

Improving the Response for Young People with Psychosis

JESSICA M. POLLARD, PhD

At first, Brandon* agreed to meet with an outreach worker to talk about outpatient treatment just because he wanted to get out of the psychiatric hospital. The 20-year-old had gone through a frightening ordeal being picked up by the police and brought to the emergency department. He couldn't recall a lot of what had happened, but he remembered believing people were out to get him and hearing voices warning him about strangers on the street.

A STEP outreach worker told Brandon about how the team at Specialized Treatment Early in Psychosis would support him in getting a job, returning to school, feeling less paranoid, and how they would work with him and his family to better understand what was going on and how to manage it. Brandon was encouraged by this conversation and agreed to give the program a try; later that day, a therapist from STEP came by to introduce herself, set up his first appointment and talk about what some of his goals for treatment might be. Brandon learned that he'd be working with a multidisciplinary team to develop an individual, recovery-oriented plan. Based on his needs, it could involve employment and school support, education for him and his family on psychosis and how to manage it, skill building, medication prescribed at minimum effective dosing, and lots of support — a model known in the United States as Coordinated Specialty Care.

Unfortunately, many transitional age youth — those in the phase from older adolescence through young adulthood — enter treatment for serious mental illness the way Brandon did: in the back

of a police car or ambulance. Typically, there are numerous opportunities when young people and their families can ask for help before that point, but few are familiar with the early warning signs of psychosis and other mental illnesses. Psychosis is a brain-based and environmentally influenced

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condition that can occur in the context of many mental disorders (for example, schizophrenia, major depression, bipolar disorder) and physical health disorders (including temporal lobe epilepsy, HIV, Parkinson disease). For a diagnosis of a psychotic disorder, one or more “positive” symptoms or the adding on of experiences that weren't present prior to onset must be present. Positive symptoms include hallucinations (having false perceptions; seeing, hearing, smelling, tasting or feeling things that aren't there), delusions (false

*Identifying details have been changed to protect confidentiality.



beliefs outside of the person’s culture that they continue to hold onto even when there is evidence to the contrary, often bizarre, paranoid, somatic or grandiose), and disorganization (jumbled up or confused thinking and speech). Primary psychotic disorders (for example, schizophrenia) often also include negative symptoms or the taking away of things that the person had prior to onset, and cognitive symptoms or thinking difficulties. Negative symptoms include decreased emotional expression, social interaction, motivation, energy and initiation. Cognitive symptoms can look very similar to attention deficit/hyperactivity disorder and include difficulty with attention, organization, planning, procedural and verbal learning, memory and abstract ability. A great screening question to elicit information about potential warning signs that a transition age youth might not bring up out of embarrassment is “Do you ever feel like your mind is playing tricks on you?” Early warning signs represent changes for the transition age youth and vary by individual but there are a lot of common signs to look for. (See box for early warning signs of psychosis.)

Even when there is recognition that something is wrong, patients and families face a fragmented health care system and experience real uncertainty about where to turn for appropriate treatment. Young people with onset of mental illness may be misdiagnosed, may have to wait weeks or months for an appointment while they are experiencing terrifying symptoms and functional decline, or may hear discouraging messages that they are doomed to a life in and out of hospitals or institutions or that they’ll be permanently disabled. Conversely, early on, when the transition age youth is experiencing milder symptoms and function has not yet been tremendously impaired, health care providers may not catch important

warning signs, or they may provide false assurances and further delay appropriate treatment.

In our work at STEP, we have seen that there are numerous help-seeking events along the way before transitional age youth actually receive the medications and specialty care they need. This is frustrating not only for patients and their families, but it can have an enormous negative consequence on the prognosis. Extensive research has demonstrated that the Duration of Untreated Psychosis, or DUP — the time it takes from onset of symptoms to an appropriate connection to treatment — is one of the strongest predictors of short- and

long-term outcomes; the longer this duration, the worse the symptoms and functioning of the individual. What is particularly tragic about these poor outcomes is that many people — such as school personnel, friends and family, clergy, youth organization staff, law enforcement and health care providers — had contact with the young person and either failed to recognize warning signs or didn’t know what actions to take if they did see them. Lack of knowledge about early signs of serious mental illness, even among medical professionals, is a huge detriment to young people at risk, most of whom will have seen a primary care provider or pediatrician at some point during the unfolding of illness.

There are many potential reasons for these lost opportunities. Stigma continues to be a pervasive problem: we don’t often talk about mental illness and, when we do, it’s usually in negative and stereotyped or outdated ways. Historically, we have not done well at treating serious mental illnesses such as schizophrenia; disability was common, and many in psychiatry used circular reasoning when someone with a psychotic disorder did recover or do well, concluding they must have been misdiagnosed and not actually had psycho-

EARLY WARNING SIGNS OF PSYCHOSIS

- Change in sleep pattern
- Decreased concentration
- Appetite disruption
- Decreased energy
- Mild perceptual abnormalities
- Overly abstract or rigid thinking
- Increased preoccupation
- Increased focus on unusual beliefs
- Abrupt mood swings or diminished affect
- Decline in hygiene
- Increased irritability
- Digressive, tangential speech
- Social withdrawal
- Loosening of associations

sis. Health care providers in general continue to get little to no education regarding serious mental illnesses, the warning signs and the importance of early intervention in these mental illnesses. What we see of disorders like schizophrenia in popular culture is sensationalized and perpetuates stereotypes of mentally ill individuals as violent, homeless, poorly functioning or disabled. In reality, people with psychotic disorders are much more likely to be victims of violence than perpetrators of it. They account for a very small percentage of violent crime, and many live and work successfully in the community. Stigma and lack of knowledge make it less likely that the families and friends around people with early warning signs of mental illness will facilitate access to care. These factors also discourage young people from seeking help out of shame and embarrassment, and the realistic concern that they may be treated poorly or discriminated against.

Why is this such an important problem to address? As the former director of the National Institute of Mental Health, Thomas R. Insel, MD,

put it, “Mental disorders are chronic diseases of young people”¹ and yet we pay them relatively little attention. While 1 in 5 young people experiences a mental disorder, our public mental health systems are geared toward older adults. Pediatric providers often are not trained in recognizing or treating serious mental illness. Schizophrenia remains the top cause of disability worldwide and an enormous health care cost — \$60 billion annually in the U.S.² People with schizophrenia die much younger, including from preventable causes such as cardiovascular disease, diabetes and cancer.³ Psychotic disorders are much more common than most people realize: 1 to 3 out of every 100 persons will experience psychosis in their lifetime. Each year 100,000 young people in the U.S. will develop psychosis. The early stage of psychotic disorders is the period of highest risk compared to other phases of illness. The numbers are daunting — the mortality rate in the first year after onset of the disease is 24 times higher than peers who don’t have psychosis.⁴ The time period also represents the greatest risk of violence

STRATEGIES FOR ENGAGING YOUNG PEOPLE WITH PSYCHOSIS INTO CARE

■ Listen first!

- Hear them out, use their language.
- Validate the experience, don’t get focused on the content.
- For example, “That sounds really frightening.”
- Ask permission before offering your perspective.

■ Attend to non-verbal cues.

- If transitional age youth appear uncomfortable, guarded or agitated, back off for a bit. Switch to a more enjoyable or neutral topic.
- Work your way back to what you need to ask but switch back as often as necessary.

■ Be mindful of your own nonverbal cues.

- Try to convey you are comfortable.
- Remain poised in response to bizarre or concerning content.

■ Normalize the experiences.

- For example, “It’s really common for young people to struggle with ...”

■ Convey optimism.

- Communicate that most people get back to their lives with support and treatment.
- Emphasize the importance of early intervention and provide analogies for early intervention with any other health problem.

■ Never take a “wait and see” approach if you see warning signs! Remember, one of the most effective strategies in improving outcomes is reducing Duration of Untreated Psychosis.

■ Refer to the nearest Coordinated Specialty Care Program for assessment and treatment.

■ Check the National Association of State Mental Health Program Directors’ Early Psychosis Resource Center listing of treatment programs to find the nearest Coordinated Specialty Care (CSC) program. If there aren’t any CSC programs nearby, there are many effective strategies that can be applied by any mental health provider willing to learn more.



toward self and others. Most of the functional decline takes place in the first few years of onset, and the longer it takes to get proper treatment, the less chance there is of recovery of functioning.

Despite these dire statistics, there is plenty of reason for optimism. Over the past few decades there has been a growing international movement, with supporting research, for early intervention and emphasis on youth mental health. The first studies in Europe and Australia demonstrated that comprehensive early intervention could dramatically improve the course of illness for young people with psychosis rather than later treatment.⁵ In Norway, a multifaceted early detection outreach and education campaign was able to bring Duration of Untreated Psychosis down to a matter of a few weeks, and independent living outcomes for patients whose condition was identified and treated early remained significantly better than those from the usual detection region over a decade later.⁶

In the U.S., as a partnership between Yale University and the Connecticut Department of Mental Health and Addiction Services, the STEP Program opened in 2006 and conducted the first randomized clinical trial of early intervention in this country.⁷ Using existing frontline staff to ensure our findings would be easily replicable, we found that one year after entering treatment over 90% of patients in STEP were vocationally engaged, they were significantly less likely to be hospitalized and spent fewer nights in the hospital when they were admitted, and experienced greater symptom improvement compared to those in usual treatment. The National Institute of Mental Health then funded a large-scale clinical trial called RAISE (Recovery After Initial Schizophrenia Episode)⁸ comparing specialized early intervention (also known as Coordinated Specialty Care) to usual treatment in sites across the country and similarly found better outcomes. Thanks in part to federal investment, such as block grants, we've gone from a handful of programs in the early 2000s over 240 Coordinated Specialty Care programs in 2019. We also have demonstrated that early detection is possible in the U.S. where there is not a streamlined single payer system as there is in Norway.

STEP ran an early detection campaign over the past four years, educating not only mental health professionals on the early warning signs of psychosis and the importance of early intervention, but also the general public, schools, colleges, universities, law enforcement, youth organizations, clergy and primary care. Despite the fragmentation of the health care system, we were able to sig-

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nificantly reduce Duration of Untreated Psychosis for patients in STEP compared to a control site in Boston.

The takeaway message from the evidence presented is that all of us who come into contact with young people in transition from childhood to adulthood, whether professionally or personally, can play a role in early detection, facilitate connection to effective care and dramatically improve trajectories. As we said in our campaign “early detection saves minds.”

Just as important as recognizing early warning signs in youth is acting on them productively. The goal is to instill the young person and their family with optimism that this is a treatable problem and to impress upon them that early treatment works. Often people with psychosis lack self-awareness that they have symptoms — this is called anosognosia — and may believe their experiences are real; it's counterproductive to get into a power struggle and much more effective to focus on the person's goals as reasons to get treatment or support. For example, in STEP we often engage people around work, school or relationship goals, and we tie treatment to helping with those aspects of functioning rather than focusing on symptoms. (See the sidebar for more guidance on facilitating access to care when you see early warning signs.)

So, what happened to Brandon? He worked with the multidisciplinary STEP team for a few years; finding the lowest effective dose of medication with his STEP psychiatrist, meeting with the employment specialist to find a job and get support around adjusting to work, getting education about psychosis and developing coping strategies with his therapist, and joining his family for sessions on communication skills and problem solving. Brandon started spending time with friends again and eventually went off to college, connecting with mental health treatment there with the support of the STEP team. Successes like Brandon's are the norm in programs like STEP and, with the help of the public, and more specifically those who work in health care whether at the provider or system level, they can become the norm for young people across the country in the early stages of serious mental illness.

JESSICA M. POLLARD is a licensed clinical psychologist, clinical director of early psychosis and an assistant professor in the Yale University Department of Psychiatry in New Haven, Conn. She is the program chair and chair-elect of the mental health section of the American Public Health Association.

NOTES

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