CHAPTER VIII

EARLY PSYCHOSIS AND TRANSITION AGE YOUTH

“The soul would have no rainbow if the eyes had no tears.”

— MINQUASS TRIBE
CHAPTER VII

EARLY PSYCHOSIS AND TRANSITION AGE YOUTH

Psychosis is a particularly relevant topic for Transition Age Youth (TAY), given that the typical onset of schizophrenia is between the ages of 16 and 25.\(^1\) The incidence of schizophrenia increases for individuals ages 15-18, during the already-challenging transition to adulthood and between child and adult mental health services, when many youth “fall through the cracks.”\(^2\) Furthermore, as discussed in Chapter II of this manual, adult services are not always accessible or appealing to young people and this is especially true of TAY who are vulnerable when experiencing a first psychotic episode.

Though the incidence of schizophrenia and other psychotic disorders is low compared to incidence of mood or anxiety disorders, with approximately 1% of individuals affected,\(^3\) it is perhaps one of the most disabling mental conditions and therefore warrants considerable attention. Psychotic disorders severely inhibit social, educational, and community functioning. Individuals with long-term psychosis are more likely to be involved with the criminal justice system, have difficulty finding and maintaining employment, and receive public assistance.\(^4\) In addition to these other outcomes, it is particularly distressing that the lifetime risk of suicide is high for individuals with psychotic disorders, with close to one in ten completing a suicide, and up to 50% attempting it.\(^5\) The risk of suicide is greater for individuals who experience stigma associated with mental illness, those who use substances, and youth.\(^6\) The rate is especially high for individuals experiencing a first break; one study found that over 15% of participants in an early psychosis program attempted suicide before beginning treatment.\(^7\)

Given the risks associated with psychotic disorders, it makes sense to allocate significant resources towards programs that will minimize its impact on individuals and their families, particularly in the early stages of the illness when adverse consequences may be avoided. However, clinical, ethical, and administrative barriers complicate treatment of first-episode psychosis.\(^8\) This chapter discusses the controversies around early intervention; reviews access to care, assessment, and first-episode treatment guidelines, highlights an early intervention program for TAY, and provides a listing of web resources for further information.

CONTROVERSIES AROUND EARLY INTERVENTION

\(^5\) Siris.
\(^6\) Siris.
A lively debate is taking place in the research literature around the costs and benefits of early intervention in psychosis. The arguments for and against early intervention are summarized in Figure 1.

Further complicating the early intervention debate is research on the effects of Duration of Untreated Psychosis (DUP). DUP is of particular interest to clinicians and researchers because it is one of the few areas in which mental health practice and policy can have a direct impact on client outcomes. Some researchers argue that untreated psychosis is neurotoxic, meaning that the chemicals released during a psychotic episode have a permanent damaging effect on the brain. However, little evidence has been found to support this theory. Longer DUP does appear to be associated with lower rates of remission as well as an increase in positive symptoms of psychosis and decreased social functioning, suggesting that unnecessarily long DUP should be avoided.

Though it is important for mental health administrators and clinicians to be aware of these controversies and to attend to current research, the reality is that TAY experiencing first-episode psychosis must have access to developmentally appropriate mental health services. A rich clinical literature attests that TAY has unique service needs that warrant specialized treatment. A young person with a psychotic disorder may not see herself as having much in common with a 50-year-old client who has been in the system for many years, and is likely to feel uncomfortable in a treatment setting where many of the consumers are older adults with chronic mental illnesses.

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10 McGorry, & Yung.
12 Shaw, & Singh.
16 Clark, & Davis (Eds.).
### FIGURE 1
**ARGUMENTS FOR AND AGAINST EARLY INTERVENTION IN PSYCHOSIS**

<table>
<thead>
<tr>
<th>For</th>
<th>Against</th>
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<tr>
<td>Mobilizes and maintains family and social supports, which is especially important as many TAY, regardless of whether or not they have a mental illness, have fragile emerging support networks(^{17, 18})</td>
<td>Limitations in assessment inhibit accurate diagnosis in the early stages of the illness and it is inappropriate and unethical to provide antipsychotic treatments to individuals who do not have a psychotic disorder(^{19})</td>
</tr>
<tr>
<td>Reduces length &amp; severity of psychotic episodes and lowers rates of hospitalization(^{20})</td>
<td>The effectiveness of early intervention is inconclusive. Early intervention appears to have a positive impact within the first year of treatment, but gains are lost within 5 years(^{21})</td>
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<tr>
<td>Decreases suicidality(^{22, 23})</td>
<td>Continuity and quality of care and medication compliance for individuals with long-term, severe mental illness have a greater effect on outcomes than early intervention(^{24})</td>
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<tr>
<td>Prevents disruption in achievement of educational and vocational goals(^{25, 26})</td>
<td>If limited resources are allocated disproportionately to a specialized early intervention teams, people with documented, long-term illnesses may receive inadequate treatment(^{27})</td>
</tr>
<tr>
<td>Lowers rates of substance abuse(^{28, 29})</td>
<td>Short-term, specialized programs for early intervention cause discontinuity in treatment because clients will eventually transfer to a program for adults with chronic mental illnesses(^{30})</td>
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<td>Supports retention of social skills(^{31})</td>
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<td>May speed recovery from first break(^{32})</td>
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<td>If offered during prodromal phases, may inhibit psychosis(^{33})</td>
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<td>Establishes a pattern of treatment compliance that will contribute to later adherence to treatment and better long-term outcomes(^{34})</td>
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</table>

\(^{17}\) McGorry, & Yung.  
\(^{19}\) Pelosi, & Birchwood.  
\(^{20}\) Tee, Ehmann, & MacEwan.  
\(^{22}\) Addington, Williams, Young, & Addington. Suicidal behavior in early psychosis.  
\(^{23}\) McGorry, & Yung.  
\(^{24}\) Linszen, Dingemans, & Lenior.  
\(^{25}\) McGorry, & Yung.  
\(^{26}\) Tee, Ehmann, & MacEwan.  
\(^{27}\) Pelosi, & Birchwood.  
\(^{28}\) Tee, Ehmann, & MacEwan.  
\(^{29}\) McGorry, & Yung.  
\(^{30}\) Pelosi, & Birchwood.  
\(^{31}\) Tee, Ehmann, & MacEwan.  
\(^{32}\) McGorry, & Yung.  
\(^{33}\) McGorry, & Yung.  
ACCESS TO CARE, ASSESSMENT, AND TREATMENT OF FIRST EPSODE PSYCHOSIS IN TAY

Access to care is critical in providing services to TAY experiencing a first psychotic episode. Some of the symptoms of psychosis, such as social withdrawal and suspicion of strangers, inhibit help-seeking. These symptoms are compounded by many adolescents’ desire for autonomy and belief in their invulnerability, further hindering intervention. Finally, many young people and their families fear the stigma associated with mental illness, particularly psychosis. Three suggestions for overcoming these barriers to treatment are:

1. Community education to increase awareness of psychosis and to decrease stigma (see Web resources section for examples)
2. Clinician education to encourage accurate diagnosis and timely referral to appropriate services
3. Sensitivity to the needs of young people and families during what for most is a frightening and distressing experience

It can also be helpful to remind families that though researchers are still studying the causes of psychotic disorders, it is clear that genetics and biology contribute to the development of psychotic disorders. Many early theories of psychosis overemphasized the role of families in causing the disorder, thus contributing to the stigma.

Careful assessment of first-episode psychosis is essential as it informs the course of treatment. To ensure a correct diagnosis, it may be necessary to delay administration of antipsychotic medication for up to 48 hours to rule out substance-induced psychosis or other co-morbid conditions. In addition to the general clinical assessments used for clients presenting with any symptoms of mental illness, the following areas are useful in an evaluation of first-episode psychosis:

- Length and progression of prodromal and psychotic periods
- Substance use
- Personality, strengths, and coping skills of the individual with psychosis, and his or her response to the symptoms (i.e. for some individuals, hallucinations and delusions are not experienced as unpleasant)
- Circumstances of referral and cultural background
- The family system and its resources

Given the potential for harm to self or others in first episode psychosis, risk assessments for suicidality, grave disability, violence to others, potential for victimization by others, treatment non-compliance, and flight risk are also necessary. An evaluation by a psychiatrist should also be completed as soon as possible.

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41 Power, & McGorry. In.
42 Power, & McGorry. In.
Before discussing treatment guidelines, a few myths about early psychosis must be addressed:

**Myth 1:** First-episode psychosis is always an indicator of long-term disability. Studies show that up to 85% of consumers presenting with first-episode psychosis recover with appropriate treatment, and many exhibit no psychotic symptoms in follow-up assessments.

**Myth 2:** Hospitalization is required. Depending on the personality of the consumer, his or her home environment, and the community supports available, a first-episode psychosis can be treated on an outpatient basis.

**Myth 3:** Individuals with psychosis lack insight. Research suggests that consumers with first-episode psychosis can be involved in treatment planning and are often aware of their state.

Debunking these myths suggests that while first-episode psychosis is cause for concern, it is not necessarily cause for alarm. Clinicians working with TAY experiencing a first psychotic episode and their families should follow the system of care principles guiding the rest of their work:

- Include the consumer and his or her family as much as possible in treatment planning.
- Be sensitive to the consumer’s cultural background and beliefs about mental illness.
- Provide treatment in the least restrictive environment possible. Collaboration with the consumer is particularly important given the developmental and symptom-related issues described above (e.g. need for autonomy, suspicion of strangers).

In the past, psychodynamic interventions were favored in the treatment of psychosis. More recently, medication combined with Cognitive-Behavioral Therapy (CBT) is the treatment of choice. In the early stages, CBT is useful in helping consumers understand their illness and the treatment options. Later, once a relationship has been developed, CBT may be helpful in challenging the positive symptoms. Though CBT appears beneficial as an early intervention, the evidence on long-term outcomes is less encouraging.

In addition to CBT, psycho-education for the consumer and his or her family related to the illness, stress management, and problem-solving is helpful. Family interventions have been found to be especially helpful when consumers are recovering from an acute psychotic episode that resulted in hospitalization; during this vulnerable transition stage, family therapy helps to stabilize the consumer, prevent relapse, and increase treatment compliance.

**EXAMPLE OF AN EARLY PSYCHOSIS INTERVENTION PROGRAM FOR YOUNG ADULTS**

Established in 1992, the Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne, Australia is a unique 18-month program exclusively for young people between the

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46 Kulkarni, J., & Power, P. In.

ages of 15-24 who are experiencing first-episode psychosis. Each consumer is assigned a case manager and doctor who individually tailor a program of individual, family, and group interventions to the consumer’s needs. A major component of the program is its partial day treatment, offered Monday through Friday. Several 10-week groups are offered throughout the day, and consumers attend groups based on their interests and their treatment teams’ recommendations. The program is organized into five “streams”: social recreational, vocational, creative expression, health promotion, and personal skills development. Additional programs are offered as needed based on the current participant pool.

In a naturalistic study (i.e. not a randomized controlled trial) of EPPIC day program participants compared to EPPIC participants not involved in the day program, researchers found that though the day participants had a lower pre-morbid level of functioning as compared to non-day program participants, at the six-month follow up, the two groups did not differ significantly along any measure. In interpreting these results, it is important to remember that a study using a quasi-experimental (non-random) design cannot control for pre-existing differences in the treatment and comparison groups that could influence the outcomes, and therefore the results must be viewed cautiously. However, the EPPIC day program shows promise in its potential to alleviate some signs and symptoms of psychosis.

In addition to the day program, EPPIC also provides community education about early psychosis prevention and intervention and runs a small (16 bed) inpatient facility.

EPPIC was implemented as a resource-rich program, but has also demonstrated that it is cost-effective when compared to other public mental health services. In a study of direct costs over twelve months, EPPIC was less expensive than traditional mental health services for psychosis. The authors of the study caution that these results are preliminary and that further research is needed, but the EPPIC model appears promising in light of the clinical and cost-effectiveness data.

WEB RESOURCES

Described above, EPPIC is a program based in Australia focusing on treatment of early psychosis in young adults.

**International Early Psychosis Association**
Promotes research and discussion of issues related to early psychosis.

**Open the Doors**
[http://www.openthedoors.com/english/01_00.html](http://www.openthedoors.com/english/01_00.html)
This organization is launching a global program to fight stigmatization of individuals with severe and chronic mental illnesses.

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50 Francey, In.

**Peer Support for Parents of Psychosis Sufferers**  
Though the organization is based in Canada, this website includes information by and for parents of individuals with a psychotic disorder that would be useful to families anywhere.

**Prevention and Early Intervention Program for Early Psychoses (PEPP)**  
[http://www.pepp.ca/index.html](http://www.pepp.ca/index.html)  
Canada-based program for early psychosis treatment that emphasizes a case management model. From their website, you can download manuals on screening, assessment, and treatment.

**Reaching People Early**  
[http://www.rethink.org/reachingpeopleearly/](http://www.rethink.org/reachingpeopleearly/)  
A project of the England-based Rethink program, a nonprofit organization providing public education and research on severe mental illnesses. Reaching people early focuses on early intervention for a wide range of mental illnesses, including schizophrenia. Their 9-page report, which discusses treatment options during 8 stages of mental illness, from the first signs to recovery, is available at [http://www.rethink.org/reachingpeopleearly/pdfs/Reaching People Report3.pdf](http://www.rethink.org/reachingpeopleearly/pdfs/Reaching People Report3.pdf)

**The Teenage Brain: Culture and Schizophrenia**  
Fascinating website for PBS program on the brain discusses development of schizophrenia in teens across cultures. You can also view a video showing how dopamine works in the brain: [http://www.pbs.org/wnet/brain/episode3/video.html](http://www.pbs.org/wnet/brain/episode3/video.html)