First Episode Psychosis

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Objectives

• Summarize the evidence based research for first episode psychosis

• Identify the components for the evidence based treatment model for first episode psychosis

• Recognize the principles of person centered care and shared decision making

• Summarize the referral process and access to first episode psychosis programs
First Episode Psychosis Research

- NIMH White Paper
- RAISE Study
- Navigate Study
- NAMI
- OnTrack NY Program
- Recent relevant articles
2014: President Obama signed the “Consolidated Appropriations Act”
   – Funds to SAMHSA to support the development of early psychosis treatment

Majority of individuals with serious mental illness
   – experience the first signs during adolescence or early adulthood
   – long delays between symptom onset and the receipt of evidence-based interventions

FEP programs in Australia, Canada, and the UK represent viable treatment models:
   – improving symptoms
   – reducing relapse episodes
   – preventing deterioration and disability among individuals suffering from psychotic illness
About **100,000 adolescents and young adults** in the US experience FEP each year

- **Peak onset 15-25 years of age**
  - Can derail a young person’s **social, academic, and vocational development**
  - Can initiate a trajectory of **accumulating disability**

- Youth are often **frightened and confused** and struggle to understand what is happening to them
• **Unique challenges** to family members and clinical providers, may include:
  – Irrational behavior
  – Aggression against self or others,
  – Difficulties communicating and relating
  – Conflicts with authority figures

• Impaired **awareness** of illness may be an additional complicating factor

• Research studies conclude that **early intervention** services for psychosis can **improve symptoms and restore adaptive functioning** in a manner superior to standard care
  • Offers **real hope** for clinical and functional recovery
In 2009, NIMH launched the **Recovery After an Initial Schizophrenia Episode (RAISE)** research initiative

- Established **Coordinated Specialty Care** programs for FEP
- Results suggest that seeking treatment early will improve life overall and help the young person achieve their life goals
- **The sooner care is sought, the sooner a person will feel better**
  - Longer **duration of untreated psychosis (DUP)** is associated with poorer outcomes
  - **Average DUP is 74 weeks!**
Clinical research conducted world-wide supports:

- Low doses of atypical antipsychotic medications
- Cognitive and behavioral psychotherapy
- Family education and support
- Educational and vocational rehabilitation

These evidence-based components often come together in specialized early intervention programs that emphasize

- Prompt detection of psychosis
- Acute care during or following periods of crisis
- Recovery-oriented services offered over a 2-3 year period following psychosis onset
Coordinated Specialty Care (CSC)
- Assertive case management
- Individual or group psychotherapy
- Supported employment and education services
- Family education and support
- Low doses of select antipsychotic agents

Youth
- Bridge existing gaps between child, adolescent, and adult programs
- Collaborative, recovery-oriented approach with person and their supports
- Shared decision making as a means for addressing the unique needs, preferences, and recovery goals
- Collaborative treatment planning is a respectful and effective means for positive therapeutic alliance and maintaining engagement
- Highly coordinated with primary medical care
• Greater improvement in symptoms
• Stayed in treatment longer
• More likely to stay in school and work
• More likely to stay socially connected than those who received only basic mental health care

• The faster into program, better the outcomes

• “Secret Sauce” – help with education and jobs

• Young adults want the same opportunities their peers have and they will stay in treatment if it helps them meet their LIFE GOALS
RAISE OUTCOMES

- Congress recognized benefits and required “set asides” 10% of MHBG – helps with training and limited program costs, but not enough to meet the need for care

- California, New York, Ohio, Oregon, Virginia supplementing with state dollars

- Challenge is expanding and funding so that every young person experiencing FEP can have access to effective care

- Providing this care should be a priority for communities to ensure that a serious condition gets a serious response
• Significant advantages in symptom ratings, participation in school or work and quality of life.

• The effects are especially pronounced for patients whose illness had lasted less than 74 weeks prior to first treatment.

• The finding that NAVIGATE was especially important for patients who received treatment early in their illness underscores the need for interventions that are tailored to new patients, to keep them from developing chronic illness.

• The National Alliance on Mental Illness (NAMI) used this program and study findings in support of a major campaign to promote broader adoption of coordinated specialty care.
“Clearly, the take-home message here is that outcomes for young people with early psychosis are better when clinicians do the right things at the right time,” said Robert Heinssen, Ph.D., director of the Division of Services and Intervention Research at NIMH.

“We’re seeing more states adopt coordinated specialty care programs for first episode psychosis, offering hope to thousands of clients and family members who deserve the best care that science can deliver.”
Higher Death Rate Among Youth with First Episode Psychosis

• **Mortality rate at least 24 times greater** than the same age group in the general population, in the 12 months after the initial psychosis diagnosis

• “These findings show the importance of tracking mortality in individuals with mental illness,” said Schoenbaum. “Health systems do this in other areas of medicine, such as cancer and cardiology, but not for mental illness. Of course, we also need to learn how these young people are losing their lives.”

• Surprisingly low rates of medical oversight and only modest involvement with psychosocial treatment providers

• “In the meantime, this study is a wake-up call telling us that young people experiencing psychosis need intensive, integrated clinical and psychosocial supports.”
A Call To Arms

• Young person diagnosed with cancer:
  – **Serious illness and serious response from health care providers**
  – Recognize the need to act quickly
  – Family receives assistance and comprehensive care
  – Now a healthy teen

• Psychosis should be treated similar, but currently:
  - **Serious, but rarely gets a serious response**
  - Don’t get care until very sick and hospitalized
  - Follow up care is simply a prescription and a recommendation to find a psychiatrist
  - Families get little to no information
  - Results are predictably poor
A Call To Arms

• Doesn’t have to be that way, research shows that we have comprehensive effective care, we must get this care to everyone

• Acting quickly is essential to secure successful future

• In US, average delay of 74 weeks for FEP treatment versus 2-4 weeks in Europe

• Young adults, families, school personnel, and PCPS don’t immediately recognize warning signs
What is Early and First-Episode Psychosis?

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Psychosis temporarily interferes with the brain’s ability to make out reality and causes

Know the Signs
These warning signs may signal early psychosis:

- Hearing, seeing, tasting or believing things that others don’t
- Suspiciousness or extreme uneasiness with others
- Persistent, unusual thoughts or beliefs
- Strong and inappropriate emotions or no emotions at all
- Withdrawing from family or friends
- A sudden decline in self-care
- Trouble thinking clearly or concentrating
ONTRACK NY PROGRAM

Have you or has someone you know started withdrawing from family and friends?

Contact Us Today

To find a program near you, visit the Contact page.

For general program inquiries, email: ontrack@ny/opentrack.org

About OnTrackNY

OnTrackNY is an innovative treatment program for adolescents and young adults who have had unusual thoughts and behaviors, or who have started hearing or seeing things that others don’t. OnTrackNY helps people achieve their goals for school, work, and relationships. Programs are located throughout New York State.

OnTrackNY teams provide services to all referred individuals meeting clinical admission criteria, without wait lists and regardless of their insurance status or ability to pay.

Learn More

Voices of Recovery

These 24 brief video clips feature individuals telling their stories about who they are and what has been helpful in managing their psychotic disorder. You’ll meet people who are single, married, in school, working, hanging out with old and new friends, and living healthy lives.

*These Recovery Videos were created as part of the RAISE Connection Program with funding from the National Institute of Mental Health.

Ryan-Turning Points

Ryan-Fulfilling My Dream

Ryan-Finding Inspiration...

Corey-Tools For Getting Better
On Track New York
Voices of Recovery

- Ryan – Fulfilling My Dream
- https://vimeopro.com/user23094934/voices-of-recovery/video/85739637
PERSON CENTERED CARE

• Way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs.

• The Importance of Recognizing Patients' Health Problems as They See Them

• Use their words!

• Care is better when it recognizes what patients' problems are rather than what the diagnosis is.

• Communication skills are a fundamental component of the approach to care that is characterized by continuous healing relationships, shared understanding, emotional support, trust, patient enablement and activation, and informed choices.

• The literature is replete with evidence that communication patterns, both verbal and nonverbal, make a difference, as measured by whether patients are more knowledgeable, more willing to adhere to recommendations, or more “satisfied” with their care.
Shared Decision Making

- Central value shaping interactions between the clinician and individual
- Clinicians provide detailed explanations of risks and benefits of all appropriate, available medications, including side effects and serious medical risks
- Help person identify and articulate their concerns
- Provide educational materials for person and caregivers
- **Decisions made JOINTLY**
- Use a decision aid “Decision Balance Worksheet” to clarify values
- Pat Deegan Common Ground decision support software
What is Shared Decision-Making?

The best kind of informed consent process

A model of decision making in which a provider and individual receiving care move from initial preference to informed preferences through a process of supported deliberation

It acknowledges:
- 2 experts in the room

It can help to clarify an individual’s values and preferences for decision-making
Stages to Conversation

Choices talk

Options talk

Decision talk

Moving from initial preference to informed preferences through a process of supported deliberation

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### How To:

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<th>Choices talk</th>
<th>Options talk</th>
<th>Decision talk</th>
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<td>• Making sure that people know that reasonable options exist</td>
<td>• Provide more detailed information on options</td>
<td>• Considering preferences and deciding what’s best</td>
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Encourage participants to involve family members in the decision-making process

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