnerable to contextual or temporal effects. We were also asking participants to give a retrospective account of events from a highly distressing period in their lives, which may lead to inaccuracies in their description of events. Finally, we have limited our study to one site, thus preventing comparisons with other FEP programs

Studies using qualitative methods make an essential contribution to the burgeoning body of literature on FEP, as it "…allows us to pursue essential questions regarding the subjective experience of psychosis and the complex social settings in which young people and their families live their lives."(Boydell *et al.* 2010, pg. 8). The discourse on pathways to care would benefit from further qualitative inquiry on such topics as the socio-cultural processes underlying help-seeking and the impact of the pathway to care on engagement with services and future help-seeking attempts. It would also be beneficial to include the perspective of service providers to gain insights on difficulties they face in identifying and responding to the signs of early psychosis, and supports that are needed to facilitate prompt referral to specialized care. This in-depth knowledge afforded by a qualitative approach is an important component to our overall understanding of pathways to care in first-episode psychosis.

CHAPTER 7 - DISCUSSION AND CONCLUSIONS

Gaining a thorough understanding of the patterns of health services use and their impact on treatment delay for patients with early psychosis is an important step towards reducing the duration of untreated psychosis, an important determinant of clinical and functional outcome. In this thesis, I have used a range of contrasting methodologies to examine patterns of service use at the population-, clinical- and individual-levels. Collectively, the manuscripts presented in this thesis provide a comprehensive picture of the complex series of help-seeking contacts and the challenges faced by patients with first-episode psychosis on their pathway to care. In this final chapter of the thesis, the primary findings that cut across the various studies are triangulated and discussed in more detail with respect to the existing literature.

The Essential Role of Primary Care

The essential role of general practitioners and other primary care providers in the pathways to care for patients with first-episode psychosis was highlighted across the different studies in our project. In Manuscripts III (population-level) and IV (clinical-level), we showed that patients who were in contact with primary care services had a reduced likelihood of contact with emergency services, including the ED, inpatient units, police, and ambulance. However, these patients also had indicators of longer treatment delay, suggesting that primary care providers may be having difficulties recognizing and responding to the signs of early psychosis. Many participants in the qualitative interviews in Manuscript V (individual-level) also described their experiences with primary care services. Although it did not emerge as one of the main themes from the qualitative analysis, the difficulties and uncertainties that primary care providers face when dealing with patients with first-episode psychosis were described by several participants, as exemplified by the following excerpt:

> "…it's so rare for them to get somebody, to get a call and be like 'I'm pretty sure I'm developing symptoms of a mental illness, and I don't know the resources, I don't know where to go.' They were able to suggest a social worker who did have the resources, but like front line they didn't know how to handle it. And even then, it still took a month before I got my appointment."
>
> *Participant #12*

There are several potential explanations for the longer treatment delay associated with primary care contact that we observed in our studies. As previously mentioned, one explanation could be that GPs and primary care providers are having difficulties recognizing cases of emerging psychosis. As we describe in Manuscript II, first-episode psychosis is a low incidence disorder, albeit a serious one, and as such, the presentation of a psychotic disorder in general practice would be a relatively rare occurrence. Indeed, general practitioners estimate that they only see one or two patients per year with the signs of early psychosis in their practice (El-Adl *et al.* 2009; Renwick *et al.* 2008; Simon *et al.* 2005; Simon *et al.* 2009), and data from Toronto suggest that less than 5% of all ambulatory mental health claims by family physicians are for psychotic disorders generally (Steele *et al.* 2006) and only a small portion of those would be for a first-episode of psychosis specifically. Patients in the putative 'prodromal' stages of a psychotic disorder often present with a heterogeneous pattern of symptomatology, including depressed mood, anxiety, sleep disturbance, social withdrawal, odd behavior, suspiciousness, deterioration in functioning, and irritability (Yung and McGorry, 1996). Although most primary care physicians are aware that there are early warning signs for psychosis, many have difficulties identifying these insidious features of first-episode psychosis, while demonstrating good knowledge of the positive symptoms, such as delusions and hallucinations (Gavin *et al.* 2008; Simon *et al.* 2009). Additionally, physicians with poor knowledge of the core signs of first-episode psychosis are more likely to report that they did not see any patients in the previous year suspected to be in the early phases of a psychotic disorder, and primary care providers may be inclined to look for the positive symptoms when investigating a suspected case of early psychosis (Simon *et al.* 2005). This is problematic, as patients with insidious and non-specific symptoms are more likely to consult their general practitioner than other service providers (Platz *et al.* 2006), and individuals at a high risk for psychosis and those who are experiencing subclinical symptoms of psychosis will often present to general practice (Murphy *et al.* 2010; Platz *et al.* 2006). Consequently, cases of early psychosis seeking help from primary care services may go undetected.

Even when the signs of early psychosis are recognized by primary care providers, there may be uncertainty regarding how to proceed. Although many family members of first-episode psychosis patients report positive experiences with general practitioners (McCann *et al.* 2011a), others report doubts that the physician was able to adequately manage the early psychosis symptoms (Etheridge *et al.* 2004; McCann *et al.* 2011a). Physicians themselves report that they lack the requisite skills and knowledge for dealing with patients with serious mental illness, and perceive these patients as too specialized for general practice (Lester *et al.* 2005). Front-line health care workers, such as general practitioners and social workers, also report being unsure of the appropriate course of action to take when difficulties arise with early psychosis patients, such as refusal to cooperate with interviews (Johnstone *et al.* 1986). We speculate that the feelings of ‘being misunderstood’ described by participants in our qualitative interviews in Manuscript V may be partly due to this uncertainty from primary care providers as to how to engage with patients who are experiencing the early symptoms of psychosis. Finally, general practitioners report that they rarely initiate antipsychotic treatment in a suspected case of early psychosis, and instead prefer a psychiatric referral or consultation to confirm the diagnosis (Verdoux *et al.* 2005).

However, organizing a prompt referral to specialized services may not always be a straightforward process. A survey of family physicians in the UK found that nearly half of respondents reported only referring suspected cases of first-episode psychosis when the referral is requested or accepted by the patient (El-Adl *et al.* 2009), and general practitioners report that the delay that arises from convincing reluctant patients to accept a referral can be longer than a month for nearly half of all cases (Verdoux *et al.* 2005). They also report delays obtaining a rapid referral due to inaccessibility of mental health services and a lack of communication with specialists (El-Adl *et al.* 2009; Verdoux *et al.* 2005). This lack of communication between service providers has also been identified as a barrier to help-seeking by family members of patients with early psychosis (Bergner *et al.* 2008; Czuchta and McCay, 2001). Participants in our qualitative study in Manuscript V also described frustrations with this lack of communication, as one of the recommendations that came out of the interviews was to improve communication between providers so patients aren’t forced to continually recount intimate or embarrassing details to strangers over the course of multiple service contacts to access help.

Patients with psychotic disorders are less likely to have a primary care physician (Bradford *et al.* 2008), and regular contact with a general practitioner increases the likelihood that individuals experiencing the symptoms of early psychosis will seek help from primary care when they are experiencing psychological distress (Skeate *et al.* 2002). The findings from this thesis suggest that improving access to primary care may decrease the likelihood of negative pathways to care for patients with first-episode psychosis, provided that primary care providers have the practical knowledge for case recognition and the health service context allows for rapid access to specialized treatment. However, clinicians encountering these patients in general practice need to feel confident in their capacity to screen, identify, and refer suspected cases of early psychosis (Boydell *et al.* 2006b). General practitioners highlight a lack of communication with mental health services as a major barrier to the success of early intervention services, and improved collaborations between primary and secondary care, such as receiving feedback on referrals and information on the diagnoses and treatment plans of patients, may be one effective strategy to improve case detection and referral rates in primary care (Gavin *et al.* 2008; Renwick *et al.* 2008; Verdoux *et al.* 2005). Continuing medical education efforts with primary care providers may be another strategy. However, a randomized trial of an educational intervention with general practitioners failed to find an impact on the number of patients referred to early intervention services (Lester *et al.* 2009), which indicates that such interventions may not improve detection rates by primary care providers. Nevertheless, the trial did find that general practitioners who received the intervention had a much shorter referral delay between first contact and referral to early intervention services (Lester *et al.* 2009), which was the portion of treatment delay that was associated with contact with primary care services in Manuscripts III and IV. Likewise, another study found that physicians who attended an education session on early psychosis were more likely to refer a case of suspected psychosis, although the intervention did not increase the number of cases identified (Renwick *et al.* 2008). Although such educational strategies may not increase the number of cases detected, they may increase awareness of early intervention services among general practitioners and improve the time to referral.

The primary care system is the most widely used service for mental health problems overall in Canada (Vasiliadis *et al.* 2005), and patients with first-episode psychosis specifically, and those with other psychiatric problems generally, would benefit from improved mental health literacy among general practitioners and other primary care providers. Our findings draw attention to the need for more in-depth investigations of the role that the primary care system plays in early intervention for first-episode psychosis, and strategies for supporting service providers in this role. "The real challenge for primary care therefore goes beyond improving the competence and knowledge of individual general practitioners or raising awareness of the new early intervention services. The concept of early intervention puts the onus on primary care and other community services to make themselves accessible, non-stigmatizing, and relevant to young people, whether dealing with a mild and self limiting depression or a major psychosis."(Shiers and Lester, 2004, pg. 1452).

The Frequent Use of Emergency Services

Patients experiencing a first-episode of psychosis are heavy users of emergency services, and this trend was evident in all components of this thesis. Manuscript III (population-level) found that nearly half of all cases received their first diagnosis of a psychotic disorder in the emergency department, and almost three quarters had contact with emergency services at some point preceding the diagnosis of psychosis. In Manuscript IV (clinical-level), we found that a large proportion of patients had their first contact with or were referred by emergency services, and nearly half of all patients additionally had contact with police or ambulance services. Thirteen of the sixteen participants in our qualitative study in Manuscript V (individual-level) also described having contact with emergency services.

Our systematic review in Manuscript I found that although patients with first-episode psychosis were heavy users of emergency services across most jurisdictions, this problem may be exacerbated in a North American context. There was a tendency for studies from European and Asian countries to report that patients made contact with physician or non-physician services, respectively, for both the first contact and referral source. In contrast, the Canadian studies reported that approximately equal proportions of patients made first contact with emergency or physician services, and the largest proportion of patients were referred to an early intervention program by emergency services. These regional differences in the findings of the pathway to care studies suggest that the reliance on emergency services demonstrated by the patients in our sample may be partially due to the Montréal health system context. Although the health care system in Canada is publically funded, GPs are not obligated to provide services, many individuals do not have a family physician, and a referral from a GP is required to access many specialized services. As previously mentioned, patients with a psychotic disorder are less likely to have a family physician (Bradford *et al.* 2008), and the frequent use of emergency services observed in our studies may be reflective of a lack of alternative options.

We speculate that the frequent use of emergency services may also be due to a lack of knowledge regarding the availability of services for individuals experiencing a mental health concern, as described by the participants in our qualitative study in Manuscript V. Indeed, patients with first-episode psychosis who use emergency services in Montréal do not have a longer DUP or a greater number of help-seeking contacts (Bechard-Evans *et al.* 2007), indicating that these services are not simply being used as a last resort when all other options have been exhausted. In-depth research on the psychology behind the help-seeking process in first-episode psychosis might help to shed some light on such issues as reasons for choosing care pathway contacts and motivation for seeking help. A more comprehensive qualitative approach than the one used in the current study would be needed to gain this depth of understanding.

Consequences of the Pathway to Care

One of the primary objectives of this thesis was to examine the consequences of negative pathways to care. Although we did not have sufficient data to examine this at the population-level, we did look at the impact of the pathway to care on disengagement from early intervention services in Manuscript IV, with little evidence of an effect. We also specifically asked participants in the qualitative interviews in Manuscript V about the impact that their help-seeking experiences had, and whether it affected the way that they would seek help the next time that it was needed. Participants commented that they were now more knowledgeable and confident regarding the resources available to them, however there was no indication that contact with ambulance, police, the emergency department or inpatient care had influenced their likelihood of seeking help in the future.

There has been a paucity of research on the consequences of the pathway to care in first-episode psychosis. A descriptive case series hypothesized that negative pathways to care may be associated with service disengagement (Compton, 2005), and contact with emergency services has been shown to have an impact on reported satisfaction with services received (Bhugra *et al.* 2004) and propensity to seek help in the future (Monteiro *et al.* 2006). The lack of an effect of negative pathways to care observed in our study must be interpreted in light of the circumstances behind contact with these services. As previously stated, many participants in our sample may have used emergency services due to a lack of alternative options, and contact in this context is very different than somebody who is brought to emergency services because of an acute psychiatric crisis. The qualitative interviews from Manuscript V also shed some light on this, as many of the participants who had contact with police or ambulance services chose to call these services themselves, usually in relation to the content of their delusions or hallucinations. The degree of coercion and lack of voluntariness associated with help seeking are more likely to have detrimental consequences than contact with emergency services, *per se*. It is also possible that admission to an early intervention program may serve as a buffer against the consequences of negative pathways to care with their focus on providing a positive treatment experience through the use of case management, a lack of exclusive emphasis on medication, and a strong orientation toward psychosocial recovery. Indeed, two of the three studies that suggested a detrimental impact of negative pathways to care were done with samples obtained from general psychiatric services (Bhugra *et al.* 2004; Compton, 2005), and the third involved interviews with family members whose views may not be reflective of the patients themselves (Monteiro *et al.* 2006). Our examination of the impact of negative pathways to care on service disengagement was merely a preliminary step towards more extensive studies on the consequences of the pathway to care in first-episode psychosis.

Few studies to date have examined the determinants of health services use in first-episode psychosis, and none have used a mixed methods design to triangulate different sources of information. Our findings suggest that few socio-demographic or clinical factors determine pathways to care in a Canadian context. Rather, service-level factors, such as having access to a primary care provider, have a stronger impact on patterns of health service use across multiple indicators. This information could help inform health care administrators and policy makers when planning mental health services, potentially providing more visible, efficacious, and timely access to psychiatric care. It could also be used to target interventions to general practitioners and other primary care providers who are likely to encounter young patients experiencing psychotic symptoms for the first time. Important next steps include the implementation of interventions to improve pathways to care, either by hastening the care pathways, removing negative pathways to care, or adding beneficial alternative routes (Sass *et al.* 2009), and an assessment of the economic impact of pathways to care (Heslin *et al.* 2011). It is hoped that by increasing access for patients experiencing a first-episode of psychosis, we can improve the outcomes of the disorder, prevent significant disability and delay in achieving social, educational, and career milestones, and help to ease the psychological distress experienced by patients and their family members during this difficult time.

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APPENDICES

Appendix A - Terms for the Medline Search for the Systematic Review

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[exp. Schizophrenia and Disorders with Psychotic Features/ OR
exp. Affective Disorders, Psychotic/ OR
psychosis.mp OR
psychotic disorder$.mp OR
severe mental illness$.mp]

AND

[exp. Health Services Accessibility/ OR
pathways to care.mp OR
pathways to mental health care.mp OR
pathways to health care.mp OR
pathways to psychiatric care.mp OR
pathways to services.mp OR
pathways to mental health services.mp OR
pathways to health services.mp OR
pathways to psychiatric services.mp]

Appendix B - Journals Included in the Manual Search for the Systematic Review

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Acta Psychiatrica Scandinavica
Administration and Policy in Mental Health and Mental Health Services Research
American Journal of Psychiatry
Archives of General Psychiatry
British Journal of Psychiatry
Canadian Journal of Psychiatry
Community Mental Health Journal
Early Intervention in Psychiatry
Psychiatric Bulletin
Psychiatric Services
Psychological Medicine
Schizophrenia Bulletin
Schizophrenia Research
Transcultural Psychiatry
Social Psychiatry and Psychiatric Epidemiology

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Garety PA, Rigg A (2001). Early psychosis in the inner city: A survey to inform service planning. *Social Psychiatry and Psychiatric Epidemiology* 36, 537-544.

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Appendix D - Diagnostic codes used in the administrative database analysis to identify incident cases of schizophrenia-spectrum psychosis

Group	Code	Diagnosis
Schizophrenic Disorders (ICD-9)	295.0	Simple Type
	295.1	Disorganized Type
	295.2	Catatonic Type
	295.3	Paranoid Type
	295.4	Schizophreniform Disorder
	295.5	Latent Schizophrenia
	295.6	Residual Type
	295.7	Schizoaffective Disorder
	295.8	Other Specified Types of Schizophrenia
	295.9	Unspecified Schizophrenia
Delusional Disorders (ICD-9)	297.0	Paranoid State, Simple
	297.1	Delusional Disorder
	297.2	Paraphrenia
	297.3	Shared Psychotic Disorder
	297.8	Other Specified Paranoid States
	297.9	Unspecified Paranoid State
Other Nonorganic Psychoses (ICD-9)*	298.9	Unspecified Psychosis
Schizophrenia (ICD-10)	F20,0	Paranoid Schizophrenia
	F20,1	Hebephrenic Schizophrenia
	F20,2	Catatonic Schizophrenia
	F20,3	Undifferentiated Schizophrenia
	F20,4	Post-Schizophrenic Depression
	F20,5	Residual Schizophrenia
	F20,6	Simple Schizophrenia
	F20,8	Other Schizophrenia
	F20,9	Schizophrenia, Unspecified
Persistent Delusional Disorders (ICD-10)	F22,0	Delusional Disorder
	F22,8	Other Persistent Delusional Disorders
	F22,9	Persistent Delusional Disorder, Unspecified
Acute and Transient Psychotic Disorders (ICD-10)	F23,2	Schizophreniform Disorder
Schizoaffective Disorders (ICD-10)	F25,0	Schizoaffective Disorder, Manic Type
	F25,1	Schizoaffective Disorder, Depressive Type
	F25,2	Schizoaffective Disorder, Mixed Type
	F25,8	Other Schizoaffective Disorders
	F25,9	Schizoaffective Disorder, Unspecified
Unspecified Nonorganic Psychosis (ICD-10)*	F29,0	Nonorganic Psychosis, Unspecified
CLSC Database	5110	Schizophrenia and Other Psychotic Disorders
CHLSD Database	21	Psychosis

*Diagnostic codes from the 9th and 10th revisions of the International Classification of Diseases (ICD)(World Health Organization, 1977; World Health Organization, 1992), from the CLSC database, and from the CHSLD database. * Diagnostic code included in sensitivity analysis only.*

CLSC - Centre Local de Services Communautaires; CHLSD - Centre Hospitalier Soins de Longue Durée.

Appendix E - Antipsychotic medications used in the administrative database analysis to remove prevalent cases of schizophrenia-spectrum psychosis

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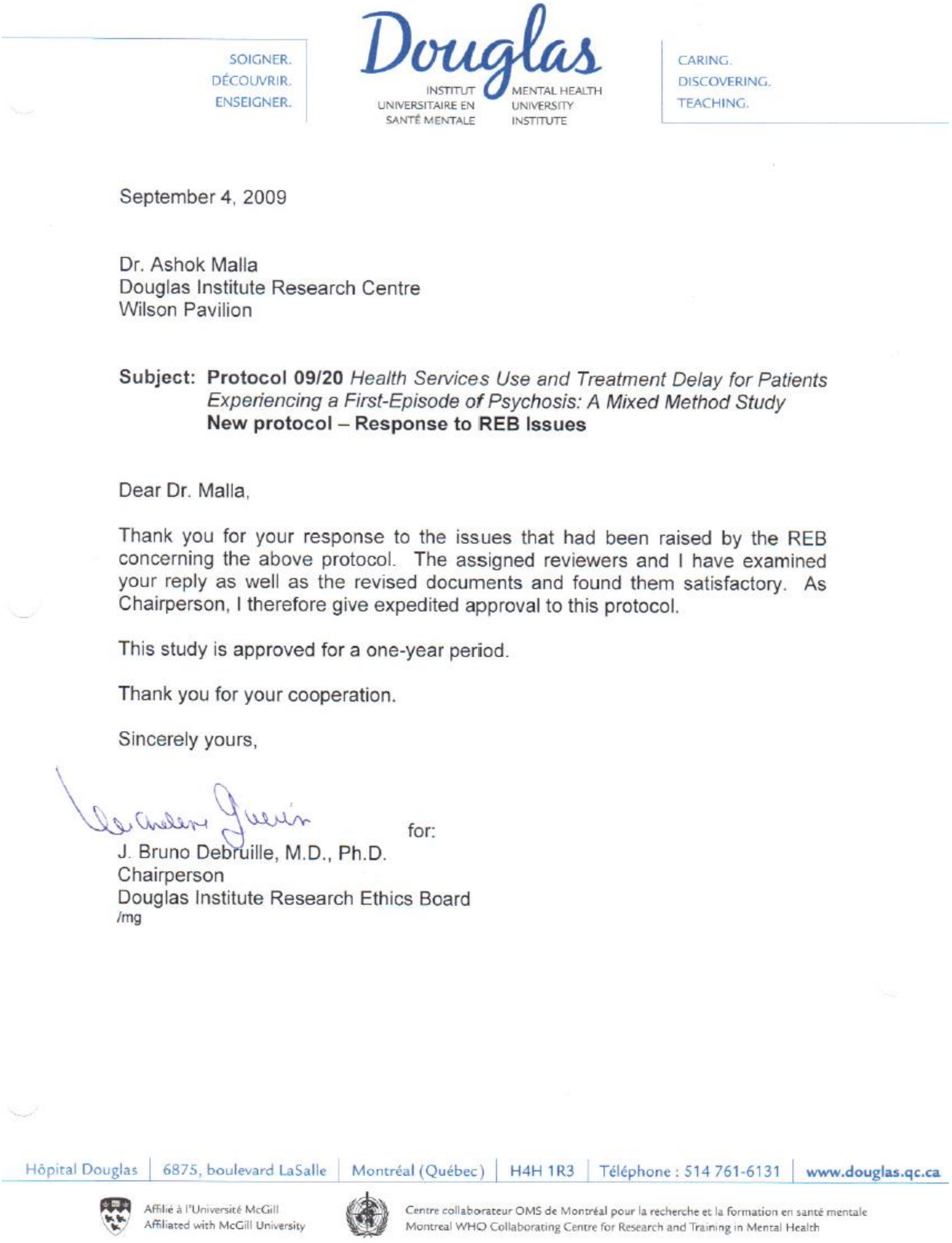
Codes	Drug
Atypical Antipsychotics	
45580	Clozapine
47052, 47278	Risperidone
47197	Olanzapine
47267	Quetiapine
Typical Antipsychotics	
1924	Chloropromazine
7176	Perphenazine
4056, 34284, 4069	Fluphenazine
4394, 43826	Haloperidol
40745, 34219	Loxapine
41863, 43202	Flupenthixol
45028	Fluspirilene
33465	Pimozide
41707	Pipotiazine
9594	Thioridazine
9620	Thiothixene
9802	Trifluoperazine
47136, 47137, 47138	Zuclopenthixol

Appendix F - Diagnostic codes used in the administrative database analysis to remove prevalent cases of schizophrenia-spectrum psychosis

Group	Code
Dementias (ICD-9)	290.X
Alcohol-Induced Mental Disorders (ICD-9)	291.X
Drug-Induced Mental Disorders (ICD-9)	292.X
Transient Mental Disorders due to Conditions Classified Elsewhere (ICD-9)	293.X
Persistent Mental Disorders due to Conditions Classified Elsewhere (ICD-9)	294.X
Schizophrenic Disorders (ICD-9)	295.X
Episodic Mood Disorders - Psychotic (ICD-9)	296.X
Delusional Disorders (ICD-9)	297.X
Other Non-Organic Psychoses (ICD-9)	298.X
Pervasive Developmental Disorders (ICD-9)	299.X
Drug-Induced Psychosis (ICD-10)	F1X.5 & F1X.7
Schizophrenia (ICD-10)	F20.X
Persistent Delusional Disorders (ICD-10)	F22.X
Acute & Transient Psychotic Disorders (ICD-10)	F23.X
Induced Delusional Disorder (ICD-10)	F24.X
Schizoaffective Disorder (ICD-10)	F24.X
Other Non-Organic Psychotic Disorders (ICD-10)	F28.X
Unspecified Non-Organic Psychosis (ICD-10)	F29.X
Affective Psychoses (ICD-10)	F30.2, F31.2, F31.5, F32.3, F33.3
CLSC Database	5110
CHSLD Database	21

Diagnostic codes from the 9th and 10th revisions of the International Classification of Diseases (ICD)(World Health Organization, 1977; World Health Organization, 1992), from the CLSC database, and from the CHSLD database.

Appendix G - Research Ethics Board approval from the Douglas Mental Health University Institute



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INSTITUT UNIVERSITAIRE EN SANTÉ MENTALE
MENTAL HEALTH UNIVERSITY INSTITUTE

CARING.
DISCOVERING.
TEACHING.

September 4, 2009

Dr. Ashok Malla
Douglas Institute Research Centre
Wilson Pavilion

Subject: Protocol 09/20 *Health Services Use and Treatment Delay for Patients Experiencing a First-Episode of Psychosis: A Mixed Method Study*
New protocol – Response to REB Issues

Dear Dr. Malla,

Thank you for your response to the issues that had been raised by the REB concerning the above protocol. The assigned reviewers and I have examined your reply as well as the revised documents and found them satisfactory. As Chairperson, I therefore give expedited approval to this protocol.

This study is approved for a one-year period.

Thank you for your cooperation.

Sincerely yours,

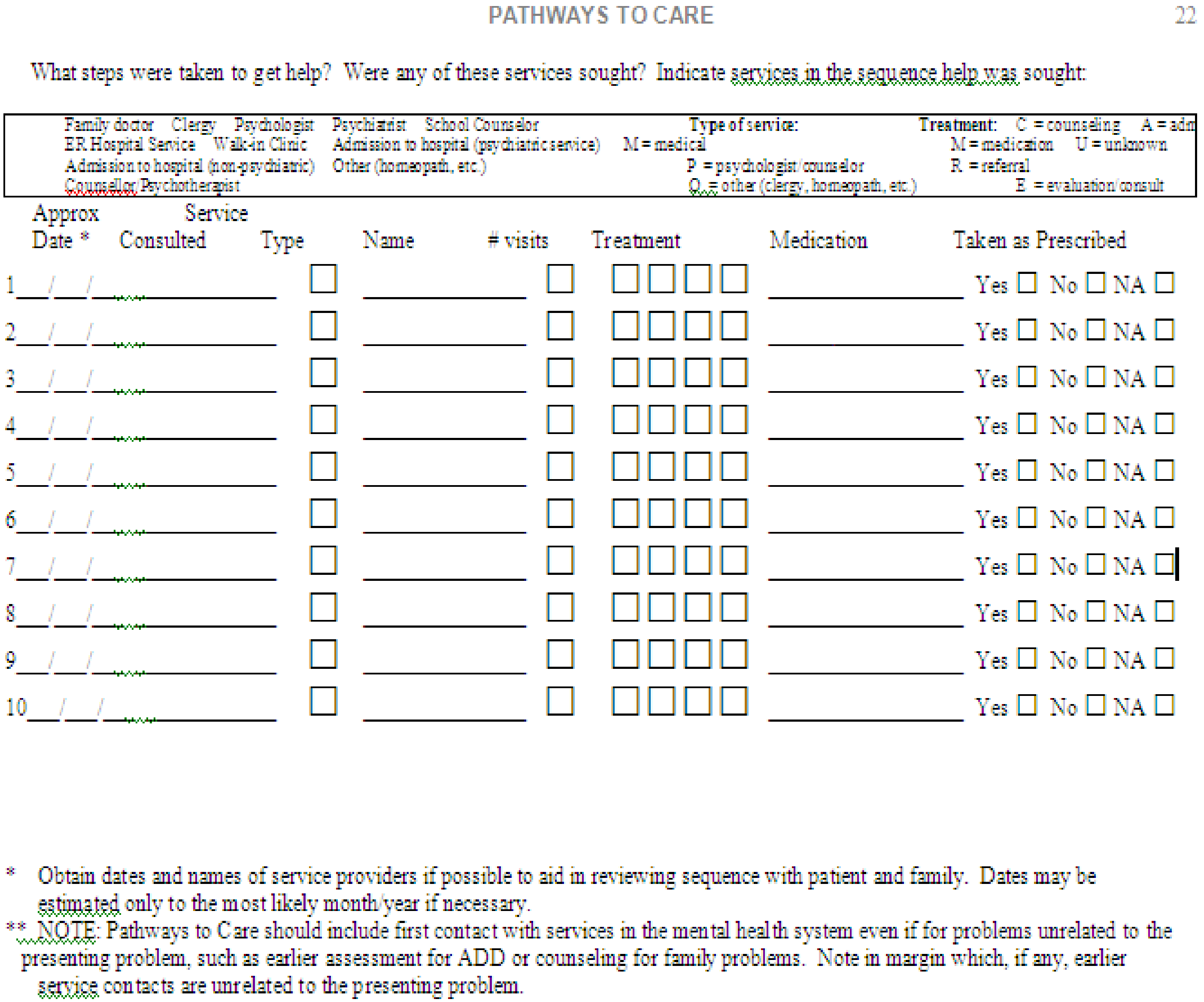
for:
J. Bruno Debruille, M.D., Ph.D.
Chairperson
Douglas Institute Research Ethics Board
/mg

Hôpital Douglas | 6875, boulevard LaSalle | Montréal (Québec) | H4H 1R3 | Téléphone : 514 761-6131 | www.douglas.qc.ca

Affilié à l'Université McGill
Affiliated with McGill University

Centre collaborateur OMS de Montréal pour la recherche et la formation en santé mentale
Montreal WHO Collaborating Centre for Research and Training in Mental Health

Appendix H – CORS data collection instrument for pathways to care data from the pathways to care analysis



What steps were taken to get help? Were any of these services sought? Indicate services in the sequence help was sought:

Family doctor Clergy Psychologist Psychiatrist School Counselor
ER Hospital Service Walk-in Clinic Admission to hospital (psychiatric service)
Admission to hospital (non-psychiatric) Other (homeopath, etc.)
Counsellor/Psychotherapist

Type of service:
M = medical
P = psychologist/counselor
O = other (clergy, homeopath, etc.)

Treatment:
C = counseling
A = adm
M = medication
U = unknown
R = referral
E = evaluation/consult

Approx Date *	Service Consulted	Type	Name	# visits	Treatment	Medication	Taken as Prescribed
1___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
2___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
3___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
4___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
5___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
6___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
7___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
8___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
9___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐
10___/___/___	__________	☐	__________	☐	☐☐☐☐	__________	Yes ☐ No ☐ NA ☐

* Obtain dates and names of service providers if possible to aid in reviewing sequence with patient and family. Dates may be estimated only to the most likely month/year if necessary.

** NOTE: Pathways to Care should include first contact with services in the mental health system even if for problems unrelated to the presenting problem, such as earlier assessment for ADD or counseling for family problems. Note in margin which, if any, earlier service contacts are unrelated to the presenting problem.

Appendix I – English version of the interview guide from the qualitative analysis

A Qualitative Study on Health Services Use in First Episode Psychosis

Patient Interview Guide

Date: ____________________________ Consent Form: ☐ Yes ☐ No
Patient ID#: _______________________ Audio Consent Form: ☐ Yes ☐ No

1. I'm interested in hearing about how you 'ended up' here at the PEPP program. If it is okay with you, I would like to start off by having you describe your process of finding help, starting from when you first began to experience the symptoms of psychosis, such as delusions and hallucinations. [PROBES: Who did you first tell about your symptoms, or who first noticed them? Who was involved in your process of getting help (ie. professionals, family, peers)? Why did you select those helpers?]

2. You mentioned a few different people who were involved in this process, such as ___(LIST THESE PEOPLE)___. How did you feel about the involvement of these people?
   OR: Some patients tell us that their family members or friends were very involved in getting them help for their symptoms of psychosis. When you were telling me your story, you didn't mention anybody…were any of your friends or family involved? [IF YES] Who was it exactly? How did you feel about the involvement of these people? [IF NO] How do you think not having the involvement of your family or friends affected your process of finding help?

3. How would you describe your experience seeking help for your symptoms of psychosis overall? [PROBE: What word would you use to describe your experience?]

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4. What made your process of getting help easier for you (and your family)? [PROBE: Why do you think that made things easier?]

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5. What made your process of getting help more difficult for you (and your family)? [PROBE: Why do you think that made things more difficult?]

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6. How have your experiences with seeking help for your symptoms had an impact on you? [PROBE: How have your experiences impacted your relationship with your clinician? Your family members? Your view of health services? Have they made you more/less likely to seek help the next time you need it? What will you do differently next time?]

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7. Do you have any suggestions or advice on how to make it easier for people who are experiencing psychotic symptoms to get help?

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8. Is there anything else that you would like to share with me about your experiences seeking help for your symptoms of psychosis?

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Thank you very much for speaking with me today, ________________. If you don’t mind, I’d just like to ask you a few quick questions about yourself. Please remember that none of the information will be used in a way that will identify you. We would just like to describe the group of people that we talked to.

a. How old are you? _________________
b. How far did you go in school? ☐ ≤ High School ☐ > High School
c. What languages do you speak? ☐ English ☐ French ☐ Other
d. Were you born in Canada? ☐ Yes ☐ No
    - If no, where were you born?

e. Which ethnic group do you consider yourself to be a part of?
____

Those are all the questions that I have for your today, _________________. Do you have any questions about the interview? Thank you very much for your time and participation!

LENGTH OF INTERVIEW:______________________________

Appendix J – French version of the interview guide from the qualitative analysis

Étude qualitative sur l'utilisation des services de santé lors du premier épisode psychotique - *Grille d'entretien du patient*

Date: __________________ Formulaire de consentement : ☐Oui ☐ Non
Patient-e #: _____________ Consentement pour l'enregistrement : Oui ☐ Non

1. Je suis intéressée à entendre comment vous êtes “arrivé” au programme PEPP. Si vous êtes d'accord, je voudrais que vous commenciez par me décrire le processus de recherche d'aide, depuis le moment où vous avez vécu les premiers symptômes de psychoses, tels que des illusions ou des hallucinations. [ENQUÊTE : À qui avez-vous parlé de vos symptômes en premier, ou qui les a remarqué en premier ? Qui était impliqué dans votre processus pour obtenir de l'aide (ex : professionnels, familles, pairs) ? Pourquoi avez-vous choisi ces personnes-là ?]

2. Vous mentionnez plusieurs personnes différentes qui étaient impliquées dans ce processus, telles que __(LISTER CES PERSONNES)___. Qu'est-ce que vous avez ressenti par rapport à l'implication de ces personnes ? OU: Certains patients nous disent que les membres de leur famille ou leurs ami-e-s s'étaient beaucoup impliqués pour leur apporter de l'aide par rapport à leurs symptômes de psychose. Lorsque vous m'avez parlé de votre expérience, vous n'avez mentionné personne... Est-ce que certain-e-s de vos ami-e-s ou certain-e-s membres de votre famille étaient impliqué-e-s ? [SI OUI] Qui exactement ? Comment est-ce que vous vous êtes senti par rapport à l'implication de ces personnes ? [SI NON] Dans quelle mesure pensez-vous que l'absence de l'implication d'ami-e-s ou de votre famille a affecté votre processus de demande d'aide ?

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3. De manière générale, comment décririez-vous votre expérience de recherche d'aide pour vos symptômes de psychose ? [ENQUÊTE: Quel mot utiliseriez-vous pour décrire votre expérience ?]

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4. Qu'est-ce qui vous a facilité le processus d'accès à l'aide ? (et pour votre famille ?) [ENQUÊTE: pourquoi est-ce que vous pensez que ça a rendu les choses plus faciles ?]

5. Qu'est-ce qui vous a rendu le processus d'accès à l'aide plus difficile ? (et pour votre famille ?) [ENQUÊTE: pourquoi est-ce que vous pensez que ça a rendu les choses plus difficiles ?]

6. Dans quelle mesure ces expériences de recherche d'aide pour vos symptômes ont-elles eu un impact sur vous ? [ENQUÊTE: Dans quelle mesure ces expériences ont eu un impact sur votre relation avec votre clinicien ? Les membres de votre famille ? Votre vision des services de santé ? Est-ce que cela vous a incité à rechercher plus/moins d'aide la prochaine fois que vous en aurez besoin ? Qu'est-ce qui sera différent la prochaine fois ?

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7. Est-ce que vous auriez des suggestions ou des conseils sur ce qui pourrait faciliter l'accès à l'aide de personne qui font l'expérience de leurs premiers symptômes psychotiques ?

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8. Y a-t-il un autre élément que vous souhaiteriez partager avec moi par rapport à votre expérience de recherche d'aide pour vos symptômes de psychose ?

9. J'aimerais résumer rapidement quelques points principaux de notre discussion, juste pour m'assurer que je vous ai compris correctement. De ce que je vous ai entendu me dire aujourd'hui, il semble que _______(RÉSUMER LES THÈMES PRINCIPAUX DE L'ENTRETIEN)______. Est-ce que je vous ai compris correctement ?

Merci beaucoup d'avoir partagé ces éléments avec moi aujourd'hui, ________________. Si vous n'y voyez pas d'inconvénients, j'aimerais encore vous poser quelques petites questions. Je me permets de vous rappeler qu'aucune de ces informations ne va être utilisée de manière à pouvoir vous identifier. Nous aimerions seulement décrire le groupe de personne à qui nous avons parlé.

a. Quel âge avez-vous ? _________________
b. Jusqu'où êtes-vous allé à l'école ? ☐ ☐ Cégep ☐ > Cégep
c. Quelles langues parlez-vous ? ☐ Anglais ☐ Français ☐ Autre
d. Êtes-vous né au Canada? ☐ Oui ☐ Non
   - Si non, où êtes-vous né ? ________________________
e. À quel groupe ethnique considérez-vous que vous faites partie ?
____

Voilà, nous avons fait le tour de toutes les questions que je souhaitais aborder avec vous aujourd'hui, _________________. Est-ce que vous, de votre côté, vous avez des questions sur l'entretien que nous venons d'avoir ? Un grand merci pour votre temps et votre participation.

LONGUEUR DE L'ENTRETIEN:______________________________

Appendix K - English consent form for participation in the qualitative analysis.

A Qualitative Study of the Use of Health Services for Patients with First-Episode Psychosis

Researchers:
Dr. Ashok Malla, M.D.; Kelly Anderson, M.Sc.; Dr. Rebecca Fuhrer, Ph.D.

This study is funded by the Canadian Institutes for Health Research.

---

1. Introduction and Purpose of the Study

- We are doing this research to learn about how people get help when they begin to experience the symptoms of psychosis. We are interested in knowing about contacts with doctors and hospitals, as well as other types of services, such as teachers and counsellors. We have chosen people with first-episode psychosis as our focus in this study because they often tell us that they find it difficult to access services and obtain the help that they need.

- You have been invited to participate in this project because you are a client at the Prevention and Early Intervention Program for Psychoses (PEPP). We are interested in hearing about your process of seeking help when you began to experience psychotic symptoms. We would also like to know about some of the things that you may have found helpful or unhelpful when you were trying to seek help.

- The information from this study will be used to make it easier for people to obtain the help that they need when they first begin to experience some of the symptoms of psychosis. We hope to involve between 20 and 30 PEPP clients in this study.

2. Description of the research

You will be interviewed by one of the researchers about your experience seeking help for your symptoms of psychosis. You will also be asked about anything that made it easier or more difficult for you to get help. Also, if you have any suggestions for how to make it easier for other people with psychotic symptoms to access help, we would like to hear them. We estimate that the interview will take between 30 and 60 minutes to complete. With your permission, the interviews will be audio recorded and transcribed so that we can be sure and accurately capture what you say.

3. Participation

Your participation in this research is voluntary. You can choose not to participate, to continue at another time, or to withdraw from this study. You can also ask that any part of the information you have given at the interview be ignored. Your decision not to participate in this project will not affect the health care or social services that you receive at PEPP, and will not affect your relationship with the researchers or the clinicians that you see at PEPP.

4. Benefits

You will be contributing to a study which could have a positive impact on health care for people with psychosis. You have the opportunity to voice your opinion about the health care system in general and about mental health care in particular.

5. Risks and Disadvantages

The interview will not involve any medical examinations or procedures, so there is no risk of physical harm. However, if you feel some tension or nervousness when you talk about your experiences, you can stop the interview at anytime. You can also ask the interviewer for the name of a person you can talk to if you want to discuss your experience.

6. Conflict of Interest

There is no conflict of interest related to this project for the researchers or the research centre.

7. Confidentiality

All personal information gathered in this study will be kept confidential, unless it is required by law. Your name will not appear in any published texts or in any health information related to the study. Quotes from your interview may be used in research reports for scientific publication, but we will not include any information that might identify you. The list of participants, the transcripts, and the audio recordings will be kept in a secured place and will only be used by the members of the research team. Your answers will not be shared with any other research participants or with your health care team. If you decide to participate in the study, a statement of your participation and a signed copy of this consent form will be placed in your medical file. A signed copy of the consent form will also be kept by the Medical Records department.

8. Compensation

At the end of your interview, you will receive $20 as compensation for your time, transportation costs, and to thank you for your contribution to our project.

9. Who can you call in case of questions or difficulties?

If you have any questions about this study, you can contact Kelly Anderson at (514) 761-6131 ext. 3353 or Dr. Ashok Malla (514) 761-6131 ext. 3418.

If you have any questions about your rights as a research participant or have an ethical concern about this project, you may contact the Ombudsman of the Douglas Mental Health University Institute at (514) 761-6131 ext. 3287 or by e-mail at ombudsman@douglas.mcgill.ca.

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INSTITUT UNIVERSITAIRE EN SANTÉ MENTALE
MENTAL HEALTH UNIVERSITY INSTITUTE

CONSENT FOR PARTICIPATION

A Qualitative Study of the Use of Health Services for Patients with First-Episode Psychosis

This study aims to understand how people get help when they begin to experience the symptoms of psychosis. I will participate in one interview and give my opinions about this subject.

The purpose and the procedure for this research, in which I have accepted to participate, have been explained to me clearly by ____________________. I have read this consent form for participants and I understand the benefits and the risks that are involved in my participation in this project. I have had the chance to ask questions, which have been answered by the research team to my satisfaction.

I understand that my participation is entirely voluntary and that I may withdraw at any time. If I choose to do so, I will not suffer any negative consequences and it will not compromise the care and services that I will receive in the future.

By signing this document, I agree to participate in this research project. I hereby confirm that I have received a copy of the consent form that I have signed, which I can keep.

____________________________________ ____________________________________
Participant signature Date

____
Name (printed)

____________________________________ ____________________________________
Signature of the person who explained the study Date

____
Name (printed)

Douglas

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MENTAL HEALTH UNIVERSITY INSTITUTE

CONSENT FOR AUDIO RECORDING

A Qualitative Study of the Use of Health Services for Patients with First-Episode Psychosis

Name: ______________________________ File #: _______________________

I, __________________________, authorize the creation of an audio recording of the interview I provide in the context of my participation in the research study *"A Qualitative Study of the Use of Health Services for Patients with First-Episode Psychosis".*

I understand that this recording will be destroyed when the information has been transcribed. All identifying information (ex. name, place of employment) will be deleted from the transcript, which will be identified only by a number. The tape will be kept in a safe place, accessible only to the research team. The recording will not be made public or used for any other purpose.

Signature: ____________________________________

Signed the _________________________________ (date), at __________________ (city)

Appendix L - French consent form for participation in the qualitative analysis.

Une Étude Qualitative sur l'Utilisation des Services de Santé de Patients Atteints d'un Premier Épisode de Psychose

Chercheurs :
Dr. Ashok Malla, M.D.; Kelly Anderson, M.Sc.; Dr. Rebecca Fuhrer, Ph.D.
Cette étude est subventionnée par les Instituts de Recherche en Santé du Canada.

---

1. Présentation et Objectif de Cette Étude

- Le but de cette recherche est de comprendre comment les gens cherchent et obtiennent de l'aide lorsqu'ils commencent à ressentir des symptômes de la psychose. Nous souhaitons en apprendre plus sur leurs contacts avec des médecins et les hôpitaux, ainsi que d'autres types de services, tels que les enseignants et les conseillers. Nous avons choisi des personnes ayant ressenti un premier épisode de psychose pour cette étude parce qu'ils nous disent souvent qu'ils ont du mal à accéder aux services et à obtenir l'aide dont ils ont besoin.

- Vous êtes invité à participer à cette étude parce que vous recevez présentement des prestations du Programme d'Évaluation, d'intervention, et de Prévention des Psychoses (PEPP). Nous aimerions en savoir plus sur la manière dont vous avez cherché de l'aide lorsque vous avez commencé à ressentir des symptômes psychotiques. Nous tenons également à connaître les aspects que vous avez trouvés utiles ou désagréables lorsque vous cherchiez de l'aide.

- Les résultats de cette étude seront utilisés pour améliorer l'accès à l'aide pour des personnes qui commencent à éprouver des symptômes de la psychose. Nous espérons impliquer 20 à 30 clients de PEPP dans cette étude.

2. Description de la Recherche

Un des chercheurs vous posera quelques questions concernant votre expérience lorsque vous cherchiez de l'aide pour vos symptômes de la psychose. Il vous sera également demandé de vous rappeler les choses qui ont facilité ou qui vous ont gênés à obtenir de l'aide. De plus, si vous avez des suggestions qui pourront faciliter les démarches pour d'autres personnes ressentant des symptômes psychotiques, nous aimerions les entendre.

Nous estimons que l'entrevue devrait durer entre 30 et 60 minutes. Si vous êtes d’accord, les entretiens seront enregistrés sur bande audio et transcrits de telle sorte que nous pouvons être certains que nous avons bien saisi ce que vous nous avez raconté.

3. Participation

Votre participation à ce projet de recherche est complètement volontaire. Vous pouvez choisir de ne pas participer, de continuer un autre jour, ou de vous retirer de cette étude. Vous pouvez également décider à tout moment que certaines choses que vous nous avez racontées soient ignorées. Votre décision de ne pas participer à ce projet n'aura pas d'incidence sur les soins de santé ou de services sociaux que vous recevez à PEPP, et n'aura pas d'incidence sur votre relation avec les chercheurs ou les cliniciens que vous voyez à PEPP.

4. Bénéfices

Vous participation contribuera à une étude qui pourrait avoir des effets positifs sur les soins de santé pour les personnes atteintes de psychose. En participant à cette étude, vous pourrez exprimer votre opinion sur le système des soins de santé en général et sur les soins de santé mentale, en particulier.

5. Risques et Inconvénients

Votre participation à l’entrevue n’entraîne aucun examen ou procédure médicale, de sorte qu'il n'existe pas de risque de dommages physiques. Cependant, si vous éprouvez une certaine tension ou nervosité lorsque vous parlez de vos expériences, vous pouvez arrêter l’entretien à tout moment. Vous pouvez également demander à l'interviewer le nom d'une personne à qui vous pouvez parler si vous voulez recevoir un support suite a cet entretien.

6. Conflit d’intérêt

Il n’y a pas de conflit d’intérêt relié à ce projet entre les chercheurs ou le centre de recherche.

7. Confidentialité

Tous les renseignements personnels recueillis pendant l'étude demeureront confidentiels, à moins d'être exigé par la loi. Votre nom ne sera associé à aucune publication en rapport avec l'étude. Certains renseignements que vous fournirez lors de votre entrevue seront utilisés dans des rapports de recherche aux fins de publication scientifique, mais il n'y aura aucune information qui permettrait de vous identifier. La liste des participants, le procès-verbal, et l'enregistrement audio seront gardés dans un endroit sécurisé, et seront utilisés seulement par les membres de l'équipe de recherche. Vos réponses ne seront pas partagées avec d'autres participants à la recherche ou avec votre équipe soignante.

Si vous décidez de participer à cette étude, une déclaration indiquant votre participation ainsi qu'une copie signée de ce formulaire de consentement seront placées dans votre dossier médical. Une copie signée du formulaire de consentement sera aussi gardée par le département des dossiers médicaux.

8. Compensation

À la fin de votre entrevue, vous recevrez $20 afin de compenser pour votre temps, les coûts de transport, et pour vous remercier de votre contribution à notre projet.

9. Qui pouvez-vous appeler en cas de questions ou de difficultés?

Pour obtenir plus d'informations sur notre étude, vous pouvez contacter Kelly Anderson à (514) 761-6131 poste 3353, ou Dr. Ashok Malla à (514) 761-6131 poste 3418.

Pour toute question reliée à vos droits en tant que participant de recherche ou tout problème éthique concernant de ce projet, vous pouvez contacter le Médiateur de l'Institut Universitaire en Santé Mentale Douglas à (514) 761-6131 poste 3287 par courriel à ombudsman@douglas.mcgill.ca.

Douglas

INSTITUT UNIVERSITAIRE EN SANTÉ MENTALE
MENTAL HEALTH UNIVERSITY INSTITUTE

CONSENTEMENT À LA PARTICIPATION

Une Étude Qualitative sur l'Utilisation des Services de Santé de Patients Atteints d'un Premier Épisode de Psychose

Cette étude vise à comprendre comment les gens obtiennent de l'aide lorsqu'ils éprouvent des symptômes psychotiques. Je participerai à une entrevue pour y donner mon opinion sur le sujet.

Les objectifs et procédures de cette recherche clinique, dans laquelle j'ai accepté de participer, m'ont été expliqués clairement par ___________________. J'ai lu ce formulaire de consentement pour participants et je comprends les bénéfices et les risques impliqués par ma participation à ce projet. J'ai eu l'opportunité et le temps de poser des questions, et je suis satisfait des réponses reçues de l'équipe de recherche.

Je comprends que ma participation est entièrement volontaire et que je peux me retirer en tout temps sans conséquences. Si je décide ainsi, je ne souffrirai pas de conséquences négatives et cela ne compromettra pas les soins et services que je recevrai dans le futur.

En signant ce document, j'accepte de participer à ce projet de recherche.

Je confirme, par la présente, que j'ai reçu une copie du formulaire de consentement que j'ai signé et que je peux conserver.

___________________________________	___________________________________
Signature du participant	Date
___________________________________	
Nom (en caractère d'imprimerie)	
___________________________________	___________________________________
Signature de la personne ayant expliqué l'étude	Date
___________________________________	
Nom (en caractère d'imprimerie)	

Douglas

INSTITUT UNIVERSITAIRE EN SANTÉ MENTALE
MENTAL HEALTH UNIVERSITY INSTITUTE

CONSENTEMENT POUR ENREGISTREMENT AUDIO

Une Étude Qualitative sur l'Utilisation des Services de Santé de Patients Atteints d'un Premier Épisode de Psychose

Nom: ______________________________ Dossier #: _______________________

Je, _________________________, autorise la création d'un enregistrement audio de l'entrevue que j'ai réalisé dans le contexte de ma participation à cette recherche *" Une Étude Qualitative sur l'Utilisation des Services de Santé de Patients Atteints d'un Premier Épisode de Psychose".*

Je comprends que cet enregistrement sera détruit une fois l'information retranscrite. Toutes informations pouvant m'identifier (ex. nom, lieu d'emploi) seront effacées de la retranscription, celle-ci étant identifiée seulement à l'aide d'un numéro. La bande sonore sera conservée dans un endroit sécuritaire jusqu'à ce que la retranscription soit complétée, et sera accessible seulement par l'équipe de recherche. L'enregistrement ne sera pas rendu public ni utilisé dans un autre but.

Signature: ____________________________________

Signé le _________________________________ (date), à __________________ (ville)