1-1-2012

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CanJPsychiatry 2012;57(10):626–633

Original Research

The Incidence of First-Episode Schizophrenia-Spectrum Psychosis in Adolescents and Young Adults in Montreal: An Estimate From an Administrative Claims Database

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Key Words: psychotic disorders, schizophrenia, first-episode psychosis, incidence, administrative database

Received February 2012, revised, and accepted April 2012.

Objective: There has been increasing interest in the psychiatric literature on research and service delivery focused on first-episode psychosis (FEP), and accurate information on the incidence of FEP is crucial for the development of services targeting patients in the early stages of illness. We sought to obtain a population-based estimate of the incidence of first-episode schizophrenia-spectrum psychosis (SSP) among adolescents and young adults in Montreal.

Methods: Population-based administrative data from physician billings, hospitalizations, pharmacies, and public health clinics were used to estimate the incidence of first-episode SSP in Montreal. A 3-year period (2004–2006) was used to identify patients with SSP aged 14 to 25 years. We used a 4- to 6-year clearance period to remove patients with a history of any psychotic disorder or prescription for an antipsychotic.

Results: We identified 456 patients with SSP, yielding a standardized annual incidence of 82.9 per 100 000 for males (95% CI 73.7 to 92.1), and 32.2 per 100 000 for females (95% CI 26.7 to 37.8). Using ecologic indicators of material and social deprivation, we found a higher-incidence proportion of SSP among people living in the most deprived areas, relative to people living in the least deprived areas.

Conclusions: Clinical samples obtained from psychiatric services are unlikely to capture all treatment-seeking patients, and epidemiologic surveys have resource-intensive constraints, making this approach challenging for rare forms of psychopathology; therefore, population-based administrative data may be a useful tool for studying the frequency of psychotic disorders.

Objectif : La littérature psychiatrique s'intéresse de plus en plus à la recherche et à la prestation de services axés sur le premier épisode de psychose (PEP), et l'information exacte sur l'incidence du PEP est essentielle pour le développement de services qui ciblent les patients aux premiers stades de la maladie. Nous avons cherché à obtenir une estimation dans la population de l'incidence du premier épisode de psychose du spectre de la schizophrénie (PSS) chez les adolescents et les jeunes adultes de Montréal.

Méthodes : Des données administratives de la population provenant de la facturation des médecins, des hospitalisations, des pharmacies, et des cliniques de santé publique ont servi à estimer l'incidence du premier épisode de PSS à Montréal. Une période de 3 ans (2004–2006) a été utilisée pour identifier les patients souffrant de PSS âgés de 14 à 25 ans. Nous avons utilisé une période de transition de 4 à 6 ans pour éliminer les patients ayant des antécédents de tout autre trouble psychotique ou une prescription d'antipsychotique.

Résultats : Nous avons identifié 456 patients souffrant de PSS, ce qui donne une incidence annuelle normalisée de 82,9 par 100 000 pour les hommes (IC à 95 % 73,7 à 92,1), et de 32,2 par 100 000 pour les femmes (IC à 95 % 26,7 à 37,8). À l'aide d'indicateurs écologiques de privation matérielle et sociale, nous avons constaté une proportion plus élevée de l'incidence de PSS chez les personnes habitant les quartiers les plus démunis, relativement aux personnes habitant les quartiers les moins démunis.

Conclusions : Les échantillons cliniques obtenus dans les services psychiatriques ne sont pas susceptibles de réunir tous les patients qui cherchent un traitement, et les enquêtes épidémiologiques ont des contraintes exigeant des ressources intensives, ce qui rend cette approche difficile pour les formes rares de psychopathologie; par conséquent, les données administratives de la population peuvent constituer un outil utile pour étudier la fréquence des troubles psychotiques.

There has been increasing interest in the psychiatric literature on research and service delivery focused on FEP. Systematic reviews have confirmed that delay in the treatment of FEP is associated with poor clinical and functional outcomes,[1,2] and outcome trajectories are typically defined within the first 2 years.[3] These findings have sparked substantial efforts in early detection, comprehensive care during the initial stages, and attempts to shorten treatment delay.[4]

The development and implementation of early intervention services requires population-based information on the incidence of FEP. Prior studies have used samples from FEP programs[5–7] and psychiatric services[8,9] to estimate incidence. However, it is unlikely that these samples will capture all treatment-seeking people, as some patients may not be referred to specialized services or may be lost to follow-up after initial contact. Other studies have obtained population-based estimates using extensive case ascertainment methods,[10,11] 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 usefulness of this information needs to be weighed against the limitations of administrative data, such as the lack of diagnostic standardization across professionals and minimal sociodemographic information.

As part of the universal health insurance program in Canada, each province administers a database for hospital and physician billing, and nearly all residents of Canada should be included in these databases. Prior research has found these data to be useful for the surveillance of psychiatric disorders,[12] and obtained estimates of disease burden are consistent with estimates from community surveys.[13] Other Canadian studies have used provincial billing data to estimate the incidence of schizophrenia generally[14,15]; however, no studies have 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,[16] but it is more restrictive than the case definition for incident schizophrenia in that the patient is expected to be in the early stages of illness. It is typically defined based on one of the following factors: the first treatment contact for any psychotic disorder; the requirement for patients to not have received prior treatment with an antipsychotic for longer than a specified period of time; or the duration of psychotic symptoms.[16] Although administrative data do not contain sufficient information for estimating symptom onset, they do have the potential to be useful for identifying an FEP based on patterns of health service contacts and antipsychotic use.

Our study sought to obtain a population-based estimate of the incidence of first-episode SSP in adolescents and young adults in Montreal using an administrative health and social services database.

Clinical Implications

- We found evidence of socioeconomic disparities in the incidence of SSP in Montreal.
- We demonstrate the feasibility of using routinely collected administrative data to obtain population-based estimates of the incidence of FEP.
- Knowledge of the incidence of psychosis in this vulnerable age group may assist in the planning and implementation of mental health services in other jurisdictions.

Limitations

- There is a possibility of having included some prevalent cases of psychosis if there has been a long duration between episodes.
- We are unable to generalize our findings to other age groups or types of FEP.
- The diagnostic codes used to identify patients have not been validated.

Abbreviations

ASSS	Agence de la Santé & des Services Sociaux
FEP	first-episode psychosis
IQR	interquartile range
RAMQ	Régie de l'Assurance Maladie du Québec
SSP	schizophrenia-spectrum psychosis
RR	risk ratio

Methods

Study Design and Source of Data

We obtained access to the linked administrative data of several health and social service providers from the ASSS of Montreal (Table 1). This database covers the years from 2000 to 2006, and consists of physician billing claims, pharmaceutical claims, and beneficiary information from the RAMQ. The RAMQ is the publicly funded health insurance plan that provides universal coverage of medical services to residents of the province of Quebec, and coverage of pharmaceuticals to about 50% of the total population

Table 1 Description of the individual datasets that comprise the linked database of the ASSS of Montreal, known as the Banque de Données Jumelées sur les Services de Santé

Source of data	Description	Variables of interest
RAMQ beneficiaries	Sociodemographic information on all RAMQ beneficiaries	Age, sex, ecological indices of social and material deprivation, and mortality (where relevant)
RAMQ medical services	Fee-for-service physician claims for all inpatient and ambulatory health care services	Procedure codes,[a] location of the procedure, physician speciality, and diagnosis[b]
RAMQ pharmaceutical program	Medications dispensed in the community to people aged 65 years or older, recipients of social assistance and those without private insurance (30% of beneficiaries aged 14 to 25 years)	Drug identification and dosage
MED-ECHO database	All hospitalizations occurring in the province of Quebec, including acute care, long-term care, and day surgeries	Primary and secondary discharge diagnoses[b]
CLSC	Contact with providers at sectorized front-line public health and social services clinics	Type of professional, reason for visit, and procedure code
CHSLD	Use of residential long-term care facilities	Type of facility and reason for needing residential services

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

[a] The procedure codes are based on the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures[37]

[b] Diagnoses are classified according to the International Classification of Diseases, Ninth Revision[38] prior to April 2006, and are classified according to the 10th revision[39] as of April 2006 (MED-ECHO database only).

(Table 1). Data are also available from the hospital discharge register, public health and social service clinics, and long-term care facilities. Data are linked using encrypted health insurance numbers.

The database includes all RAMQ beneficiaries residing in Montreal at any point from 2000 to 2006, inclusive. It contains information on medical services, pharmaceutical claims, and hospitalizations obtained anywhere in Quebec. There are no private institutions in the area where patients with a psychotic disorder could otherwise have received treatment.

Approval to access the data was obtained from the Research Ethics Board at the Douglas Mental Health University Institute, a health care facility within the McGill Academic Health Network. All data in the ASSS database are anonymous.

Case Ascertainment

The sampling frame consisted of people aged between 14 and 25 years living in Montreal between 2004 and 2006, inclusive. We chose this restricted age range to increase the likelihood that cases were first episode, as the onset of psychotic disorders typically occurs during the late teens and early twenties.[17] We identified patients with SSP, which included diagnoses of schizophrenia, schizophreniform disorder, schizoaffective disorder, or delusional disorder. Cases were identified by the presence of one of the following: a physician claim for SSP with a psychiatric procedure code; a clinic visit for schizophrenia or other psychotic disorder and a procedure code for a mental health or emergency visit; or a hospitalization with a primary or secondary discharge diagnosis of SSP.

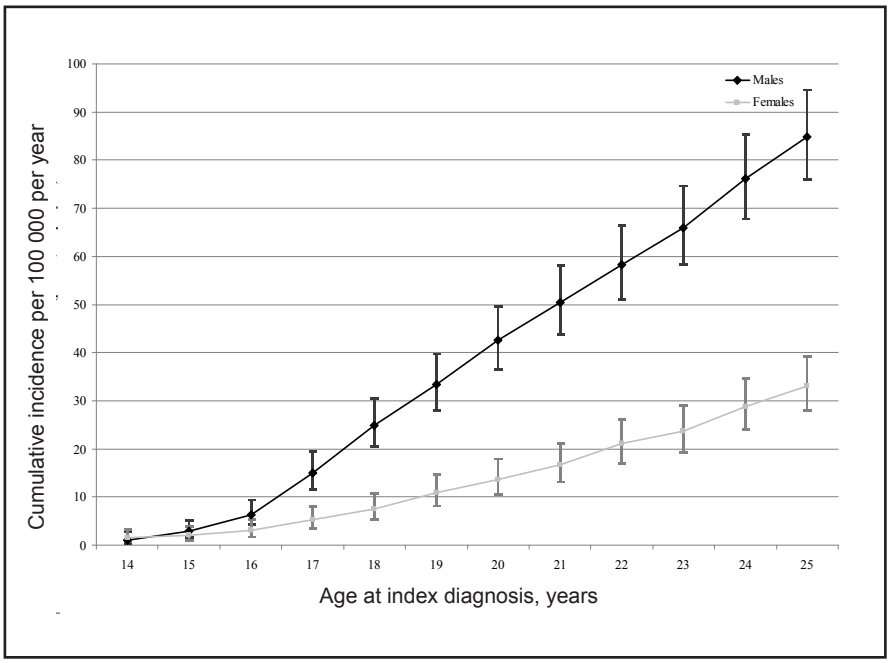
To remove prevalent cases, we excluded people with a prior medical claim, clinic visit, hospitalization, or long-term care admission for any psychotic disorder, including affective, organic, and substance-induced psychoses. We also excluded people with a prior prescription of any antipsychotic. These exclusions are consistent with the clinical definition of FEP used by many early intervention programs, which typically limit enrolment to previously untreated patients.[16] The clearance period for excluding prevalent cases ranged from 4 to 6 years, depending on the year of onset. The codes that were used to construct our sample are available from the authors on request.

To assess the impact of our case definition on incidence estimates, we conducted sensitivity analyses that included patients with a history of unspecified psychosis prior to the index diagnosis of SSP. A large proportion of people with this initial diagnosis are subsequently diagnosed with schizophrenia as the clinical presentation changes or additional information on prior symptomatology becomes available.[18,19]

Sociodemographic Variables

Available sociodemographic data included sex, age at index diagnosis, and an ecologic measure of socioeconomic disparities.[20] The index of material and social deprivation was developed in Quebec using census data, and scores

Figure 1 Crude cumulative incidence estimates of first-episode SSP in Montreal for patients up to the age of 25 years



are assigned at a high level of geographical resolution, the 6-digit postal code. Material deprivation was constructed using the proportion of the population without a high school diploma, the employment-to-population ratio, and average income. Social deprivation was constructed using the proportion of the population who live alone; are separated, divorced, or widowed; and are in a single-parent family.[20] The deprivation scores were divided into quintiles based on the provincial distribution, and people were assigned a score from 1 (least deprived) to 5 (most deprived).

Data Analysis

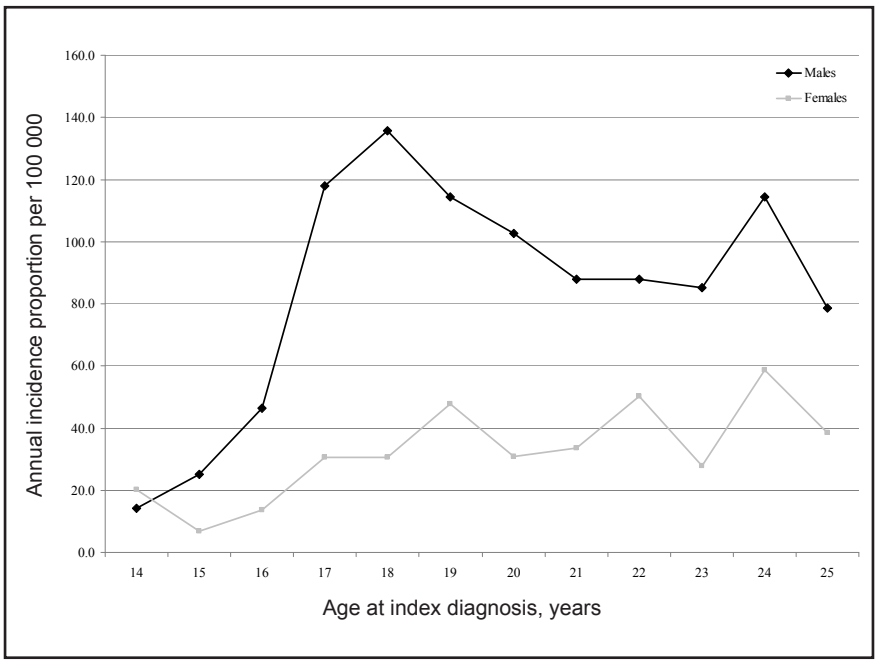
We estimated the annual incidence proportion of first-episode SSP with 95% confidence intervals using the Wilson score method without continuity correction.[21] We also used direct standardization to adjust estimates for age and sex, and 95% confidence intervals were calculated using the method described by Rothman and Greenland.[22] Using the standardized proportions, we estimated RRs for the sociodemographic variables with 95% confidence intervals.[22] The denominator data were obtained from the RAMQ,[23] and represent the average population aged between 14 and 25 years with valid RAMQ coverage residing in Montreal between 2004 and 2006 (about 15% of the population). To estimate the population at risk for each stratum of material and social deprivation, we used the frequency of deprivation scores from the sampling frame of the database, and applied this distribution to the denominator data obtained from the RAMQ. Incidence estimates were stratified by deprivation score and standardized to the 2006 Quebec population using the data provided by the creators of the Material and Social Deprivation Index.[20]

Results

We identified 456 patients with first-episode SSP (323 males and 133 females) within our selected age group. The median age at index diagnosis was 20 years (IQR 18 to 23) for males and 21 years (IQR 19 to 24) for females. Over 25% of patients resided in the areas corresponding to the worst stratum of material deprivation, and almost 40% resided in the areas corresponding to the worst stratum of social deprivation. Deprivation scores were missing for 9 patients, as scores cannot be assigned to about 2% of the Quebec population.[24] The service contact that yielded the index diagnosis was emergency services (emergency department or inpatient) for 60% of patients, a community-based physician for 33%, and a nonphysician for 7%. The index diagnosis was made by a psychiatrist for 69% of all patients.

The cumulative incidence of SSP to age 25 years is shown in Figure 1, and the annual incidence proportion by age and sex is shown in Figure 2. The incidence for males was more than twice as high as females (RR 2.57; 95% CI 2.09 to 3.16), with a standardized annual incidence of 82.9 per 100 000 for males (95% CI 73.7 to 92.1), and 32.2 per 100 000 for females (95% CI 26.7 to 37.8) (Table 2). The incidence of SSP was significantly higher among people living in the most materially deprived areas (RR 1.75; 95% CI 1.33 to 2.30) and among people living in the most socially deprived areas (RR 1.84; 95% CI 1.28 to 2.64), relative to people living in the least deprived areas. For both deprivation indices, the incidence of SSP was also higher in the third and fourth strata, although this trend was nonlinear (Table 2).

Figure 2 Crude annual incidence estimates of first-episode SSP among adolescents and young adults in Montreal, by age and sex



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

Our sensitivity analyses that included additional patients with a history of unspecified psychosis identified 611 patients (435 males and 176 females). This yields an annual incidence proportion of 113.7 per 100 000 for males (95% CI 103.5 to 124.9), and 43.8 per 100 000 for females (95% CI 37.8 to 50.7). The RRs were attenuated in the sensitivity analysis, but the observed trends were unchanged (data not shown).

Discussion

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

It is difficult to compare our estimate of the incidence of first-episode SSP to those from other jurisdictions, owing to inconsistencies in the included age range and diagnostic subgroups of psychosis. Based on estimates reported for similar age groups,[5,7,10] and given that SSP accounts for about 65% of first-episode cases,[8,10] we suspect that our estimate for males is likely higher than previously reported, whereas our estimate for females may be lower. The latter could be due to our exclusion of affective psychoses and the restricted age range of patients, as females account for more than 50% of FEP patients with affective psychoses, and tend to be older at first contact.[10]

In a Canadian study using administrative data to estimate the prevalence of schizophrenia in British Columbia, Goldner et al[14] introduced the term contact prevalence. In our study, we have estimated the contact incidence of first-episode SSP. Contact incidence is distinct from treated incidence, as people with psychotic disorders may access health services but not subsequently engage with psychiatric treatment. It is also distinguished from true incidence, as not all people with psychotic disorders may come in contact with health services.[14] There will be 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.[14, p 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. Vanasse et al[15] estimated the annual incidence of schizophrenia in Quebec among people 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 67 to 120 per 100 000 for males, and from 77 to 90 per 100 000 for females.[25] These discrepant findings are likely due to differences in the case definition. We were attempting to measure the incidence of the first-episode of SSP; therefore, we removed people who had a history of any psychotic disorder. Conversely, the aforementioned studies[15,25] only

Table 2 Annual incidence estimates and RRs obtained from an administrative database for the sample of adolescents and young adults with first-episode SSP in Montreal (*n* = 456)

	Population at risk		Patients							
Denominator population	*n*	%	*n*	%	Crude incidence[a]	95% CI	Adjusted incidence[a,b]	95% CI	RR[b]	95% CI
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										
1 (Least)	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
5 (Most)	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										
1 (Least)	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
5 (Most)	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

Ref = reference category

[a] Average annual incidence per 100 000 population

[b] Estimates standardized for age and sex

Some values do not sum to 100% because deprivation scores cannot be assigned to about 2% of the Quebec population.[24]

excluded those with a prior diagnosis of schizophrenia. We also had prescription data for nearly 75% of our sample, and we removed people with prior antipsychotic use, in keeping with clinically relevant case definitions of FEP. Further, our study used multiple data sources, thereby increasing the likelihood of identifying prevalent cases and improving the sensitivity of our case definition.

Prior evidence suggests that men are significantly younger at first contact with services than women[10]; therefore, we have likely underrepresented women in our sample. This may partially account for the greater sex differences we observed in incidence estimates than is typically observed when the entire age spectrum is considered. We also did not find sex differences in the median age at index diagnosis. The age distribution of our sample was truncated by design, which impacts the observed median. Indeed, other studies using samples restricted to adolescence and early adulthood have also reported a similar age at first contact for males and females.[5]

We found evidence of socioeconomic disparities in SSP incidence. Neighbourhood-level factors have been shown to impact on the risk of SSP,[26] and ecologic studies report an association between deprivation indices and psychiatric admission prevalence for psychosis.[27,28] It is unlikely that the disparities we observed are the result of social drift, as our sample was relatively young, and many would be expected to have parental addresses on file. However, this finding could be explained by unmeasured confounding from variables that are unavailable in the database, such as ethnicity and migration status.[29]

Our analyses are limited by the time span of available data, and we may have included prevalent cases if there was a long duration between episodes. However, the 4-year cumulative incidence of relapse in FEP is 75%, and a large proportion of remaining patients never have a second episode.[30] The aforementioned study by Vanasse et al[15] from Quebec assessed different algorithms for identifying incident cases of schizophrenia, and the algorithm most similar to our study yields positive-predictive values of 78% to 87% for a 4- to 6-year clearance period. These estimates were based on the full age spectrum for schizophrenia and are likely higher for our sample given the young age range. We estimate that only a small proportion of included patients may be prevalent cases.

We only included patients with SSP and thus are unable to generalize our findings to other types of FEP. We opted to exclude patients with non-SSP because there is evidence that cases of nonpsychotic affective disorder may be incorrectly coded as an affective psychosis using the International Classification of Diseases, Ninth Revision, classification system.[31] Indeed, when we included affective psychoses in our case definition, we obtained incidence estimates that were much higher than expected, with about 60% of the sample comprised of patients with affective psychoses, whereas clinical data suggests an expected proportion of about 25% to 30%.[8,10,32]

We also did not assess changes in diagnostic categories over time. Using data from prior studies[18,19,32–35] that have evaluated the diagnostic stability of FEP, we estimate that the positive-predictive value of a diagnosis of SSP at initial contact ranges from 85% to 97%, and the negative-predictive value ranges from 64% to 85%. These high positive-predictive values indicate that few people in our sample are likely to have a non-SSP disorder. The negative-predictive values suggest that about 15% to 35% of people initially diagnosed with non-SSP psychosis are later found to have SSP; therefore, we have likely missed some patients. This number is expected to be minimal, given that non-SSP accounts for only 25% to 30% of all FEP patients.[32] We evaluated diagnostic stability to some extent in our sensitivity analysis; however, we are unable to fully assess the impact of this without validation studies. We may have also included people with subclinical psychotic symptoms who would not meet diagnostic thresholds for an early intervention program.

We could have reduced the likelihood of misclassification by excluding people with only one instance of a diagnostic code for psychosis; however, we did not want to miss patients who are diagnosed with a psychotic disorder and do not return for follow-up. A brief examination of contacts following the index diagnosis indicates that about 15% of patients 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 owing 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 these factors.

Finally, our analyses are limited by the availability and accuracy of the data. We may have missed patients who sought treatment outside of Quebec, and we do not have data on important risk factors for psychosis, such as ethnicity and migration status.[29] We also do not have information on duration of antipsychotic use; therefore, we may have excluded patients who had a prior prescription for an antipsychotic but would nonetheless meet the clinical case definition for FEP. Similarly, we may have inadvertently dropped cases who may have had a prior prescription for an antipsychotic for an off-label indication, although we feel the likelihood of this is low in combination with a diagnostic code for psychosis. The structure of the database prevents us from calculating more accurate person-time denominators, as people are only included for a given year if they had contact with services. We are also not aware of any studies that have validated the RAMQ codes for psychosis specifically, which is a common problem when using administrative data for psychiatric research.[36] 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 reliability across different service providers and systems of care.

Conclusions

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 perspective, we may gain additional insights on the epidemiology of FEP, the patterns of health services use, and the use of pharmacotherapy in this patient population. This population perspective is also crucial for designing adequate early intervention services. Given that samples obtained from psychiatric services are unlikely to capture all treatment-seeking patients, population-based administrative data are an important source of information for research on FEP and its impact on population health.

Acknowledgements

We gratefully acknowledge Jean-Pierre Bluteau and the ASSS of Montreal for assistance with, and access to, the administrative database. This work was supported by a Canadian Institutes of Health Research (CIHR) Interdisciplinary Capacity Enhancement Grant in Health Inequalities (Project number HOA-80072). Ms Anderson is supported by a Frederick Banting and Charles Best Canada Graduate Scholarship from the CIHR. Dr Fuhrer holds a CIHR Canada Research Chair in Psychosocial Epidemiology, and Dr Malla holds a CIHR Canada Research Chair in Early Psychosis. Dr Abrahamowicz is a James McGill Professor at McGill University. The authors have no conflicts of interest regarding the publication of this manuscript.

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