Removing Barriers to Treatment of First-Episode Psychotic Disorders

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Objective: To describe changes aimed at removing barriers to appropriate and timely assessment and treatment of first-episode psychosis (FEP) and to present descriptive data regarding the potential impact of such changes on treated incidence, referral patterns, and treatment delay.

Method: We collected demographic and clinical information, including duration of untreated psychosis (DUP), on 196 persons referred for an initial assessment over a 3-year period.

Results: The number of identified FEP cases increased and DUP decreased over the 3-year period. The data suggest a differentially greater reduction in DUP in cases referred from sources other than health care.

Conclusion: These preliminary results suggest that, when setting up programs for FEP, relatively simple changes designed to improve access may improve treated incidence and reduce treatment delays.

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Clinical Implications

- We describe systemic changes in referral and assessment procedures implemented as part of an early-intervention program.
- Preliminary data suggest that simple changes to referral and assessment systems may remove barriers and reduce treatment delays.
- There are encouraging indications that referral sources not related to health care have the capacity to refer first-episode cases to appropriate treatment.

Limitations

- The data presented are observational, may need to be extended over a longer period, and include a historical control.
- Sources of referral data are limited to the source leading directly to admission to the program.
- The nature of the design and small number of subjects may limit the generalizability of the results.

Key Words: *early intervention, psychosis, schizophrenia, duration of untreated psychosis, DUP, source of referral, barriers to care*

It has been suggested that treatment delay in psychotic disorders may be related to poor outcome (1–3). Some studies have failed to demonstrate such a relation (4,5); however, 2 recent reviews have concluded that, unresolved methodological differences among studies notwithstanding, sufficient evidence exists to support an inverse relation between treatment delay in first-episode psychotic (FEP) disorders and clinical outcome (6,7). It has also been proposed that improving FEP outcome involves providing phase-specific treatment in addition to reducing treatment delays (7,8).

Table 1 Demographic and clinical characteristics			
	1997	1998	1999
All cases			
Total number assessed	43	75	78
Confirmed positive cases(male/female)	31(20/11)	55 (43/12)	48 (36/12)
Confirmed negative cases(male/female)	11(5/6)	18 (10/8)	28 (14/14)
Refused full assessment	1	2	2
Positive cases only			
Median age (IQR)	24.1 (19.9 to 30.4)	21.7 (19.4 to 30.7)	23.4 (19.5 to 30.7)
Percent single or never married	71.0	74.5	83.3
Education			
Less than high school (%)	41.9	43.6	34.0
High school only (%)	22.6	34.6	38.3
More than high school (%)	35.5	21.8	27.7
Duration of untreated psychosis median (IQR)	24.8 (10.8 to 47.6)	23.8 (10.4 to 51.7)	11.6 (4.47 to 31.4)
Referral source			
Acute or hospital based (%)	45.2	40.0	52.1
Community-based health (%)	45.2	40.0	33.3
Other than health (%)	9.6	20.0	14.6
IQR = Interquartile range			

A substantial proportion of individuals experiencing FEP disorder face long treatment delays, ranging from a few weeks up to an average of 1 to 2 years. Barriers to appropriate care, likely to exist at different levels of traditional referral and treatment systems, often result in multiple visits before an appropriate referral is made (9,10). More recent work at a specialized early-psychosis program in Canada has indicated that, on average, FEP patients make 2.3 (range, 1 to 6) help-seeking contacts following the onset of psychosis; most of these are made to emergency services and family physicians (11).

This paper outlines an approach to reducing barriers to appropriate treatment. It involves systemic changes implemented in an early-intervention clinical program in an urban setting. We present preliminary data on treated incidence, referral patterns, and treatment delay during the program's first 3 years.

Methods

General Program Description
The Prevention and Early Intervention Program for Psychoses (PEPP-London) is a community-oriented, comprehensive, multidisciplinary assessment, treatment, and research program serving a predominantly urban population of

approximately 400 000. A more detailed description of the program can be found at the Web site www.pepp.ca and has also been provided in previous publications (12,13).

Changes to Promote Early Access
Referral Policy. The program has an open referral policy, encouraging referrals not only from traditional sources, such as family physicians, emergency services, and inpatient units, but also directly from community social services, educational institutions, families, and individuals themselves. At the program's inception, descriptive brochures were sent to all health-related referral sources in the catchment area, including community psychiatrists, psychologists, family physicians, and other community health care workers.

Prompt Response to Referrals. A quick-response system was put in place. This consisted of immediate contact by an experienced mental health nurse and an offer for initial assessment within 24 to 48 hours.

Inclusion Criteria
An initial assessment is offered to all outpatient referrals who live in the catchment area, are aged 16 to 50 years, have no outstanding criminal charges, and have not been treated with antipsychotic medication for more than 1 month (except for

Figure 1 Proportion of diagnostic subgroups over the 3-year period
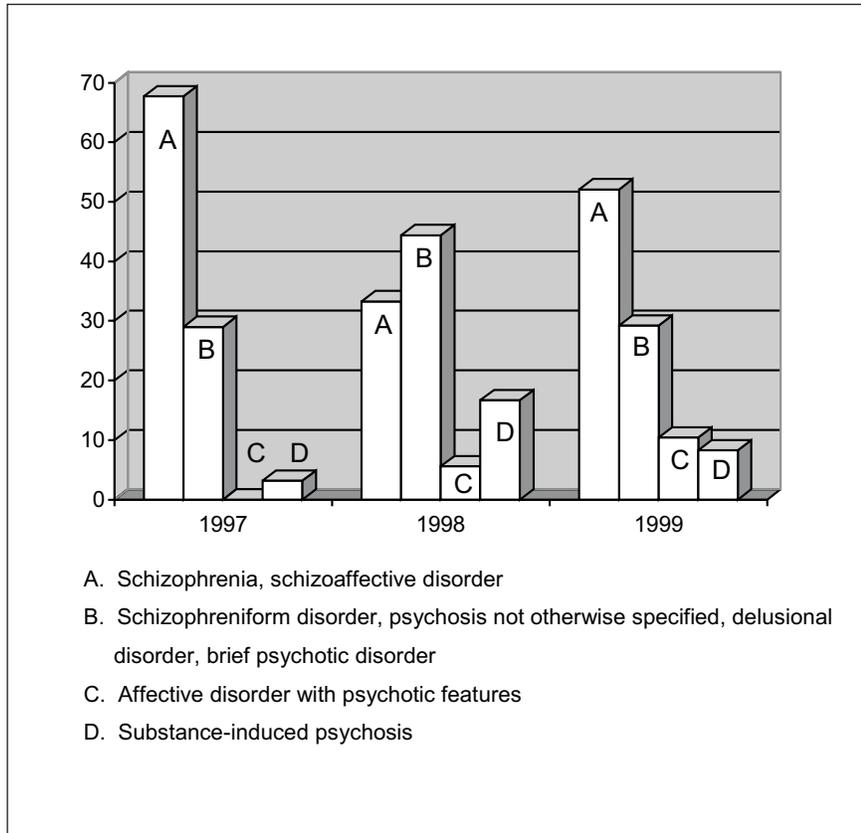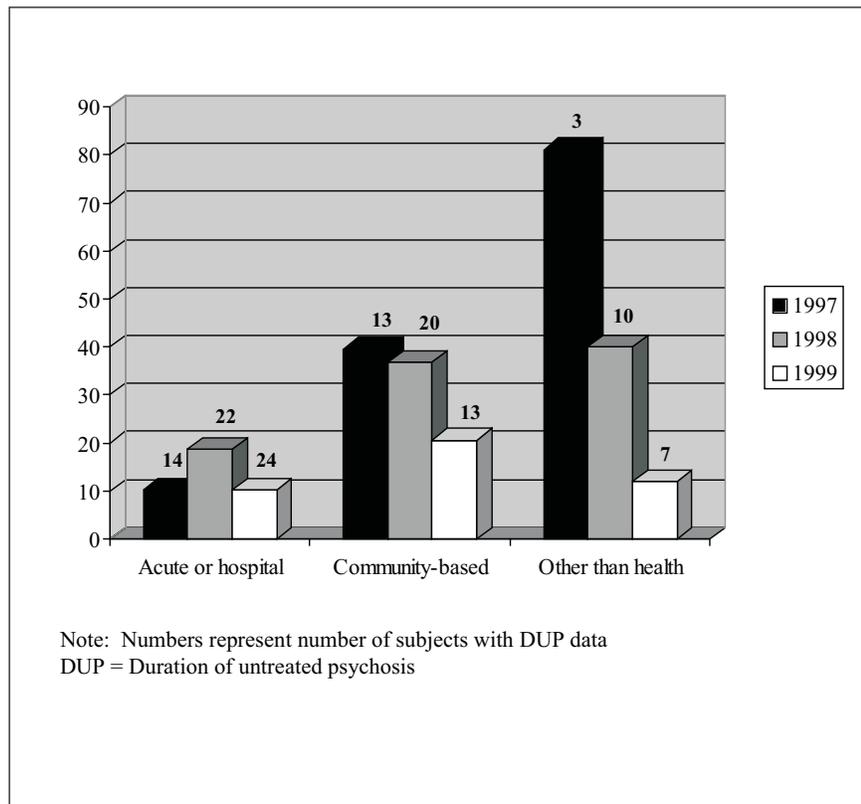

A. Schizophrenia, schizoaffective disorder

B. Schizophreniform disorder, psychosis not otherwise specified, delusional disorder, brief psychotic disorder

C. Affective disorder with psychotic features

D. Substance-induced psychosis

Figure 2 Median DUP in weeks by referral source

Note: Numbers represent number of subjects with DUP data
DUP = Duration of untreated psychosis

the program's first year, when the maximum allowed time on antipsychotic medication was 3 months). The narrower criterion of 1 month reflects better the definition of "first-episode" and increases chances of a more homogeneous sample for assessing baseline symptom levels.

Data Collection and Analysis

We collected demographic and clinical data for all individuals who received an initial assessment between January 1, 1997, and December 31, 1999. We considered a referral to be a positive case if the person met DSM-IV (14) criteria for a psychotic disorder at the time of the initial assessment, confirmed later through a Structured Clinical Interview for DSM-IV (SCID) (15). For summary purposes, we categorized diagnoses into the following 4 groups, based on symptom and duration criteria: 1) schizophrenia or schizoaffective disorder; 2) schizophreniform disorder, psychosis not otherwise specified (NOS), delusional disorder, and brief psychotic disorder; 3) affective disorder with psychotic features; and 4) substance-induced psychosis. We grouped referral sources into 3 categories: 1) acute or hospital-based (that is, inpatient admissions and emergency room), 2) community-based health service (that is, family physicians, urgent consultation services, and community psychiatrists), and 3) other than health service (that is, family members, friends, educational institutions, community services, and self).

Details on assessment procedures and methods used to calculate duration of untreated psychosis (DUP) are available from previous publications (12,13). We applied a significance level of 5% to all statistical tests. Ethics approval for this study was provided by the Research Ethics Board for Health Sciences Research Involving Human Subjects of the University of Western Ontario.

Results

Case Definition and Treated Incidence

During the 3-year period, 196 individuals (131 male subjects and 65 female subjects)

were assessed, 68 (35%) referred through the inpatient unit and 128 (65%) through the outpatient and community referral system (see Table 1). Positive cases identified were 72.9%, 73.3 %, and 62.0% in 1997, 1998, and 1999, respectively. Five subjects refused a full psychiatric assessment. Based on the number of positive cases identified, the annual age-specific (that is, age 16 to 50 years) treated incidence rates were 15.0, 26.6, and 23.2 per 100 000 in 1997, 1998, and 1999, respectively. As might be expected, not all positive cases were later confirmed to be suffering from a nonaffective psychotic disorder at follow-up. The frequency of other psychotic disorders was as follows: affective psychosis, 8 (4.4%); substance-induced psychosis, 4 (3.0%); and a psychotic disorder due to a medical condition, 1 (0.7%). Excluding these subjects from the sample, the annual age-specific (that is, age 16 to 50 years) treated incidence rates for nonaffective psychosis were 15.0, 23.2, and 20.3 per 100 000. Apart from statistically nonsignificant fluctuations, demographic patterns remained consistent across the 3-year period.

Diagnoses

An increase in the relative proportion of cases diagnosed with schizophreniform disorder, psychosis NOS, and brief reactive and substance-induced psychoses coincided with the increase in treated incidence in 1998 (see Figure 1). These increases appear to be associated with reduced proportions of those with a diagnosis of schizophrenia and schizoaffective disorder. The pattern in 1999, however, was similar to that seen in 1997. These differences in the relative proportion of diagnoses were not statistically significant.

Treatment Delay

Data required to determine DUP were available for 126 of the 134 individuals identified with FEP. The other 8 individuals refused or withdrew from treatment prior to completion of the assessment. The overall median DUP was 19.4 weeks (interquartile range [IQR], 7.3 to 44.8). Table 1 shows median DUP levels for each of the 3 years. The changes in DUP over time, while substantial in 1999, failed to reach statistical significance.

Referral Source

Table 1 lists the relative proportion of positive cases arriving from each referral-source subgroup for each year. We examined changes in DUP over time according to the referral-source subgroups (Figure 2). The changes over time in the relative proportion of positive cases and median DUP according to referral source, while not statistically significant, suggested increased referrals and reduced DUP from referral sources other than health care.

Discussion

Following changes designed to improve access for potential FEP patients, treated incidence increased, the annual proportion of patients with a diagnosis of schizophrenia decreased, and there was some shift in the referral sources of positive cases. In addition, treatment delay was reduced, especially for cases referred from sources other than health care. While substantial, these changes failed to reach statistical significance—very likely because small numbers were involved. While the observational nature of this study and lack of statistical significance of the findings may limit their generalizability, the data do suggest several potentially important patterns that need to be tested in larger samples over longer periods of time.

The observed decrease in treatment delay in year 3 suggests that the changes designed to improve access may have removed certain barriers over time, although its real significance can only be confirmed if this reduction is sustained in future. The pattern reported here also suggests that the systemic changes may have circumvented the traditional community-based health referral system and its associated delays (16). If replicated, it will confirm the suspected potential of school counsellors and family members to initiate referrals early after the onset of psychosis, provided there is a clinical service that will respond promptly to their referral. The observed lack of change in DUP over the 3 years in cases arriving through acute or hospital-based sources also suggests that a proportion of patients are unaffected by such systemic changes.

In conclusion, relatively simple changes in service delivery to FEP patients appear to initially increase the number of identified cases requiring treatment and lead to reduced DUP. While these findings are encouraging, the nature of this study and the relatively small sample limits their generalizability. A longer study period is needed to ascertain the stability of these changes.

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Résumé : Éliminer les obstacles au traitement du premier épisode des troubles psychotiques

Objectif : Décrire les changements visant à éliminer les obstacles à l'évaluation appropriée et opportune ainsi qu'au traitement du premier épisode psychotique (PEP), et présenter des données descriptives quant à l'effet éventuel de ces changements sur l'incidence traitée, les modes d'aiguillage et le délai de traitement.

Méthode : Nous avons recueilli des données démographiques et cliniques, y compris la durée de la psychose non traitée (DPNT), auprès de 196 personnes envoyées pour une première évaluation, sur une période de 3 ans.

Résultats : Le nombre de cas de PEP reconnus s'est accru et la DPNT a diminué sur la période de 3 ans. Les données indiquent une réduction de la DPNT différentiellement plus importante dans les cas envoyés de sources autres que des services de soins de santé.

Conclusion : Ces résultats préliminaires laissent croire que, quand on élabore des programmes pour les PEP, des changements relativement simples destinés à améliorer l'accès peuvent améliorer l'incidence traitée et réduire les délais de traitement.