

# Prevention and Early Intervention Program for Psychoses (PEPP)

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## Abstract

**The Prevention and Early Intervention Program for Psychoses (PEPP) was established in 1997 for individuals with first-episode non-affective psychotic disorder. The objectives of PEPP are to improve outcomes for clients by providing a prompt, comprehensive, coordinated and effective treatment program as well as to advance research concerning early intervention for psychotic disorders. This article describes the clinical and research program and the lessons learned.**

## Introduction

Psychotic disorders, such as schizophrenia, are amongst the most personally disruptive and costly of psychiatric conditions. Although medical interventions have proven effective in reducing positive symptoms such as hallucinations and delusions, their impacts on negative symptoms, including reduced motivation and expressiveness, and other characteristics associated with the illness, are less robust (Miyamoto et al. 2012). Psychosocial interventions also have proven benefits on symptoms, functioning and quality of life (Turner et al. 2014) but are not always readily available in effective form (Lehman and Steinwachs 1998).

Symptoms of psychosis typically have their onset in late adolescence or early adulthood. If they are not successfully treated, psychotic illnesses can have a very deleterious impact on the

long-term prospects of affected young people as exemplified by repeated hospitalizations, high rates of unemployment, poor quality of life and high rates of suicide. It is important, therefore, to promptly provide the best possible treatment to those who develop a psychotic disorder.

Over the past 20 years, there has been considerable enthusiasm for reforming mental health services in order to provide excellent care more quickly, particularly for young people (Coughlan et al. 2013). Much of this work has been spearheaded in the field of early intervention for psychotic disorders (McGorry 2015). The Prevention and Early Intervention Program for Psychoses (PEPP), in London, Ontario, was one of the first developed within North America for the purpose of providing better services more quickly to improve outcomes for young people with psychotic disorders. From its inception in 1997, PEPP has been an integrated clinical and research program devoted to not only developing and providing improved clinical care but also evaluating outcomes for patients, developing a research base for improving service delivery and better understanding the nature of psychotic disorders and determinants of outcome ([www.PEPP.ca](http://www.PEPP.ca)).

## Clinical Program

The core features of the PEPP clinical program include the following:

- a) Initiatives for case detection and rapid assessment of previously untreated individuals showing possible symptoms of psychosis; prompt initiation of treatment of those found to have a non-affective psychotic disorder. To facilitate case identification, PEPP has carried out education programs with schools, community service agencies and healthcare providers concerning the symptoms of psychosis and the importance of early intervention. In addition, PEPP has an open referral policy, responding to enquiries from anywhere in the community — including families and potential clients — without the need for physician referral. Initial screening is carried out by a psychiatric nurse or social worker within 24 hours and, if indicated, this is followed by an appointment for a full assessment with a psychiatrist, offered within one week. Individuals between the ages of 16 and 40 with a previously untreated psychotic disorder who live in the defined catchment area are immediately accepted into the program — there is no waiting list. Those who present with other mental health problems are referred to alternative services.
- b) Following admission to PEPP, a treatment plan is developed in collaboration with the client and, when feasible, family. Using standardized scales, assessments of symptoms, functioning and living circumstances are carried out on a regular basis during the individual's treatment to assess progress and identify needs, and treatment plans are updated as indicated.
- c) Flexibility in assessment and treatment approaches in order to facilitate engagement. There can be significant barriers to an individual's willingness to accept treatment, even when a psychotic disorder is clearly present. These barriers include an ill person's poor insight about the presence of a disorder (Amador and David 2004) and the perceived stigma of having a serious psychiatric illness (Corrigan 2004). It is sometimes necessary to show considerable flexibility and creativity to facilitate and maintain engagement. Assessments and clinical interventions are, when necessary, undertaken outside of the clinic, including in the home. While pharmacological interventions can be essential, we do not insist that clients take medications in order to be provided with support and education. In order to encourage engagement and reduce disruptions, hospital admission or compulsory treatment is used only when absolutely required. Considerable efforts are made to negotiate a shared understanding of what is wrong and what is required between clinicians and families.
- d) Provision of comprehensive and coordinated pharmacological and psychosocial interventions to quickly address the acute symptoms of psychosis and bring about recovery. Given evidence of fragmented and poorly coordinated delivery of services for individuals with psychotic disorders

in the past (Bachrach 1986), an assertive case management model (Mueser et al. 1998) is central to PEPP. The case manager is responsible for ongoing assessment of the client's needs, coordinating interventions and advocating for the client's needs.

- e) Provision of interventions designed to achieve several outcomes. Often, the first priority is reduction of the disruptive and bizarre symptoms of psychosis, which can include hallucinations and delusional thinking. Pharmacological interventions are usually an essential factor in addressing such symptoms. The rationale for choice of antipsychotic medication is explained, and treatment is generally initiated with as low a dose as possible and gradually increased as needed. Symptom response and side effects are closely monitored. When adherence to oral medications is problematic, longstanding injectable preparations can be used. Often, particularly over the first months of treatment, adjustments in type and dosage of medication are required.

Experiencing a psychotic disorder is very disruptive to a young person's life, often accompanied or preceded by difficulties in school or work, disruptions in interpersonal relations and social support, substance abuse, anxiety and/or depression and the so-called negative symptoms of social withdrawal, decreased motivation, emotional expression and social engagement. These phenomena (often exacerbated by the stigma of having a serious mental illness) can present major barriers to an individual's full personal, social and functional recovery. PEPP provides both individual and group interventions to address these concerns.

All clients receive supportive therapy from their case managers. Specific psychological interventions, such as cognitive behavioural therapy, are provided through the Program's clinical psychologist to address problems with anxiety, depression and substance use. Interventions are also delivered through several group formats, including the Recovery through Activity and Participation (RAP) group, which provides low-stress activities to enhance daily functioning; the Youth Education Support (YES) group, which is designed to assist clients in the process of recovery by preventing relapse and encouraging resumption of important roles; and Cognitively Oriented Skills Training (COST) group, which addresses any challenges in cognitive functioning in order to facilitate clients' return to school or work.

- f) Involvement of families. Psychotic disorders have implications for the families of those afflicted, and families often play an important role in identifying the psychosis and facilitating engagement in treatment and recovery. From the time of initial contact with PEPP, strong efforts are made to involve families in the assessment process, in

## Lessons Learned

Our experience in developing the program, our research, and findings from other centres, support the following conclusions relevant to delivering early intervention services for individuals with psychotic disorders.

- Earlier intervention (shorter treatment delay) is associated with better treatment outcomes (Marshall et al. 2005; Norman et al. 2007).
- Reducing treatment delay is challenging (Cassidy et al. 2008; Lloyd-Evans et al. 2011) and needs to include educating both the public and healthcare professionals about the symptoms of psychosis and the need for early intervention.
- Specialized early intervention services for psychosis, which are designed to specifically address barriers to service engagement and the needs of young people experiencing psychotic illness, bring about better outcomes than standard mental health services (Craig et al. 2004; Petersen et al. 2005). Continuing to provide less intense specialized services increases the likelihood that benefits will persist (Norman et al. 2011). There is evidence that early intervention programs can also lead to healthcare cost savings (Goldberg et al. 2006; McCrone et al. 2010).
- Recovering from a psychotic disorder requires more than the reduction of acute symptoms through medication and includes psychological, functional and social dimensions (Norman et al. 2013; Windell et al. 2012). Addressing psychological and social influences, as well as substance use, are important in bringing about broader recovery (Carr et al. 2009; Norman et al. 2012b; Windell and Norman 2013).
- Ideally, there should be ongoing monitoring and measurement of the services being provided to clients and families and of their outcomes. It is important to keep examining the logic and effectiveness of the program. This would help in the identification of areas needing improvement and lead to necessary adjustments in the program model and service delivery (Rossi et al. 2004). Although the rationale for such an approach seems impeccable, there are considerable difficulties in obtaining reliable and relevant information in the context of a busy clinical service and regularly providing feedback to the program. Ideally, there would be personnel whose time could be devoted to facilitating such a process, but few programs can support such a resource. Even with such supports, obtaining the necessary information from busy clinicians who are already struggling to meet broader institutional reporting requirements is challenging.
- The symptoms of an acute psychotic episode are often very distressing and disruptive and can require hospitalization. Dedicated beds for specialized early psychosis care, and close coordination between the services provided by an early intervention program such as PEPP and inpatient services, are essential (IEPA Working Group 2005). In addition, physical proximity to an inpatient service allows prompt and effective response to situations where there is urgent need for hospitalization and also facilitates the engagement of first-episode inpatients into PEPP. On the other hand, it is also desirable that early intervention programs be located in non-stigmatizing community settings. Balancing these needs and protecting the required inpatient resources has proven difficult.
- As noted earlier, there are several psychological, social and economic aspects to recovery. Given the young age at which psychotic disorders usually occur, issues related to employment are very important. Employment can provide financial benefits and may also yield benefits for symptoms and psychological well-being (Burns et al. 2009; Priebe et al. 1998). The addition of an employment counsellor to our staff has been helpful in beginning to address clients' employment needs, but much remains to be done. The development of a supported employment program (Mueser and McGurk 2014) and possibly the development of social enterprises (Gilbert et al. 2013) would be of considerable assistance in increasing actual employment rates among our clients, but these require additional resources.
- Early intervention services are by definition time-limited (IEPA Working Group 2005). For those clients requiring continuing specialized care, it is important that appropriate long-term services be available (Kam et al. 2015). There have been significant difficulties in accessing such services within the London region, resulting in many clients continuing to receive follow-up services from clinicians within PEPP. This situation results in the diversion of resources and threatens the program's capacity to continue to provide ready access to services for individuals and families dealing with a recent-onset psychotic disorder.

supporting engagement and treatment and in facilitating recovery. Families themselves usually need help and PEPP endeavours to provide this help through education about the illnesses and treatments, as well as practical advice and support for coping with the challenges families face. These have been provided through educational workshops, which include information on the nature of psychosis, treatment and psychosocial issues related to outcome; individual family interventions; and a parent support group. In addition, video materials were developed to help educate and support families. Families can provide important mutual support for one another and can be strong advocates for those with psychotic disorders and provision of required services (Norman et al. 2008a).

Intensive treatment within PEPP usually occurs for a minimum period of two years, with additional follow-up for up to a total of five years.

## Research

From its inception, PEPP has functioned as an integrated clinical and research program, focusing on pathways to care (Norman and Malla 2009), treatment outcomes for our clients (Norman et al. 2011), the influence of treatment delay on recovery (Norman et al. 2007; Norman et al. 2012a), the stigma associated with psychotic disorders (Norman et al. 2008b), the nature and determinants of recovery from psychosis (Windell et al. 2012), as well as furthering understanding of the basic pathology of schizophrenia and related psychotic disorders (Manchanda et al. 2005; Manchanda et al. 2014).

## Conclusions

Although we and our colleagues at PEPP feel some satisfaction in what has been accomplished, we are very aware of the continuing challenges in developing and evaluating an early intervention program for psychosis. Even though PEPP has now been in existence for almost 20 years, we must always consider it a program under development. Its ongoing evolution has to respond to new knowledge generated in the field (e.g., Bird et al. 2010; Wunderink et al. 2013); the evolving standards of care (Addington et al. 2009) and our own recognition of our clients' current needs and weaknesses of the program. These challenges have to be addressed while dealing with constraints posed by the local mental health service delivery system. **HQ**

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