Evidence Summary

Coordinated Specialty Care for First-Episode Psychosis

What is First-Episode Psychosis?

The term first-episode psychosis (FEP) refers to the population of individuals between the ages of 16 and 35 who are experiencing their first active or acute psychotic episode. Psychotic symptoms associated with this grouping fit within the schizophrenia spectrum, including schizophrenia, schizotypal (personality) disorder, and other psychotic disorders. It is estimated that 100,000 adolescents and young adults in the United States between the ages of 15 and 25 will experience FEP each year (McGrath, Saha, Chant, & Welham, 2008). In a sample of Australian FEP patients, aged 15 to 29 years old, incidence was highest for males aged 20 to 24 and females aged 15 to 19 (Amminger et al., 2006).

Psychotic symptoms include changes in thinking, mood, and behavior. The pattern and intensity of symptoms can vary among individuals and change over time. Characteristic symptoms during the active psychotic phase include combinations of the following:

- **Confused thinking**, in which the person may have trouble making sense, have difficulty concentrating, attending, remembering, and following conversations. Thinking and speech may be disorganized, confused, pressured, or slowed.
- **False beliefs (delusions)**, in which a person’s unyielding conviction of a reality seems implausible and unrealistic to others. Delusional people may believe that agencies such as the FBI, CIA, or KGB are spying on them, or inserting alien thoughts, impulses, sensations, or feelings via microwaves, TV, radio, or newspapers. Delusional beliefs may also involve a sense of grandeur and special mission, purpose, and identity.
- **Perceptual disturbances (hallucinations)**, in which individuals report experiences of sounds or voices, images, strange tastes, or smells experienced that are not actually present. These altered sensory experiences often are associated with beliefs that the individual is being poisoned, conspired against, or has special powers.
- **Changed feelings**, including mood swings, periods of unusual excitement, withdrawal, lack of energy, anger, anxiety, dampened emotions, and feelings of being detached and cut off from others and the world.
- **Changes in behavior**, including uncharacteristic changes in previous patterns of interests, involvements, and activities. The individual may become unpredictable, erratic, unstable, preoccupied, unusually active, or lethargic.
- **Marked deterioration** in overall functioning, in which individuals are often frightened and confused; struggle to make sense of what is happening to them; behave irrationally; have difficulties communicating, trusting, and relating; experience evidence-impaired insight and awareness of illness; often aggress against themselves or others; and come into conflict with authorities.

Individuals experiencing these symptoms can experience disrupted development in a broad range of life domains and developmental tasks. These include individuation from family of origin and increased risk for complications such as suicide, comorbid substance use, violence, and criminality (Nordentoft, Mortensen, & Pedersen, 2011).

**The Importance of Early Intervention**

Early intervention with FEP individuals is critical to prevent the harmful effects of psychotic disorders on cognitive and social functioning (Malla, Norman, & Joober, 2005). Studies of first-episode cohorts have demonstrated an association between longer duration of untreated psychosis (DUP) and poorer outcomes across several domains, including severity of psychotic symptoms, negative symptoms, social functioning, and reduced likelihood of symptom remission (Hegelstad et al., 2012; Marshall et al., 2005). Longer duration of untreated psychosis is associated with poorer response to antipsychotic medication treatment (Marshall et al., 2005) and more pronounced structural brain abnormalities (Keshavan & Amirsadri, 2007). The first years after initial onset of psychotic symptoms represent a critical period over which to change the long-term course and outcome of psychotic disorders (Birchwood, Todd, & Jackson, 1998). Empirically based pharmacologic and psychological treatments have been demonstrated to be effective in improving outcomes and decreasing harmful long-term effects during this critical “window of opportunity” (American Psychiatric Association Working Group on Schizophrenia, 2004; National Institute for Health and Clinical Excellence, 2003; Birchwood et al., 1998).

**Disengagement from First-Episode Treatment**

One consistent challenge for treating FEP is the high rate of disengagement from treatment. A review of 10 articles describing clinical predictors of client disengagement from coordinated specialty care (CSC) programs indicated that approximately 30 percent of participants disengage from services (Doyle, Turner, & Fanning, 2014). Variables consistently reported to influence disengagement from services were duration of untreated psychosis, symptom severity at baseline, insight, substance use and dependence, and involvement of a family member. Clients
who enter a CSC program without family involvement and support as well as those who maintain persistent substance use are at highest risk of disengagement.

Disengagement as a result of persistent substance use is common among individuals suffering from FEP—in part because substance use is common among this population with about 37 percent of FEP participants meeting criteria for comorbid substance use (Addington & Addington, 2001). Higher relapse rates for FEP clients with comorbid substance use have also been reported (Malla et al., 2008). It is apparent that the addition of early identification of individuals with comorbid substance use and substance use treatment efforts in CSC programs are necessary to reduce risk of service disengagement and improve outcome (Doyle et al., 2014).

**Coordinated Specialty Care Programs**

Coordinated specialty care (CSC) is one model for treating FEP. Under this model, a team of specialists work with clients to develop a treatment plan based on shared decision making (National Institute of Mental Health, 2014). The plan can include a mix of services, including psychotherapy, medication management geared to individuals with FEP, family education and support, case management, and work or education support. CSC programs for FEP patients have been implemented successfully in countries around the world, including the United Kingdom, Australia, Canada (Srihari et al., 2015), Scandinavia (Petersen, Jeppesen, & Thorup, 2005), France (Oppetit et al., 2016), Greece (Kollias et al., 2016), Norway (Grawe, Falloon, Widen, & Skogvol, 2006) and the United States. (Srihari et al., 2015). CSC programs improve symptoms and restore levels of adaptive functioning in a manner superior to standard care efforts (Bird et al., 2010; Srihari et al., 2015).

In response to the high rates of disengagement by FEP patients with comorbid substance use disorders, Addington and Addington (2001) added a Stopping Substances Group in their early-psychosis specialized treatment program, employing a variety of strategies to attain the following goals: 1) educate participants about the effects of drugs and alcohol; 2) develop commitment to reduce or abstain from substance use; 3) develop awareness of barriers to achieving goals; and 4) learn and develop strategies to reduce or abstain from substance use. The authors have developed a manual to guide therapists and a workbook for participants, which is available on request. Other FEP early intervention programs have also included substance use treatment as a component and reported significant declines in substance use (Nordentoft et al., 2014).

**Evidence of Effectiveness**

A series of rigorous, randomized controlled trials have provided promising evidence that CSC programs can benefit individuals experiencing FEP.

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Representative Early Studies of Coordinated Specialty Care Programs

Early studies of CSC programs provide evidence of the effectiveness of this model in addressing FEP. The first, a randomized controlled trial (RCT), assessed the impact of the Lambeth Early Onset intervention program on 144 residents in England; participants had a median age of 25 and met screening criteria for first- or second-episode psychosis (Craig et al., 2004). The second RCT, the Danish OPUS study, included 547 community clinic patients aged 18 to 45 years who had a diagnosis within the schizophrenia spectrum and prior exposure to antipsychotic medication for less than 12 weeks continuous (Petersen et al., 2005).

Results of the Lambeth study indicated that at 18 months, patients in the CSC program were more likely than standard treatment patients to maintain contact with psychiatric services, to have fewer readmissions to hospitals, better medication adherence, and social and vocational functioning (Craig et al., 2004). The Danish OPUS study results indicated that the CSC group was more likely to have remained in treatment, was more satisfied with care, had significantly lower levels of psychotic (hallucinations, delusions, thought disorder) and negative symptoms, and fewer secondary problems such as substance use and burden on the family (Thorup et al., 2005) than standard treatment participants. A 5-year follow up of the OPUS participants indicated that more CSC participants were living independently as opposed to living in an institution (Bertelsen et al., 2008). Health economic analyses indicated that OPUS treatment was more effective than standard care at 2 years, and was cheaper and resulted in better outcomes in terms of ratings of overall functioning on the Global Assessment of Functioning (GAF) scale at 5-year follow up (Hastrup et al., 2013). A 10-year follow up indicated reduced severity of negative symptoms and psychiatric bed days in favor of OPUS treatment (Secher et al., 2015). The OPUS research team suggested that research is needed on the potential benefits of lengthening the duration of intervention from 2 to 5 years (Wils et al., 2016).

Recent Studies of Randomized Control Studies of Coordinated Specialty Care Programs

Two more recent studies also provided evidence that CSC programs can improve outcomes for individuals experiencing FEP. The first study was designed to assess the impact of the specially designed Specialized Treatment in Early Psychosis (STEP) program for individuals with FEP. The STEP treatments included assertive community care, family education and therapy, social skills training, cognitive therapy, supported employment and education, and individualized medication management. This RCT included 120 participants between the ages of 16 and 45 within 5 years of onset of psychosis who had not received more than 12 weeks of treatment with...
antipsychotic medications in their lifetime (Srihari et al., 2015). Results at 1-year follow up indicated that STEP participants had less inpatient utilization, compared with those in usual treatment (77% versus 56%, respectively), evidenced more improved vocational outcomes, were more likely to remain in contact with outpatient mental health services, evidenced greater improvement in ratings of symptoms and GAF ratings of overall functioning, and showed more improvement in measures of community functioning, compared with usual care patients. The STEP project also demonstrated the feasibility of implementing CSC programs in community mental health centers (Srihari et al., 2015).

In 2008, NIMH launched a second effort, the Recovery After an Initial Schizophrenia Episode (RAISE). The RAISE program was designed to develop, implement, and evaluate team-based multi-element treatment programs for first-episode psychosis (FEP) in community clinics (Azrin, Goldstein & Heinssen, 2016). This RCT included 404 individuals to assess the impact of the NAVIGATE experimental treatment program (Mueser et al., 2015), which included the core interventions of resilience-focused psychotherapy, family education and support, supported education and employment services, and personalized medication management. The 2-year outcome data for the RAISE–ETP program indicated that the 223 recipients of the RAISE treatment program remained in treatment longer (did not drop out), evidenced greater improvement in quality of life and symptoms of psychopathology, and evidenced higher levels of involvement in work and school, compared with participants in standard community care (Kane et al., 2016). Participants with shorter duration of untreated psychosis of (<74 weeks) evidenced greater improvement in quality of life and psychopathology, compared with those with a longer duration of untreated psychosis (> 75 weeks) and those assigned to standard community care (Kane et al., 2016).

A third NIMH-sponsored study, the RAISE Connection Program, was designed to develop, deliver, and evaluate the feasibility of delivering CSC programs in publicly funded mental health clinics. Participants included 65 individuals, aged 15 to 35 (mean age of 22) who met criteria for a diagnosis of schizophrenia, schizoaffective disorder, delusional disorder, or psychosis not otherwise specified. Results indicated that participants in the RAISE Connection Program evidenced significant reductions in clinical symptoms, improved social and occupational functioning, and increased rates of school and work participation at follow up (Dixon et al., 2015).

**Sources for CSC Program Training Materials**
The RAISE Connection Program produced an array of user-friendly materials to facilitate dissemination of CSC programs in community settings interested in delivering coordinated specialty care for early psychosis. These materials are publicly available from the NIMH website (https://www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml) and include

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CSC program-planning and decision-support tools, training and implementation manuals, and resources for supervising staff and monitoring treatment fidelity. Additional program materials include videos; manuals on outreach and recruitment, supported employment and education, psychopharmacology, performance quality, and treatment fidelity; costs and staffing estimates; and interactive early-psychosis program-planning tools. In addition, a Danish handbook about OPUS treatment, which can serve as a manual for staff members, is also publicly available (Nordentoft et al., 2014).

**Funding and Training Resources**

From 2014 through 2016, the U.S. Congress allocated funds for evidence-based programs that address the needs of individuals with early serious mental illness. These funds, administered by the Substance Abuse and Mental Health Services Administration (SAMHSA) through the Community Mental Health Services Block Grant program, were allocated to subsidize FEP services not covered by insurance, including assertive outreach, care coordination, and supported employment and education. Since 2014, 32 states have announced plans to initiate or expand early treatment programs for FEP by combining SAMHSA funds with services reimbursed by public or private insurance and, in some cases, with increased state funding. This represents a 16-fold increase since the beginning of the RAISE initiative (Kane et al., 2016). In 2015, the Centers for Medicare and Medicaid Services (CMS) indicated support of Medicaid coverage for CSC in its Joint Informational Bulletin to State Medicaid Directors (Centers for Medicare and Medicaid Services, 2015), jointly issued by CMS, NIMH, and SAMHSA, which described mechanisms for funding and expanding programs (Azrin, Goldstein & Heinssen, 2016). NIMH has been attempting to build on the rapid expansion of the CSC programs in clinics across the country to establish an Early Psychosis Intervention Network (EPINET); this is designed to integrate and use the data collected during routine care for scientific inquiry and to foster a progressive healthcare environment. It is anticipated that EPINET will accelerate research and foster establishment of new standards for early-psychosis care by fostering practice-based research collaboration among clinicians, academic researchers, and CSC service users (Azrin et al., 2016).

**Conclusion**

Comprehensive specialized care (CSC) programs for first-episode psychosis (FEP) have been demonstrated to be effective in improving both clinical and functional recovery outcomes for participants. Analyses indicate that CSC programs are superior to standard care in terms of reducing risk of relapse, reducing risk of suicide, decreasing need for hospitalization, improving prospects for recovery, decreasing family disruption and distress, and reducing disruptions to work and education (Azrin et al., 2016; Hastrup et al., 2013). CSC programs for FEP may provide useful conceptual models for translational treatment research programs for other serious mental

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disorders. Ongoing evaluation and monitoring of CSC programs are critical to assure quality of services and integrity of program implementation. To this end, NIMH has developed and made publicly available comprehensive guidelines and staff training manuals to facilitate expansion and development of CSC-based programs in community clinics.

References


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