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A model for rapid access to early intervention for psychosis: Description, evaluation and scale-up potential

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<u>Abstract</u>

- **Aim:** This paper aims to describe the entry protocol of the Prevention and Early Intervention for
- 3 Psychosis Program (PEPP)-Montreal, an early intervention program for psychosis. The protocol is
- 4 designed to fulfill a key objective of the early intervention movement reducing delays to accessing
- 5 high-quality care. The paper also aims to describe how this rapid entry protocol can be deployed in other
- 6 services interested in reducing delays in initiating treatment.
- **Methods:** PEPP provides rapid, easy access to quality care by placing a single, well-trained professional,
- 8 the intake clinician, at the point of entry. Anyone can refer a youth directly and without formalities to the
- 9 intake clinician who responds promptly and sensitively to all help-seeking, whether by a youth, a family
- member, a school counsellor or anyone acting on behalf of a youth in need. To promote accessibility,
- PEPP guarantees an initial assessment within 72 hours; maintains relationships with referral sources; and
- 12 conducts awareness-enhancing outreach activities.
- Results: Since 2003, PEPP has received 1,750 referrals, which have all been responded to within 72
- hours. Families have been involved in the intake process in 60% of the cases and hospitalization may
- have been averted in over half of the referrals originating from emergency-room services. Another
- indicator of success is the very low turnover in the intake clinician's position. Overall, the PEPP model has
- succeeded in providing rapid, engaging, easy and youth-friendly access to high-quality care.
- **Conclusion:** The success of this protocol at PEPP has inspired the entry protocols at other first-episode
- psychosis services. Its ability to provide rapid, engaging access to high-quality services may allow this
- protocol to become a model for other early intervention services for psychosis and other mental illnesses.

21 Keywords

health services accessibility, early intervention, first episode psychosis, intake, youth

23 Introduction

- 24 Early intervention for psychosis comprises two conceptual components —reduction of treatment delays
- and enhanced, phase-specific treatment (e.g., low-dose antipsychotic therapy, case management, family
- interventions, etc. (Norman and Malla, 2001, Iyer, 2014) Many early intervention services prioritize
- 27 enhanced care, but not all specifically aim to reduce treatment delays, including delays after the initial

referral (White et al. 2015). This is true despite the growing recognition that the presence of high-quality services alone cannot ensure timely treatment: reducing treatment delays may also require focused, well-conceived interventions (Lloyd-Evans et al., 2011).

The impetus to reduce treatment delay (measured as duration of untreated psychosis, or DUP) is rooted

in the notion that prolonged DUP is detrimental on many fronts (Marshall et al., 2005, Birchwood, 1999). Two themes prevail in the literature on reducing treatment delays in first-episode psychosis. The first focuses on formally-developed, systematic early case identification initiatives (Srihari et al., 2014, McGorry et al., 1996, Malla et al., 2014). The second concerns pathways to care (Norman et al., 2004) before reaching early intervention services, as research shows that multiple steps are often necessary to reach early intervention services, often through circuitous, difficult, disengaging and traumatic pathways (Singh and Grange, 2006).

DUP includes delays before help is first sought (help-seeking delay); delays between help-seeking and referral to an early intervention service (referral delay); and delays between being referred and receiving care (engagement delay) (Bechard-Evans et al., 2007). Reducing help-seeking and referral delays, and simplifying referral routes to early intervention services is certainly important. However, it is equally important to ensure that once referred (or self-referred) to early intervention services, people have rapid, direct and engaging access to an initial evaluation and care. As the International Early Psychosis Association Writing Group's standards outline, "Mental health services should provide user-friendly easy access to assessment and treatment.... Assessment should be timely, depending on urgency, and flexible in terms of location." (IEPA, 2005)

Despite this consensus, little is known about whether and how early intervention services ensure rapid, engaging access. Approaches vary widely and even early intervention services can suffer from poor accessibility. A survey found wide variations across Canada in the mechanisms of entry into early intervention services and delays between referral and care (Nolin et al., 2016).

It is also unknown whether entry to early intervention services is easier or faster than to regular care. If pathways to EI services are indeed simpler and post-referral delays shorter, the mechanisms in place to achieve this have rarely been described in the literature. This is an important knowledge gap because the

way a service responds to help-seeking may have implications for the future service engagement of youths and carers (Andrade et al., 2014). Knowing how well services respond to referrals can constitute a continuous, inexpensive and scalable means of improving case identification. A prompt, friendly and sensitive response to referrals and consistent feedback regarding outcome of the referral to the referral source can prompt referral sources to make more and timelier referrals.

This paper describes an innovative easy-entry, rapid-response assessment system at a Canadian first-episode psychosis program and perspectives acquired over its 14-year history. We will also describe the opportunities and challenges encountered in scaling this model up to emerging broad-spectrum youth mental health services nationwide.

Methods

Setting

The Prevention and Early Intervention Program for Psychosis (PEPP) is a clinical-research unit at a Montreal psychiatric hospital affiliated to McGill University. The program, established in 2003, was modelled on one in London, Ontario. PEPP serves young persons with first-episode psychosis from a specific catchment area with a population of 400,000. Its services are free and covered by public healthcare.

Inclusion criteria for follow-up at PEPP are: age 14 to 35 years old; DSM-IV diagnosis of non-affective or affective psychotic disorder. Exclusion criteria are: organic causes (e.g. epilepsy), IQ of less than 70, previous exposure to antipsychotic medication of greater than one-month duration. and substance-induced psychosis (a comorbid diagnosis of substance abuse or dependence is not an exclusion criterion).

The inclusion/exclusion criteria for the PEPP program were established given its mandate as a clinical-research program providing services within a given catchment area. In order to ensure that the program is providing services to young people presenting with a previously untreated and unresolved first episode of psychosis, the 30-day exposure to antipsychotic medication exclusion criterion is used.

Following international guidelines for specialized early intervention services for psychosis (IEPA, 2005), PEPP offers assertive outreach and follow-up for two years through case management and pharmacological and psychosocial interventions (lyer et al., 2015b). Treatment focuses not only on symptom remission but also on service engagement and functional and subjective recovery. PEPP's clinical team currently includes one full-time clinical coordinator; one full-time intake clinician; 5__ psychiatrists (who between them offer full-time coverage); 7.5 full-time case managers from various backgrounds (social work, nursing, occupational therapy and allied disciplines); part-time staff including a nutritionist, an employment specialist, psychologists; and student interns offering a range of treatments such as cognitive-behavioural therapy, drama therapy, art therapy, and various group interventions. PEPP's treatment protocol is described in greater detail elsewhere (Iver 2015b).

Key principles guiding access to PEPP

- The following are core features of PEPP's entry and assessment model that, together, ensure direct, rapid and engaging access to its services.
- 93 Open and direct referral system
 - To limit barriers to access, PEPP offers an open and direct referral system. Referrals can come from any source (youths themselves or their families, teachers, health professionals, emergency departments, or others acting on their behalf, etc.). No forms or official procedures are required (e.g., a referral from a general practitioner is not a prerequisite). Initial contact can be made in person or by phone or email.
- 98 Guaranteed quick-response protocol
- All referral sources are directly contacted by PEPP and an initial evaluation is offered within 72 hours.

 Though PEPP usually responds within 24 hours, a 72-hour limit is set to accommodate weekends. The

 initial contact is most often over the phone, and used to facilitate engagement early on and to go over

 basic inclusion/exclusion criteria (e.g., age).
 - Intake clinician: A well-publicized, engaging, single point of first contact

The key to PEPP's guarantee of rapid, engaging access is a trained non-physician mental health professional called the intake clinician. Serving as a single point of initial contact, this clinician is *directly* accessible and responds promptly to referrals. This clinician's time is dedicated entirely to responding to help-seekers and conducting initial evaluations.

As the first point of contact, the intake clinician fosters service engagement early on by adopting a youth-friendly, engaging attitude; offering flexibility and choice in the location and timing of assessment; and focusing the intake interview on clients' personally salient goals (e.g., resuming school/work). Depending on clients' or carers' preferences, the intake clinician meets them at PEPP, their home or school or a community location like a café.

Many youths with first-episode psychosis live with or are close to their families (Szmukler and Bloch, 1997)) who often initiate help-seeking (Anderson et al., 2013, Boydell et al., 2006). Because family involvement is known to improve long-term service engagement, medication adherence and outcomes (Coldham et al., 2002, Doyle et al., 2014) the intake clinician engages families at the outset by involving them in the initial assessment (except if clients forbid it).

Some patients are not invited for a face-to-face initial evaluation if it is ascertained in the initial phone contact that PEPP services may not be appropriate, considering PEPP's inclusion/exclusion criteria (e.g., client is older than 35). For all others, the intake clinician conducts an initial, face-to-face evaluation (using a semi-structured intake interview guided by the client's needs and pace) to establish if PEPP services are appropriate. When necessary, she consults with a psychiatrist, to whom she has immediate access, to confirm the nature of the presenting problem, assess risk and promptly initiate any appropriate psychopharmacological interventions and medical evaluations (EEG, MRI, etc.). Clients can receive a psychiatrist's evaluation outside PEPP, at a location of their choosing.

Sometimes, the intake clinician initially works only with the family member or significant adult (e.g., school counselor) who first contacted PEPP. She supports this carer and coaches them on how to propose help-seeking to their young family member. The intake clinician provides family members basic psychoeducation; offers them support and advice for dealing with crises; and links them to pertinent

community supports and services. Family members may also be linked to PEPP's family peer support group directly during the intake process.

The intake clinician orients clients and their families/carers to what can be expected from treatment. She uses the first contact as an opportunity to establish clients' needs and goals, and discuss how PEPP can help them achieve their recovery aspirations. This prioritization of personally salient goals (rather than symptoms) often proves significant in securing the engagement of youths who may not otherwise be open to receiving services for psychosis.

Whether or not a youth is accepted into PEPP, the intake clinician often contacts referrers with an update. This fortifies links with referral sources and encourages more and more appropriate referrals in the future. When PEPP services are inappropriate, the intake clinician often recommends and/or makes referrals to apt services, helping youths and their families navigate a complex healthcare system. Though they are sometimes beyond the purview of a typical intake process, these additional steps help connect youths to appropriate services quickly. If outside treatment deemed urgently necessary (e.g. for a severe manic episode without psychotic symptoms) is not immediately available, the PEPP team initiates treatment and continues following clients until their transfer to more appropriate services.

Thus, by fulfilling diverse roles and functions, the intake clinician ensures that young people and their families have early and engaging access to treatment, even if it is not at PEPP.

Strong linkages through early identification and outreach

As a catchment-based program, PEPP gets referrals from several fixed sources in the community. (Rickwood et al., 2007) For early case identification (Friis et al., 2005), it is important that these frontline entities recognize the signs and symptoms of psychosis and know how to refer people to appropriate services. Close connections with these referral sources have helped reduce the DUP and make pathways to care more direct and less traumatic. To that end, PEPP's ongoing early identification and outreach activities include visits to general practitioners and schools; distributing pamphlets; academic detailing on signs of psychosis using videos; and highlighting PEPP's open referral system. Many of these materials, including the video advertisements, were developed for a formal early identification study conducted in

2006 focused on the education of all potential referral sources (Malla et al., 2014). These in-person presentations and booster sessions were facilitated by PEPP staff, particularly the intake clinician. Most of PEPP's early identification and outreach activities involve the intake clinician. This helps potential referral sources connect personally with the clinician who will handle their referrals.

Results

Below are key results from the implementation of PEPP's entry and assessment model.

Open and direct referral system

From January 2003 to May 2016, PEPP had over 1,750 referrals. By volume, the largest referral sources were emergency services, family/self-referrals and inpatient units. Referral sources have become increasingly diverse over time (Figure 1).

Guaranteed, quick-response protocol

100% of referrals to PEPP since 2003 were responded to within the 72-hour benchmark. The median time from referral to official entry into PEPP following initial evaluation was 16 days Official entry into the PEPP program occurs after the initial evaluation by the intake clinician and a formal psychiatric assessment (see Figure 2).

Intake clinician

Qualifications, training and support

Continuously since 2003, PEPP has operated with a single intake clinician whose background has been in social work, nursing, psychology or allied professions. There has been little turnover in this role, with the current clinician being with PEPP since 2013 and his predecessor holding the post for nine years. This stability has allowed the intake clinician to develop and sustain relationships with referral sources in the community. It reflects the support and satisfaction intake clinicians enjoy and suggests that the model may be practically and feasibly implemented in other early intervention settings.

Building and sustaining the intake clinician's capacities through initial training and continuous supervision has been instrumental to the model's success. Their training has revolved around the precepts and

philosophy of early intervention, the signs and symptoms of psychosis, psychoeducation, risk assessment and clinical measures/tools. Trainees shadow trained intake clinicians and clinical staff and are introduced to PEPP's family support group coordinator and key health and social service partners. The entire PEPP team meets at weekly rounds to present and discuss intake reports and generate group feedback on complex, ambiguous or difficult presentations. More systematic reviews of response to referrals in terms of delays, approach, emphasis on engagement, etc. occur every quarter.

PEPP's intake clinicians have received approximately 170 referrals annually. Around 60% of these referrals have met PEPP's inclusion criteria. Of those excluded, 44% did not have psychosis; 4% did not meet the age criterion; 13% had taken antipsychotic medication for over one month; 34% did not live in the catchment; and 5% were not accepted for other reasons (e.g., symptoms explained by medical conditions, loss of contact, etc.) The proportion of referrals not meeting inclusion criteria has remained unchanged since 2003. However, there have been peaks in referrals associated with press releases or other media attention, with a majority of these involving referrals not eventually appropriate for PEPP.

In a significant number of cases, family members or carers have been involved in the intake process, usually being present in person. Since 2012, when family involvement began being systematically recorded, families have been involved in over 60% of initial assessments. In 7% of cases, clients explicitly forbade family involvement. In 33% of cases, extenuating circumstances (e.g. clients being international students, refugees, etc.) precluded family involvement.

Early identification and outreach

Because most referrals to PEPP come from its host hospital's emergency department, the intake clinician has fostered a close relationship with its staff. When presented with a youth who may meet PEPP criteria, emergency staff contact the intake clinician who either initiates an immediate evaluation, or engages the client and schedules an in-person meeting at PEPP as soon as possible. This may have drastically minimized the amount of time that many youths with psychosis spent at the hospital emergency.

54% of emergency department referrals had their intake assessment take place in ambulatory settings such as the emergency room, outpatient settings (including at PEPP itself), or in the community. The

remainder required hospitalization. Thus, the frontline deployment of the intake clinician may have averted inpatient hospitalization for over half the youths presenting with psychosis at one psychiatric emergency unit. It is also likely to have reduced the referral delay for patients referred from the ER (median: 0.42 weeks, range -8.57 to 196 weeks) that would have occurred if emergency staff simply discharged clients with PEPP's contact information. These are prominent illustrations of how PEPP's intake clinician gives young people a "soft landing" into early intervention services by bypassing potentially traumatic pathways to care.

Over time, PEPP's intake clinician has fostered relationships with numerous catchment-area healthcare and community organizations. A semi-structured interview, called Circumstances of Onset and Relapse Schedule(Norman and Malla, 2002) has recorded every client's sources of referral, help-seeking contacts before entering PEPP and treatment delay indices. This interview, conducted by trained research staff within the first few months following entry to PEPP, constructs a timeline of the client's life, from the development of symptoms to their help-seeking efforts until entry to PEPP. The timeline is presented to the research team, including one senior psychiatrist, and consensus is reached on several key measures such as DUP, defined as the time between onset of psychotic symptoms and commencement of one month of continuous antipsychotic treatment. In addition to furthering research (Bechard-Evans et al., 2007, Cassidy et al., 2008, Malla et al., 2005, Malla et al., 2014), these indices continuously inform outreach targets and activities.

At PEPP, the median DUP for all accepted clients is 114 days/16.35 weeks (range: 0-512 days). This is significantly shorter than the DUPs of 6-12 months, or more, that many other early intervention services report (Albert et al. 2017, Lloyd-Evans et al., 2011, Marshall et al., 2005). PEPP's median referral delay is 1.28 weeks (range: -13.2- 445 weeks). This short referral delay may at least in part result from the intake clinician's strong links with community referral sources. A negative value indicates that a client was referred to PEPP before developing full-threshold symptoms, for example, if the client was experiencing sub-threshold psychotic symptoms. Specifically, these clients were first followed in PEPP's sub-program for youth at ultra-high risk for psychosis (Pruessner et al., 2015) and immediately accepted into the PEPP

program when they developed threshold-level psychotic episode. In these cases, their initial referral date to PEPP is used, hence the negative measure of delay.

Discussion

PEPP's rapid access system and its demonstrated impacts in reducing wait-times to services are particularly noteworthy in Canada, where long wait lists and delays before services can be accessed are the norm (Barua et al. 2015, Kowaleski et al. 2011).

One of the chief components contributing to rapid access to our program is an open referral system, which bypasses the more traditional filter system where primary care is a required first step to accessing psychiatric services (Goldberg and Huxley, 1990). However, even given the possibility that youth or informal sources of help could contact PEPP directly, the majority of referrals still arose from formal health services. This reflects the need to not only reduce systemic barriers to services, but also to carry out active community outreach to increase self- and carer referrals.

The increase in diversity in referral sources to PEPP over the past 14 years may represent an increase in awareness of the clinic, following media coverage, and/or an increase in awareness of the signs and

symptoms of psychosis, especially among community-based primary care settings and the educational

sector. Both these areas were targeted through formalized early identification initiatives directly aimed at

potential referral sources in the community.

The intake and initial evaluation model described herein has been implemented effectively since 1997 at the PEPP program in London, Ontario and since 2003 at PEPP-Montreal. Its replicability is attested to by its deployment at three other first-episode psychosis programs in Montreal. These deployments were done in 2008, 2010 and 2012 facilitated by PEPP-Montreal's training and knowledge translation activities. Though these other Montreal early intervention services have adopted a similar model for rapid intake, none have evaluated its effectiveness through a systematic assessment of DUP and specifically, of referral and engagement delays. Thus, we cannot confidently comment on whether the same success in reducing delays has been achieved by these similar programs.

This is important to note, given that 'timely contact with referred individuals' was highlighted by expert

consensus as one of the chief components of early intervention for psychosis services (Addington, et al. 2013). Yet in many cases, early intervention services either do not reach this target or do not have the available data to report on this component (White et al. 2015).

Our model requires a commitment to ensuring rapid access that goes beyond a philosophical framework and necessitates additional resources, including well-established clinical supervision. Daily challenges described by PEPP intake clinicians include occasionally dealing with high referral volumes; engaging clients who are reluctant to enter services; and matching individuals who do not meet our intake criteria to other more appropriate services. Many of these other services do not share a similar emphasis on rapid access and have long waiting lists.

Concluding thoughts

Despite wide acceptance of the need for rapid-access early intervention services, their availability and accessibility remain inconsistent. Our protocol's demonstrated success in providing rapid, engaging access to high-quality first-episode psychosis services makes it a model for early intervention services for psychosis and other mental illnesses.

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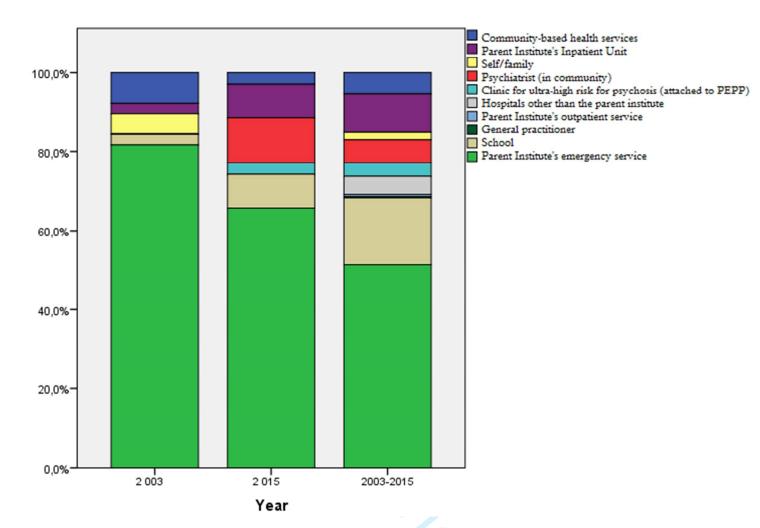
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Figure 1. Referral sources to PEPP over the years from 2003-2015

Figure 2. Referral and intake procedure at PEPP

Figure 1. Referral sources to PEPP over the years from 2003-2015.



PEPP is a progam located in a larger psychiatric institution called the Douglas Mental Health University Institute which houses other services like the ER, non-first episode psychosis outpatient services, inpatient services, etc.

