Early Onset Psychosis and the Importance of Treatment

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Disclosures

None
Acknowledgements

OnTrackNY Central Staff
OnTrackNY Teams
OnTrackNY Clients

Objectives

• To describe key challenges of the delivery of care for individuals with early psychosis: Before, During and After
• To describe the key components of clinical care delivery
New Federal Funding Accelerates Adoption of Evidence-Based Care for First Episode Psychosis

<table>
<thead>
<tr>
<th>Dates and Milestones</th>
<th>Cumulative Number of States with Early Psychosis Intervention Plans</th>
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<tbody>
<tr>
<td>July, 2009 RAISE studies begin</td>
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<tr>
<td>December, 2013 RAISE feasibility study completed</td>
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<tr>
<td>April, 2014 NIMH/SAMHSA provide guidance to states</td>
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<tr>
<td>December, 2014 H.R. 88 ($25M set-aside for FEP)</td>
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<tr>
<td>October, 2015 RAISE clinical trial completed</td>
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<tr>
<td>October, 2015 CMS coverage of FEP intervention services</td>
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<tr>
<td>December, 2015 H.R. 2029 ($50M set-aside for FEP)</td>
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Overall Challenges

Before
To understand the role of DUP in outcomes in schizophrenia
To identify bottlenecks in the pathway to care for individuals with FEP

During
To understand the components and outcomes of CSC
To identify important gaps in knowledge about FEP treatment

After
To understand what is known about follow up studies of FEP services
To identify the challenges for providing optimal follow up care

Center for Practice Innovations
New York State Psychiatric Institute
Building best practices with you.
Key Scientific Finding Driving FEP Care

- Longer duration of untreated psychosis (DUP) is associated with *poorer* short term and long term outcome
- DUP is the time between onset of psychosis and specified treatment (e.g., antipsychotics or CSC)

![Graph showing the relationship between DUP and quality of life](image)

**Shorter vs. Longer Duration of Untreated Psychosis (DUP) on Quality of Life (p<0.03)**
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Coordinated Specialty Care

Clinical Services
• Case management, Supported Employment/Education, Psychotherapy, Family Education and Support, Pharmacotherapy and Primary Care Coordination

Core Functions/Processes
• Team based approach, Specialized training, Community outreach, Client and family engagement, Mobile outreach and Crisis intervention services, shared decision making


NAVIGATE Participants Stayed in Treatment Longer
Time to Last Mental Health Visit
(Difference between treatments, p=0.009)
From: Comprehensive Versus Usual Community Care for First-Episode Psychosis: 2-Year Outcomes From the NIMH RAISE Early Treatment Program

Figure 1. One-year hospitalization and vocational engagement outcomes among STEP participants and those in usual treatment

- Hospitalized during 6 months before enrollment
- Hospitalized during 1 year after enrollment
- Vocationally engaged at enrollment
- Vocationally engaged 1 year after enrollment

STEP, Specialized Treatment Early in Psychosis. Between-groups comparisons: for hospitalization rates (adjusted for pretreatment hospitalization), omnibus $\chi^2=5.60$, df=1, $p=0.018$; for vocational engagement (adjusted for pretreatment vocational engagement), omnibus $\chi^2=9.56$, df=1, $p=0.002$.
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5-Year Follow Up of LEO Study

18-Month RCT comparing specialized early intervention service to usual care (N=144)
Rewduced admissions and percentage admitted in LEO experimental condition at 18 months
No differences observed in the 18 month-period preceding year 5 (N=99)

Secher et al. Schiz Bull 41 (3) 617-26 2015

10-Year Follow-up of OPUS Study

• RCT comparing 2 years of multi-element team based model to usual care (N=547)
• 10-year follow up recruited 347 (63%)
• Evidence of a differential 10-year course in the development of negative symptoms, psychiatric bed days, and possibly psychotic symptoms in favor of OPUS treatment, differences were driven by effects at earlier follow-ups and had diminished over time.

Secher et al. Schiz Bull 41 (3) 617-26 2015
Comparison of mean level of symptoms and functioning at entry into PEPP and at two and five year follow up

<table>
<thead>
<tr>
<th></th>
<th>Entry</th>
<th>2 Year</th>
<th>5 Year</th>
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<tr>
<td><strong>Mean (SD)</strong></td>
<td></td>
<td></td>
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<tr>
<td>SAPS Global</td>
<td>10.34(3.36)</td>
<td>2.23(2.77)</td>
<td>2.12(2.83)</td>
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<tr>
<td>SANS Global</td>
<td>11.73(6.44)</td>
<td>6.44(4.52)</td>
<td>5.71(4.22)</td>
</tr>
<tr>
<td>Psychotic Dimension</td>
<td>3.05(0.93)</td>
<td>0.94(1.20)</td>
<td>0.71(0.98)</td>
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<tr>
<td>Negative Dimension</td>
<td>2.59(1.02)</td>
<td>1.64(1.08)</td>
<td>1.41(1.05)</td>
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<tr>
<td>Disorganized Dimension</td>
<td>1.79(1.08)</td>
<td>0.44(0.65)</td>
<td>0.28(0.53)</td>
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<tr>
<td>GAF</td>
<td>22.08(17.10)</td>
<td>52.66(28.31)</td>
<td>60.85(16.61)</td>
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The Long List of Challenges

- Optimizing model—we are not there yet
- Developing and training workforce
- Solidifying financing model
- Developing more effective strategies to reduce DUP and reach community
- Considering how to sustain benefits
- Empowering the community to demand these services

Key Care Processes

- Person centered
- Recovery-oriented—strengths based, hopeful
- Shared decision making
- Cultural competence
Person-Centered Care

1. Client’s goals are important and the team is there to support these goals and preferences.
2. Client’s perspective about what is going on and what can be most helpful is understood and respected.
3. Team will work closely and collaboratively with the client.

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


How To:

**Choices talk**

- Making sure that people know that reasonable options exist

**Options talk**

- Provide more detailed information on options

**Decision talk**

- Considering preferences and deciding what’s best

Encourage participants to involve family members in the decision-making process
Roles/Staff

- Team Leader
- Primary Clinician/Therapist/Family
- Outreach & Recruitment Coordinator
- Supported Employment/Education Specialist (1.0 FTE)
- Nurse (0.2 FTE)
- Physician/NP (0.3 FTE)
- Peer (0.5 FTE)

Team Leader

- Provides or ensures administrative and clinical supervision to team members
- Facilitates weekly team meeting
- Facilitates communication among team members
- Monitors referral and evaluation process and discharge and linkage process
- Acts as liaison between team and host agency
Primary Clinician/Therapist

- Master’s or doctoral level clinician who is the primary resource for the client and family
- Coordinates assessment of service needs
- Works with the client to create the treatment plan within a shared decision-making framework
- Provides OnTrack core sessions, psycho-education, supportive therapy and coordination of care

Psychotherapy

1) a general supportive approach which includes case management
2) a focus on cognitive behavioral treatment principles
PC Core Sessions

Core Sessions are in the Primary Clinician manual:

1. Introduction to the Team
2. Early Intervention and Recovery
3. Shared Decision Making
4. Enhancing my Social Skills (optional)
5. Understanding How Drugs and Alcohol Affects My Recovery (optional)
6. Learning to Manage Difficult Feelings (optional)
7. Increasing Engagement Through Behavioral Activation (optional)
8. My Cultural Background, My Choices and My Recovery
9. Identifying and Using My Personal Strengths and Supports
10. Transition from the Team: What’s Next (Phase 3)

Therapeutic Goals

- Symptom-based formulation
- Target distress and disturbance
- Increase insight and understanding of illness
- Improve coping
- Reduce stress
- Prevent relapse
What are Recovery Coaching Interventions?

- Interventions help people to learn and use new skills
- These skills help people to achieve personally meaningful goals
- Include:
  - Social Skills Training
  - Substance Abuse Treatment
  - Coping Skills Training
  - Behavioral Activation

Common Reasons to Use RC Interventions

**Client:**
- worries marijuana use will worsen symptoms but doesn’t want to lose friends by refusing to smoke after school (SA interventions)
- has difficulty motivating to engage in everyday activities (behavioral activation)
- does not want to take medication and afraid he will lose his job if paranoia returns (coping skills, collaborate with SEES specialist and MD)
- wants to start dating again in college but has not been on a date since she first experienced psychosis (social skills)
Prescriber/Psychiatrist

• The prescriber/psychiatrist engages the client in shared decision making about medication and the next steps in medication treatment
• Engages client around health and wellness more generally
• Engages client supports as appropriate

Nurse

• Supports the prescriber and works with client around decisions about medications
• Engages client around health and wellness more generally
• Engages client supports as appropriate
General Approach to Psychopharmacologic Treatment

• Recovery-oriented - What does this mean?
  o Oriented towards participants’ values and goals
  o Decisions are guided by principles of Shared Decision-Making
  o Taking medication is not a requirement for participating in OnTrack

• Use of evidence-based algorithm that accounts for variability in therapeutic response, side effect sensitivity, adherence, diagnostic uncertainty

• Addition of mood stabilizers or antidepressants if mood symptoms do not resolve with antipsychotic medications

Psychiatrist/NP & Nurse
Roles within the Team

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<thead>
<tr>
<th>Psychiatrist/NP</th>
<th>Nurse</th>
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<tr>
<td>• Engages participant in shared decision making process about medication</td>
<td>• Supports medication management &amp; health monitoring activities</td>
</tr>
<tr>
<td>• Monitors for side effects and other health issues</td>
<td>• Provides wellness education</td>
</tr>
<tr>
<td>• Assesses safety</td>
<td>• Assists in health care coordination</td>
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Dosing & Delivery

→ What should our goal be in dosing an antipsychotic medication?
  • Use lowest effective dose
  • Aim to stay within the lower half of the recommended dose range due to increased efficacy of antipsychotic meds in FEP & greater sensitivity to side effects

→ What role do LAIs have?
  • Offer long-acting injectable medications as an option
  • Any of the available LAIs

Refractory symptoms

→ How would you respond if a client continues to experience distressing symptoms and/or EPS after 2 adequate antipsychotic medication trials?

Clozapine should be considered early in the course of treatment-resistant symptoms, and should not be considered a treatment of last resort
RN Visits

Core session
Follow up as needed for:
- Health monitoring (vitals, labs)
- Supporting medication management
- Education
- Health care coordination

Health Monitoring

Baseline measurements

Ongoing monitoring
- Labs
- Vitals
- Side effects
Supported Education and Employment Specialist (SEES)

- Takes the lead in assisting the client with employment and education goals.
- Provides services based on the Individualized Placement and Support (IPS) Model

Context

- Age appropriate goals for youth with FEP:
  - Continuing with, or returning to school and/or work
- Myth: work and school are stressors that could exacerbate symptoms
  - Research is now clear that engaging in work and school is an important part of healing and recovery
  - People in recovery report that work and/or school was central to their recovery
Supported Education & Employment Specialist Role

- For those who are currently in school or work, the SEES can help the individual maintain the connection.
- For those who had previously been in school or work, the SEES can help the individual to re-establish a connection.
- For those who have never worked, the SEES can help the individual to establish a connection with employers.
- For those who desire, the SEES can help the individual develop education and career plans.

Core Competencies

- Engagement
- Assessment
- Planning
- Benefits counseling, if appropriate
- Job/education development
- Working with ACCES-VR, if appropriate
- Follow-along supports
Vignette #1
Focus on Client Preferences

- Hospital staff informed the SEES that the participant wanted to return to college
- Hospital staff ordered cognitive testing which revealed cognitive impairment
  - Concluded client wouldn’t be successful
- SEES focused on client preferences
  - Plan developed to support return to school
  - Client earned degree in 2 semesters

Peer Specialist

- Brings a lived experience of personal mental health struggles and is actively engaged in a process of self discovery and recovery
- Helps to build and model mutual and reciprocal relationships through an explicitly non-clinical framework
- Helps team understand the voice of the client by emphasizing alternative perspectives
- Change agent role- may be part of a larger peer movement working to evolve the mental health system through advocacy
Phase 1: Outreach, Engagement and Bridge Building

1. Outreach
   - Identifying potential referral sources
   - Conducting outreach presentations

2. Engagement
   - Describing program & conveying The Spirit of OnTrackNY
   - Being an initial “face” of the team

3. Bridge Building
   - Serving as a bridge between team members and participants when they experience ambivalence about treatment

Phase 2: Relationship Building

1. Relationship Building
   - **Connection** - key in initiating relationships, happens when first meeting participants, includes curiosity, acceptance, warmth and engagement
   - **Worldview** - unique and based on personal experience, shapes our personal assumptions and how we interpret others’ stories, *important to develop our awareness about this*
   - **Mutuality** - focus on learning from one another as opposed to helping
Phase 2: Non-Traditional Understandings of Psychosis

Peer Specialists should:

• Share and discuss multiple frameworks for understanding life experiences such as psychosis

• Intentionally use language in the service of listening to make space for complex personal stories of recovery and resilience.

Co-Creating Support and Wellness Tools: Key Tasks

• Navigating Complex Systems
• Inspiring Participants to Develop Vision and Tools
• Facilitating/Co-Facilitating Groups
• Collaborating with the Supported Employment and Education Specialist
• Working with Participants and Families
Phase 3: Identification of Future Needs and Service Transitions

• Guide participants and families in transitioning from OnTrackNY
• Reflect on strengths, goals and acquired skills For self-advocacy

Connect individuals to local resources
• Peer-run organizations, interest groups, mental health support groups

Influencing the Team Culture

When Peer Specialists join the team:
• New perspective and skill set are introduced into the team culture
• Team members will experience a culture shift as clinicians learn to work with Peer Specialists and vice versa
• Peer Specialists will have many opportunities to positively influence the team’s dynamics and practices
Outreach and Recruitment Coordinator Activities

- Multiple team members may conduct activities but ORC takes lead
- Master’s or doctoral level clinician who coordinates outreach and recruitment activities
- Organizes and tracks presentations to publicize team activities
- Screens individuals referred to the program and evaluates clients for eligibility

Outreach Purpose and Process

- Outreach informs community providers about criteria, treatment model and how to refer
- Outreach can occur with providers and agencies, including:
  - Inpatient units, Outpatient programs, Emergency rooms, Area schools, Professional, client and family agencies
- Types of Outreach:
  - Mass and personal emails, Phone calls, Presentations
Evaluation

• Evaluation begins with the first phone call
• Clinicians trained to handle new referrals, screen potential clients, and field calls
• Symptom ascertainment and eligibility screening:
  o psychotic symptoms
  o mood disorders
  o substance use
• Review evaluation decisions with team when appropriate

What Can Happen When Families Are Involved?

Impact of Single-Family and Multiple-Family Approaches on Relapse Rates in Major Outcome Trials

• Average relapse rates across 11 RTC’s (N = 895)
• Mean length of treatment = 19.7 months

Working with Families

1. Early engagement with family, starting from pre-intake activities and selection of OnTrack program for loved one’s care
2. Family sessions with the Primary Clinician for ongoing support
3. Meetings with all team members (individually or as a group)
4. Family psychoeducation in individual sessions
5. Monthly family psychoeducational groups that provide a forum for families to meet one another and learn together
6. Connections to community education/support services/resources, such as NAMI’s Family to Family program

Working With Families

7. Brief family consultation with the **Primary clinician** to address specific problems or needs; examples include skills training on conflict resolution, compromise and negotiation, or communication skills
8. Crisis intervention and safety planning
9. After-hours access to team
10. Long term planning (transition)
11. Open lines of communication with any team member
Summary

• We are at a transformative moment in the treatment of individuals experiencing early psychosis

• We need to consider early detection, maximizing treatment, and maximizing ongoing care—many unanswered questions.

• CSC has several components. The evidence base is evolving.