A Community Outreach and Education Model for Early Identification of Mental Illness in Young People

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Abstract: *Objective*: The Portland [Maine] Identification and Early Referral (PIER) program was established in 2000 as a prevention system for identifying and treating adolescents and young adults at high risk of an initial psychotic episode. Community outreach and education to targeted groups was the primary method for identification.

Methods: Community outreach and education is defined as any activity designed to inform key audiences about the importance of and methods for early detection and intervention of psychosis in adolescents and young adults. PIER program staff presented information on the early warning signs of psychosis and how to make a referral to target audiences within a young person's social network.

Results: Community outreach resulted in the referral of 780 youths who met demographic criteria, yielding 404 cases that were deemed sufficiently at risk to be eligible for formal assessment. After screening and assessment by PIER staff, 37% of community referrals were found to be at high risk for psychosis, and another 20% had untreated psychosis, yielding a correct-referral efficiency ratio of 57%. In addition, community educational presentations were significantly associated with referrals six months later.

Conclusions: In its efforts to create a system of early identifiers for young people at the beginning stages of mental illness, the PIER program has developed a new model for community health education that has shown that it is possible to engage community members in the identification of adolescents and young adults who are experiencing the early symptoms of a psychotic disorder.

Keywords: Clinical high-risk, community education, community outreach, early intervention, family intervention, indicated prevention, public health, prodromal psychosis, psychosis, schizophrenia.

Mental disorders affect over 44 million Americans annually. The estimated prevalence rate of mental illness is 26.2% for adults (U.S. Department of Heath and Human Services [DHHS], 1999; Kessler, Chiu, Demler, & Walters, 2005). Over two-thirds of those with a mental disorder also experience some form of disability, which impacts their ability to work and perform the daily tasks of living (Kennedy *et al.*, 1997). In addition to the human costs, mental disorders exact a large financial toll. The national costs for schizophrenia alone amount to an estimated $62 billion (Wu, *et al.*, 2005). Mental disorders also affect children. In the United States, one in ten children and adolescents suffer from mental illness severe enough to cause some level of impairment (Shaffer, *et al.*, 1996; Burns, *et al.*, 1995). Approximately 2.9 million children (5.3%) receive treatment other than or in addition to medication for emotional and behavioral difficulties (Simpson, Cohen, Pastor, & Reuben, 2008).

There are several categories for mental disorders, including anxiety, mood, impulse control, substance abuse, and psychotic disorders (American Psychiatric Association, 1994). Within psychotic disorders, specific diagnoses include schizophrenia, bipolar disorder, and major depression. A psychotic disorder typically emerges gradually over months or years. Initial signs and symptoms prior to the beginning of active psychosis often include social withdrawal, loss of interest in pleasurable activities, unusual or uncharacteristic behavior, or decline in social, occupational or academic functioning (DHHS, 1999). Over the past twenty years, research has indicated that there is a pre-psychotic (prodromal) phase for those who develop a psychotic disorder (Falloon, 1992; McGlashan, 1996; Klosterkötter J, *et al*, 2001; Hafner, *et al*, 2004). Improved identification of signs and symptoms characterizing this phase affords new opportunity for earlier intervention and the possibility of significantly improving the longer-term outcome of those at risk (Kutash, Duchnowski, & Lynn, 2006).

BACKGROUND

The Portland Identification and Early Referral (PIER) program, located at the Maine Medical Center in Portland, Maine, is a treatment research program with these goals: (a) identifying and treating early adolescents and young adults at risk for a psychotic episode in order to offset the development of a severe mental illness, specifically schizophrenia, bipolar disorder or major depression; and (b)

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reducing the incidence of major psychotic disorders by early detection and treatment. Between May 2001 and December 2009, the PIER program has provided treatment, support, and guidance to over 200 young people between ages 12 and 25 and their families who live in the Greater Portland, Maine area.

Using a combination of community outreach and education and clinical interventions, the PIER program: 1) Educates the community, particularly school professionals, mental health clinicians and primary care physicians who are likely to encounter young people in the early stages of psychosis; 2) identifies and equips those groups to identify young people who are displaying early signs of psychosis; 3) evaluates an individual's risk for actual psychosis; 4) engages individuals and their families in the treatment process and equips them with the skills to provide the support that research shows is necessary for secondary prevention; 5) treats those who are at substantial risk of psychosis with psychosocial and psychopharmacological interventions with demonstrated efficacy for psychotic disorders; and 6) establishes collaborative networks with other professionals to provide on-going educational, occupational, psychosocial and pharmacological support toward the attainment of appropriate health, educational, vocational, and social developmental milestones.

In 2006, the Robert Wood Johnson Foundation (RWJF) recognized the potential of the PIER program to be a national model for early intervention of severe mental illness. In response, RWJF created the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP), a six-site replication study of the PIER Program. EDIPPP seeks to reproduce the PIER program's clinical and community outreach components in six cities across the United States, including: (a) Albuquerque, New Mexico; (b) Glen Oaks, New York; (c) Portland, Maine; (d) Sacramento, California; (e) Salem, Oregon; and (f) Ypsilanti, Michigan. Because community outreach is a critical component of the PIER program's model, PIER provided extensive training and supervision in the PIER program's community outreach and education model and methods to all EDIPPP sites. Sites were given regular technical assistance and monitoring to assure fidelity to the model.

The purpose of this article is to describe the development, implementation and methods of the community outreach and education component of the PIER program. A companion article provides background, rationale, description and community identification results of the clinical and assessment components (McFarlane *et al.*, 2010).

COMMUNITY OUTREACH FOR MENTAL HEALTH INTERVENTIONS

Historically, the focus of psychiatric and behavioral health services has been on treatment interventions rather than secondary prevention (Kutash *et al.*, 2006). Early identification and treatment of severe mental illness, specifically psychotic disorders such as schizophrenia, bipolar disorder, and major depression, is a relatively young endeavor for American mental health research and services (McGlashan, 1996). The success of early identification depends on the accurate recognition of the earliest warning signs in a young person by someone in that person's community network. For young people between 12 and 25, that network primarily includes educational professionals, healthcare providers, friends, family members, and mental health clinicians.

Initial efforts at general and targeted community outreach and education for the purpose of early referral to psychiatric services were initiated outside of the United States (Falloon, 1992; Edwards, Francey, McGorry, & Jackson, 1994; Krstey *et al.*, 2004; Joa *et al.*, 2008). English, Australian, Danish and Norwegian initiatives identified stakeholders outside of the mental health system who could provide committed participation in the early detection effort. Stakeholders were recognized as people in a unique position, by virtue of their occupation, family relationship or ongoing friendship, to identify young people demonstrating the early mental changes suggestive of a developing psychosis. Published studies now demonstrate that community members and healthcare professionals can effectively identify and refer those who are manifesting the early warning signs of a psychotic disorder.

In the United States, there have been no similar efforts to implement and investigate the effectiveness of both broad public awareness and targeted community education and outreach for mental health early intervention. Community education and outreach are traditional public health approaches (Thomas, Crouse Quinn, Billingsley, & Caldwell, 1994; Luepker *et al.*, 1994; The World Health Organization, 2004), yet there are no published data on their use or outcomes for the prevention or early intervention of major mental illness in the United States.

THE COMMUNITY OUTREACH AND EDUCATION MODEL

The PIER program defines community outreach and education as any activity designed to inform key audiences about the importance of and methods for early detection and intervention of psychosis in adolescents and young adults. The goals of community outreach and education are: (a) To increase knowledge of early warning signs for psychotic disorders; (b) to increase appropriate referrals of youth at risk; (c) to create and support a system of professionals and community members trained in the identification of young people in the beginning stages of developing a severe mental illness; and (d) to decrease barriers to early identification, including stigma.

When the PIER program was established, there were no American examples to use as a model for its community outreach for mental health services. Early intervention in the United States was associated with services for children under five (Pinto-Martin *et al.*, 2004; U.S. Department of Education, 2002). The PIER program's community outreach and education methods were developed using ideas and strategies from several sources, including public health education, communications, school-based early identification, and the lessons learned by international

researchers (Falloon, 1992; Edwards, *et al.*, 1994; Krstey *et al.*, 2004; Joa *et al.*, 2008).

The PIER program outreach model can be conceptually described using constructs from two prominent behavioral theories: Theory of Planned Behavior (Ajzen, 1985) and Social cognitive theory (Bandura, 1986). The theory of planned behavior states that individual *intentions* to engage in goal-directed behavior (e.g., making a referral) are predicted by the individual's attitude toward the activity (e.g., positive vs. negative), subjective norms (i.e., whether the individual experiences social pressure to engage in the activity), and behavior control (i.e., whether or not there are physical, contextual or psychological barriers to the individual's performance of the behavior). Behavior control is conceptually related to Bandura's (1977) notion of self-efficacy; a component in Social cognitive theory. The effect of attitudes, subjective norms, and behavior control on *actual performance of the behavior* is mediated (at least partially) by intention and perceived likelihood of efficacy. The PIER program outreach model targets the knowledge, attitudes and behaviors of those who are in a position to identify young people showing the early warning signs of psychosis.

Social cognitive theory maintains that it is possible to facilitate individual behavior change by modifying an individual's personal and environmental factors to encourage healthful behavior (Maibach and Cotton, 1995). Fig. (**1**) demonstrates the application of social cognitive theory to the PIER program's community outreach and education. The PIER program outreach model seeks to modify environmental factors by making it easy to contact the PIER program. The program also focuses on modifying personal factors, by increasing knowledge about the program and promoting the referrer's beliefs that the referral will be efficacious and beneficial to the young person and possibly the referrer. In addressing both the environmental and personal factors, the theory predicts an increased probability of receiving an appropriate referral to the program.

When the PIER program was created in 2000, staff recognized the need to introduce community organizations to its non-traditional approach of early intervention and disease prevention, and contrast it with traditional treatment of an established mental illness. The next task was to teach those who worked with or cared for young people about the early warning signs of a psychotic disorder, as well as the process for, and benefits of, making a referral to the PIER program. Through frequent and targeted community outreach and education, the PIER program established a network of early referrers, consisting primarily of education and healthcare professionals who had been trained by the PIER program.

PIER PROGRAM COMMUNITY OUTREACH AND EDUCATION AUDIENCES AND STAFFING

Before the PIER program began its community outreach and education, it convened a steering council, comprised of community members representing various disciplines and interests. Members included educational professionals (teachers, nurses, social workers, administrators, college health and mental health service providers), primary care and pediatric physicians, community mental health professionals, governmental representatives, parents, and elected officials. The purpose of the steering council was to advise the PIER program on the development of outreach messages and materials, and to help identify, prioritize, and engage key audiences. The steering council was also crucial in connecting PIER program staff with gatekeepers for identified audiences.

In addition, the steering council and PIER program staff conducted a community asset mapping process (Kretzmann and McKnight, 1993; Fiscus and Flora, 2001). Through this process, PIER and the steering council were able to identify resources and existing relationships, both of which are critical to the success of the community outreach and education. As a result of this process, staff identified the following key audiences: Middle and high school staff; college and university health and mental health services staff; healthcare professionals; mental health professionals; social and human service providers; youth-oriented community agencies; law enforcement and judicial agencies; multi-cultural groups and their elders; and parents and youth.

Many health and social service programs designate a single staff member to conduct community outreach and education. However, because this component is central to the PIER program's methods, *all* PIER program clinical staff members participate in outreach and communication. With this design, the PIER program's community outreach and education efforts maximize a community's exposure to the clinical staff members who ultimately provide the consultation and treatment services, which is expected to increase the likelihood of appropriate referrals.

Once the key audiences were identified, PIER program staff contacted organizations to offer free professional education sessions. Interest in the PIER program varied widely; some organizations immediately scheduled presentations, while others responded only after several calls over many months. Once connections were made, PIER program staff gave a presentation to the organization's staff about the program mission and rationale, modern concepts of mental illness, the early warning signs of psychosis, and the referral process. PIER program staff distributed educational materials, such as bookmarks, booklets and handouts, to participants.

To facilitate balance of clinical responsibilities and community outreach and education, PIER staff developed a multi-staged approach. The first stage included the identification of primary and secondary audiences. The second stage was to establish priorities among those audiences in order to maximize the number of community members exposed to the community outreach and education messages, beginning with those most likely to observe the early warning signs in young people, such as high school social workers. In addition, different staff members provided leadership for different audiences, usually based on professional discipline. For instance, the PIER social worker met with school professionals while the team physician met with healthcare professionals. PIER program staff found that returning annually or biannually to schools, colleges, universities, and medical practices provided the opportunity to train new staff, as well as to provide a "booster" course

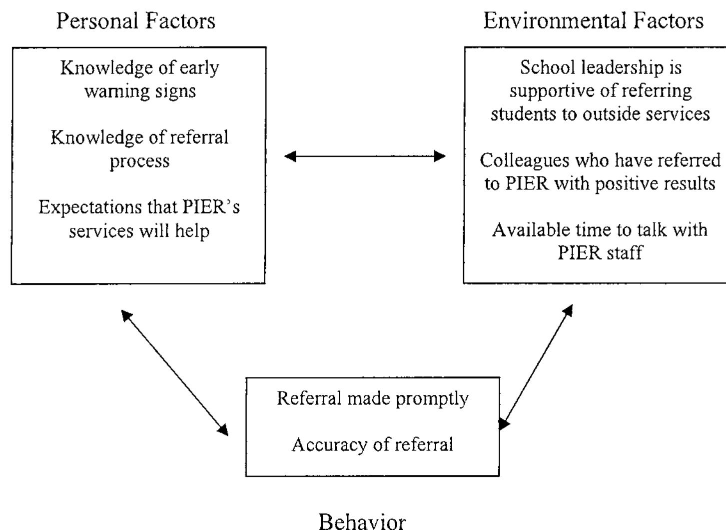

Fig. (1). Application of the Social Cognitive Theory to Early Identification and Referrals of Young People at Risk for Severe Mental Illness.

for existing personnel that included case studies and research updates.

PIER PROGRAM COMMUNITY OUTREACH AND EDUCATION METHODS

The PIER program staff developed standard community outreach and education presentations tailored to specific audiences, such as school nurses and pediatricians. Each presentation included the following key elements: 1) Modern concepts of psychotic disorders; 2) early stages of mental illness; 3) early warning signs of psychosis; and 4) instructions on how to make a referral.

The presentation also reinforced that while early identification of developmental and behavioral issues is often common practice within school settings, early identification of mental health issues in adolescence is often impeded by cultural norms or expectations. (Harrison, 2005; President's Commission on Excellence in Special Education, 2002).

The PIER program also initiated activities to increase general public awareness of the program. These included movie theater advertisements, an art contest for area high school students, sponsorship of the local minor league baseball team, and participation in community health events. A website[1], which was graphically designed to appeal to adolescents and young adults, was developed and promoted at all community outreach and education events. Visitors to the website could anonymously learn about mental illness and the early warning signs, download all of the PIER program's educational handouts, and watch several PIER program videos.

Results of the outreach and education program have been promising (McFarlane, *et al.*, 2010). To summarize, the community outreach resulted in referral of 780 youths who met demographic criteria, yielding 404 cases that were deemed sufficiently at risk to be eligible for formal assessment. After screening by PIER clinicians and rigorous assessment by research interviewers, 37% of those community referrals were found to be at high risk for psychosis, and another 20% had untreated psychosis, yielding a correct-referral efficiency ratio of 57%. In addition, community educational presentations were significantly associated with referrals six months later. Perhaps the most telling result was that half of the referrals, as intended, were from outside the mental health system, and at least half of them were deemed accurate. Referrals from mental health and other, non-mental-health professionals were equally accurate. In the end, 75% of the screened referrals were found to already have, or be at risk for, a major psychiatric disorder, and most were treated earlier than would be expected in most American communities. The approach is limited by its inability to identify young adults who develop early signs and symptoms and are not observed by any of the community outreach key audiences. Through EDIPPP, the ability of other communities to replicate the model and results described here will be tested, with initial results expected in 2012.

SUMMARY

By adapting traditional psychological theories and employing public health methods, such as asset mapping and stakeholder engagement, the PIER program has demonstrated that the principles of community health education can successfully be applied to a mental health initiative. Additionally, the PIER program has shown that it is possible to engage community members in the identification of adolescents and young adults who are experiencing the early symptoms of a psychotic disorder.

IMPLICATIONS FOR PRACTITIONERS

Many public health initiatives, including tobacco prevention (Curry *et al.*, 2007; Curry, Sporer, Pugach, Campbell, & Emery, 2007; Green *et al.*, 2007), safe sexual practices (Coyle, Kirby, Marin, Gomez, & Gregorich, 2004), and alcohol prevention (Perry *et al.*, 1996), target

[1] The website, www.preventmentalillness.org, continues to be available to the public, even though the PIER program is not currently taking referrals or providing clinical treatment.

adolescents directly, seeking to influence their knowledge, attitudes and practices. The PIER program, however, sought to change the behavior of school and healthcare professionals, as well as adolescents themselves, community members and parents, in order to prevent mental illness. Using existing connections and having a solid understanding of its community resources, the PIER program had remarkable success in gaining access to those who interface with adolescents and young adults, particularly school professionals. In its efforts to create a system of early identifiers for young people at the beginning stages of mental illness, the PIER program has developed a new model for community health education that, in contrast to traditional mental health education, strengthens capacity for proactive engagement of key stakeholders in youth mental health. With the help of personal and professional connections, a compelling message, available resources, and a skilled and dedicated staff, the PIER program has demonstrated that community members can accurately identify young people in the beginning phases of psychotic disorders and successfully refer them to specialized assessment and care.

DISCLOSURES

Dr. McFarlane is the Director, and Ms Downing is a faculty member, of the PIER Training Institute, LLC, which provides on-request training and consulting services for evidence-based practices and early psychosis programs.

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ABBREVIATIONS

EDIPPP = Early Detection and Intervention for the Prevention of Psychosis Program

DHHS = U.S. Department of Heath and Human Services

PIER = Portland Identification and Early Referral

RWJF = Robert Wood Johnson Foundation

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