Development of an early psychosis public education program using the PRECEDE–PROCEED model

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Abstract

Early diagnosis and treatment are recognized strategies to reduce the long-term functional effects of chronic diseases, including psychotic disorders such as schizophrenia. Treatment may be delayed if youth, young adults and parents are not aware of the early signs and symptoms of psychosis, the need for early diagnosis and treatment and where and how to get help. This article describes the use of the PRECEDE component of PRECEDE–PROCEED model as a conceptual framework in the development of an early psychosis public education program’s objectives designed to meet the learning needs of the target population (youth and young adults ages 15–30 years and their parents). The PRECEDE framework provided a strong conceptual model in the program’s planning.

Introduction

The Early Psychosis Treatment Service, in Calgary, Alberta, opened in 1996 to offer quick and easy access to treatment for all individuals with first-episode psychotic disorders in the population of 954,000. The goals of the service are early identification of the illness, a reduction in secondary morbidity, reduction of the frequency and severity of relapse, the promotion of normal psychosocial development and reduction of the burden for families and caregivers [1].

The Early Psychosis Treatment Service also provides gatekeeper education to improve awareness of the illness and the availability of the treatment program among health professionals and youth workers. An early detection program can teach family physicians, mental health workers, school and college counselors, community youth workers and others to identify changes in social functioning and insidiously developing symptoms [2], potentially resulting in increased referral rates to early intervention services [3]. With this gatekeeper educational program in place, the average time between the onset of the illness and the time to treatment [duration of untreated psychosis (DUP)] in the early psychosis treatment service has been decreased to 1 year, from an average of 2 years. This treatment delay of 1 year remains a serious problem, especially because treatment effects seem to be best during the early phases of illness [2]. In order to decrease the DUP further, a public education program targeting youth and young adults (ages 15–30 years) and their parents in the community was developed. If successful, the program should allow more people to access help before they are sick enough to require hospitalization. This paper describes the planning of the goals and objectives of a public education program designed to reduce the DUP.

Methods

The development of the public education program’s objectives began with a comprehensive review of
the literature. This included a review of the overt signs and symptoms of psychosis, accompanying functional disabilities, delay in seeking treatment, stigma and the effect of the disease on other family members. In addition, Canadian initiatives have been explored including consideration of previous surveys and marketing research.

**PRECEDE framework**

The PRECEDE component of the PRECEDE–PROCEED framework was used as an educational diagnostic model to plan the psychosis public education program. PRECEDE stands for ‘Predisposing, Reinforcing and Enabling Causes in Educational Diagnosis and Evaluation’ in planning health education [4–6]. PRECEDE starts with the desired outcome of the interventions and works systematically backward through seven phases. Using the activities outlined in Phases 1–6 of the PRECEDE framework, the literature review findings were systematically assessed by applying the criteria of ‘importance’ and ‘changeability’ to develop the educational objectives of the Early Psychosis Public Education Program.

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**Results**

**Epidemiology and social diagnosis**

For the psychosis public education program, the quality of life problem identified was the significant functional disability and suffering due to chronic schizophrenia. The psychoses are a group of disorders of which schizophrenia is the most significant. According to the World Health Organization ten-country study, the first-episode psychosis annual incidence rate is 10 per 100 000 population aged 15–54 years for a narrow definition, such as Diagnostic and Statistical Manual of Mental Disorders IV schizophrenia, or 20 per 100 000 for a broader definition [7]. The broader definition of psychosis comprises the schizophrenia spectrum of disorders (schizophrenia, schizophreniform disorder, brief psychotic episode, psychosis not otherwise specified and delusional disorder) that are admitted to the Calgary Early Psychosis Treatment Service. The Early Psychosis Treatment Service is a regional program that accepts all first-episode subjects in the Calgary region.

In Calgary, the 2001 population of individuals aged 15–54 years was 591 000. Thus, Calgary’s estimated annual incidence rates of schizophrenia are approximately 59 (narrow definition) to 118 (broad definition) cases per year. The Early Psychosis Treatment Service admits ~100 patients per year; the mean DUP varies (depending on the cohort) between 1 and 2 years, and about one-third are hospitalized prior to program entry [1]. In Calgary, the 15- to 35-year-old population comprises 95% of the referred patients.

Schizophrenia is a life-long illness that affects up to 1% of the population at some point in their lives. Typically, the onset of the disorder occurs in teenagers and young adults which can result in suffering in affected individuals and their families, and place a significant burden on the health care system. The direct cost of schizophrenia to the Canadian health care system is $1.12 billion annually [8]. Chronic psychotic disorders cause disturbances in one or more major areas of functioning such as work, academic, interpersonal relations and self-care. The consequences of disorders, such as schizophrenia, include an increased suicide rate, social disability, social stigma, impact on caregivers and social costs [9]. Many individuals experience poor or declining social functioning for years before the first manifest psychotic phase [10, 11]. Mortality rates for individuals with schizophrenia are at least twice those for the general population, with the leading cases of death being suicide and other accidents.

The World Health Organization [9] has identified schizophrenia as an important public health problem. Schizophrenia meets the four criteria that indicate a need for public health action: (i) frequent and widespread occurrence; (ii) results in severe disability and suffering; (iii) effective methods are available for dealing with the condition and (iv) the interventions are acceptable to patients, families and society.

There is growing evidence that early diagnosis and treatment of psychosis can improve the outcome of schizophrenia [12, 13]. The average DUP prior to appropriate treatment is generally 2 years.
The range in the published literature is between 1 and 3 years [14]. This treatment delay is a serious problem, especially because treatment effects seem to be best during the early phases of illness [2]. It is believed that the overt symptoms of psychosis and the accompanying functional disability that are present at the time of diagnosis emerge late in the neurodegenerative process [15]. The research to date indicates that DUP is both an independent predictor of and influencing factor in both short-term and long-term outcomes in first-episode psychosis [16].

Despite some unresolved methodological issues, there is an agreement that enough evidence exists to support the relationship between treatment delay in first-episode psychosis and poorer clinical outcome [17, 18]. The long DUP is a specific health-related problem that can lead to the significant functional disability and suffering due to chronic schizophrenia. It has been proposed that reducing treatment delays can assist with improving clinical outcome in first-episode psychosis [19–21].

**Behavioral factors**

Early intervention has been shown to be associated with more rapid and complete recovery [10, 11]. Consequently, there is a need to increase help-seeking behavior among those members of the general public who suspect that an early psychosis may be present or developing in someone they know.

Approaches, designed to reduce barriers to early diagnosis and appropriate treatment, have been found to reduce treatment delays in individuals referred to a first-episode psychosis treatment program. These approaches include having an open referral policy that accepts referrals, not only from the traditional medical sources (i.e. family physicians, community mental health workers, emergency departments and inpatient units) but also from the community sources, such as educational institutions, community youth workers, families and the individuals themselves [21].

Addington et al. [22] studied the help-seeking behavior of individuals with first-episode psychosis and determined the number of attempts it took before adequate help was received. Help-seeking concerns varied from more general symptoms to psychotic symptoms. Help-seeking attempts were found to begin in the early stages (prodromal phase) of the illness and to continue on into the florid psychotic phase. The majority (85%) reported concerning behaviors both in the period prior to the onset of the psychosis and during the period of untreated psychosis. Both prodromal and psychotic symptoms are being noticed early in the course of the illness. Despite having concerns, more than half of the individuals did not make any attempt to seek help prior to the onset of psychotic symptoms. Even when symptoms developed, concerns usually escalated to an emergency level before help was sought. The investigators concluded that both improved public education and improved gatekeeper education may be helpful in reducing the time required for individuals developing a psychosis to receive timely access to diagnosis and treatment.

Larsen et al. [23] conducted a comprehensive review of the early intervention in psychosis literature and an assessment of early interventions at the prodromal phase (primary prevention) and those that focus on shortening the DUP (secondary prevention), and concluded that the reduction of DUP appeared to be ‘the most promising strategy’ to the prevention of the significant functional disability and suffering due to chronic schizophrenia.

The Early Detection and Treatment of Psychosis (TIPS) project, which consists of early psychosis treatment programs in Rogaland County and Oslo County in Norway, and in Roskilde County in Denmark, conducted a social marketing study to determine if it is possible to increase a population’s help-seeking behavior in the early phases of psychiatric disorders. Using an historical cohort control design, the study compared the impact of an extensive marketing of the TIPS project on Rogaland County’s population’s help-seeking behavior compared with Oslo County and Roskilde County which did not have any marketing activities. In this project, the investigators combined three simultaneous strategies to change the DUP. These included public education, gatekeeper education and an active outreach assessment team. The TIPS project was successful in modifying help-seeking behavior.
resulting in a reduction in the mean DUP from 1.5 to 0.5 years [24].

Wilson [25] suggested that application of the PRECEDE model to the prevention and early diagnosis of mental illness offers a great deal of potential for successful public mental health education. It is proposed that a focus on the most changeable behaviors related to mental health and comprehensive assessment of the factors contributing to these behaviors could provide a basis for the reduction of significant human and economic burden of chronic mental illness.

It was concluded that one of the most significant modifiable behavioral factors impacting DUP in Calgary is help-seeking in individuals experiencing symptoms of early psychosis, their close friends and their immediate family members [1].

**Educational factors**

These phases of PRECEDE involve the identification, sorting and classification of the ‘predisposing, enabling and reinforcing factors’ that affect the health-related behaviors [4]. According to the model, there is a natural hierarchical order in the sequencing of the modifiable factors that influence help-seeking behaviors. Predisposing factors must be changed before enabling factors and enabling factors need to be addressed before reinforcing factors. That is, individuals may not expend much effort in seeking help for psychotic symptoms if they are unaware of the existence of early psychosis as a mental health problem, the need for early diagnosis and treatment and the existence of an early psychosis treatment program in Calgary. If they are unaware of psychosis, and the need for early diagnosis and treatment, they will have little motivation or commitment to the goal of that behavior. Experiences with the gatekeepers education programs in Calgary indicate that there is a significant lack of awareness among those professionals. Thus, it was assumed that the general public would be at a lower or similar level of awareness, with respect to early psychosis as a mental health problem, the need for early diagnosis and treatment and where to go for help, than health professionals.

**Predisposing factors**

According to Green et al. [4], predisposing factors are the individuals’ or populations’ knowledge, attitudes, beliefs, values and perceptions that facilitate or inhibit health behaviors.

**Knowledge**

Knowledge alone does not necessarily lead to behavioral change in the general population [4–6, 26, 27]. In patients with schizophrenia and their family members, educational initiatives have had some short-lived effects [28]. However, some authors speculate that educational interventions received earlier in the course of the psychotic illness could positively influence motivation for help seeking in patients [29, 30] and increase vigilance behaviors in their family members [31]. It may be that delays in help-seeking behaviors are to some degree associated with a lack of community knowledge about psychosis and the services available to them [32]. Therefore, heightened community awareness may be a significant first step in helping to identify an emerging psychosis so that the time to treatment initiation is reduced.

In addition, patients may not have the ability to recognize their own psychotic symptoms. In the World Health Organization’s 1973 International Pilot Study of Schizophrenia, 97% of patients with recent onset psychosis lacked insight into their illness [33], as did between 60 and 89% of schizophrenia patients in other trials [34, 35]. Although *post hoc* awareness is common after initiation of pharmacological therapy [34, 36], the disorganized thoughts and alterations in perceptions and feelings can make it difficult for patients to relate their experiences in the very early stages [37, 38]. Once perceptual impairment becomes firmly established, patients may not be aware of their psychotic symptoms or, if they are aware, may not believe that their symptoms are related to an illness of any kind [39, 40]. As such, an uninformed public or families may hold individuals accountable for their illnesses or expect them to take responsibility for their own help seeking when they might be unable to do so [38].
Prior to the inception of this project, it was not known to what extent members of the Calgary community were aware of the resources that are available to them should they, or someone they know, develop symptoms of psychosis. Further, it was not known to whom either youth or their parents would first look to for help or information.

**Attitudes, values and beliefs**

Attitudes and fallacious beliefs regarding psychosis contribute to stigma toward both individuals and families suffering from mental illness. It is hypothesized that such stigmatization may contribute to significant delays in seeking treatment [41, 42] and profound feelings of confusion, anger, isolation and shame [39, 41]. When particularly strong cultural/community-specific stigma is associated with acquiring a psychiatric label, families may deny or normalize symptoms [43] and patients fearing rejection by others may provide non-psychiatric reasons for their illness when hospitalized [44, 45]. As such, the understanding of beliefs and values held by members of our community must be identified since help-seeking behaviors and medical treatment may be influenced and even delayed by individual, family, social and cultural perceptions and beliefs specific to a population [4–6].

**Perceived needs and abilities**

In the case of psychosis, treatment seeking is influenced by a combination of factors relating to sociodemographics, disorder, personality, family and health services [46]. Often behavior displayed by youth and young adults can be labeled as ‘bad’ when it is really something much more serious. Bad behavior is not always what it seems [47]. Parents may not perceive the need that their child has for diagnosis and treatment of psychosis if they do not have adequate knowledge to recognize that their child is experiencing a mental illness. Parents may not associate some early symptoms of psychosis with the disorder (i.e. inability to function at school or work, development of poor hygiene and grooming habits), or they may attribute the child’s difficulty at school to other problems. Creating public awareness of these early symptoms will help parents identify the need for early diagnosis and may facilitate help seeking.

**Enabling factors**

Since enabling factors are the requisite skills and resources required to perform a health behavior [4–6], it was important to establish which factors represented barriers to help seeking for symptoms of psychosis. The pilot of the Early Psychosis Treatment Service, youth worker education program, indicated that there was a significant lack of awareness about early psychosis, its signs and symptoms and the need for early diagnosis and treatment among community youth workers, school nurses, teachers and counselors.

**Reinforcing factors**

Reinforcing factors are those consequences of action that determine whether the action is supported positively or negatively [4–6]. Whether or not the reinforcement of the action is positive or negative depends on the attitudes and behavior of significant people in the individual’s life. Social stigma can be a negative reinforcing factor when one has been labeled with a psychiatric illness. Family members in particular perceive stigma as a major problem and siblings may be negatively impacted as family attention becomes focused on the sibling who has been diagnosed [48, 49]. Although many patients receiving the newer atypical medications experience minimal side effects, patients often become non-compliant about taking their medication [49]. Some patients may be hesitant to take their medication on an ongoing basis as they find it difficult to accept that they have a chronic mental illness. This may be related to the stigma of being labeled with a mental illness, which acts as a negative reinforcing factor for help-seeking behavior.

**Administrative diagnosis**

Approaches, designed to reduce barriers to early diagnosis and appropriate treatment, have been
found to reduce treatment delays in individuals referred to a first-episode psychosis treatment service [21]. These approaches include having an open referral policy that accepts referrals, not only from the traditional medical sources (i.e., family physicians, community mental health workers, emergency departments and inpatient units) but also from the community sources, such as educational institutions, community youth workers, families and the individuals themselves [21, 22].

Figure 1 summarizes the factors associated with help-seeking behavior in early psychosis. The goal of the Early Psychosis Public Education Program is to decrease the current DUP by 50% (from the current 1–2 years to 12–6 months or less) by conducting a public education campaign. The objectives of this education intervention are to increase awareness of psychosis, increase recognition of the need for early diagnosis, increase public awareness of the availability of the Early Psychosis Treatment Service in Calgary and provide information about where and how to obtain help if an early psychosis was thought to be developing. Changes will be measured in the target population’s awareness of (i) the symptoms of early psychosis, (ii) the need for early intervention for someone with signs of early psychosis and (iii) how to get help for someone with the signs of early psychosis.

The long-term goal of the Early Psychosis Public Education Program is assisting in improving clinical outcome in first-episode psychosis and reducing the significant functional disability and suffering due to chronic schizophrenia. Expected outcomes of the project include that (i) the average time between the onset of psychosis and the time of treatment (DUP) for patients admitted to the Calgary Early Psychosis Treatment Service will decrease by 50% from 1 year to 6 months, (ii) Calgary youth and parents will demonstrate an improved awareness of symptoms of psychosis compared with baseline awareness of psychosis, (iii) the need for early diagnosis, increase public awareness of the availability of the Early Psychosis Treatment Service.
(i.e. prior to the educational intervention) and (iii) Calgary patients with psychosis will have fewer hospital days before accessing appropriate treatment compared with before the early psychosis public education program.

Although a previous survey of knowledge, attitudes and beliefs regarding schizophrenia was completed in Calgary 4 years previously as part of the World Psychiatric Association’s Global Campaign to Fight Stigma and Discrimination Because of Schizophrenia [42], several potentially influential factors have taken place. First, there have been several highly publicized murder trials of mothers suffering from long-term post-partum depression with psychotic features. Second, the release of the motion picture ‘A Beautiful Mind’, about the struggles and successes of living with schizophrenia. In light of these events and the fact that the previous survey was focused on the stigma related to schizophrenia and not early psychosis, it was believed prudent to re-establish a baseline determination of the knowledge, attitudes and beliefs regarding schizophrenia-related psychosis within the Calgary region’s population. Thus, the project will begin with a baseline survey to assess the knowledge, attitudes and beliefs about psychosis; information needs and preferences and current help-seeking strategies. The results of this survey will function as a formative evaluation [6], prior to the creative conceptual development of the public education campaign.

**Conclusion**

A public education program cannot be based upon what we, as professionals, decide the public does or does not know about a specific issue. Planning, key to any successful public education project, must include a thorough literature review and the adoption of a conceptual framework that will systematically guide the process. The PRECEDE component of the PRECEDE–PROCEED model provided an excellent conceptual framework for the development of an Early Psychosis Public Education Program targeting youth and young adults (ages 15–30 years) and their parents in the Calgary community. This model provided defined stages that could be systematically utilized in program planning, development and evaluation. The goal of the early psychosis public education program is to reduce the DUP in referrals to the early psychosis treatment service by at least 50% by increasing public awareness of psychosis as a medical condition, the symptoms and the importance of early diagnosis and treatment. The target of the proposed public education program was defined as high school and post-secondary students and their families within the Calgary Health Region. The objectives of this program include increasing help-seeking behavior and creating awareness that there is an Early Psychosis Treatment Service in Calgary.

A great amount of information has been provided to patients and their families in both the Early Psychosis Treatment Service and via the gatekeeper education program. The knowledge gained during the development of the Early Psychosis Public Education Program can inform mental health professionals about best practices for provision of information to patients and their families in clinical practice.

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**Conflict of interest statement**

None declared.

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