Family Member/Support Person Engagement During Care For First Episode Psychosis

Challenges & Strategies to Move Us Forward

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Objectives

- Explore family member experiences prior to and during care that impact engagement.
- Describe the importance of family/support person involvement and how experiences prior to coordinated specialty care can impact individual outcomes.
- Describe racial inequities in family engagement.
- Describe how community outreach and campaigns can be used to improve initial engagement among families.
LET’S START WITH PATHWAYS TO CARE...
What is Pathways to Care?

"The sequence of contacts with individuals and organizations prompted by the distressed person’s efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response of these efforts."

EXPERIENCES THAT PREDATE PRODROME PERIOD

PRODROMAL PERIOD

ONSET OF PSYCHOSIS

PATHWAYS TO CARE

Pathways to Mental Health Services

- Misattribution of symptoms
- Stigma
- Uncertainty
- Multiple diagnoses
- Hospitalizations
- Multiple sources of support
- Multiple contacts with MH services

POSITIVE AND NEGATIVE EXPERIENCES

Cabassa et al., 2013. Understanding pathways to care of individuals entering a specialized early intervention services for first episode psychosis
Oluwoye et al., 2020. Family experiences prior to the initiation of care for first-episode psychosis: A meta-synthesis of qualitative studies
RACIALLY & ETHNICALLY DIVERSE FAMILIES’ PATHWAYS TO CARE ARE INEQUITABLE
“[Inpatient facility] wanted to detain [my son] for the 90 days and they wanted to put him indefinitely in the State Hospital, [that's] when you have criminal activity you did crime, and I kept trying to explain to the county designated responder this is a young man who has never been in trouble with the police! He went to a parochial school, he is an upstanding citizen, he's a college student! But she wouldn't listen to me, her staff wouldn't listen to me, it was basically, I feel that because my son was African American he was targeted and we have to do what they say because once you get involuntarily committed you have no say in it.”

Oluwoye et al., 2022. The unique pathways to coordinated specialty care for Black families navigating early psychosis: A preliminary report
FAMILY MEMBERS HAVE A KEY ROLE IN FACILITATING THE PATHWAY TO MENTAL HEALTH SERVICES & OTHER RESOURCES & SUPPORT
Why Focus on Family Members?

- Large majority (88%) of individuals reside with a family member
- Responsible to keeping and attending appointments
- Financial support
- Emotional support

Oluwoye et al., 2020. Understanding differences in family engagement and provider outreach in New Journeys: A coordinated specialty care program for first episode psychosis
Why We Involve Family Members?

• Primarily responsible for the initiation of treatment or first hospitalization

• Limited family involvement is linked to a longer duration of untreated psychosis

• Interactions with family members and inpatient staff is associated with the initiation of outpatient services

Compton et al., 2008. Mode of onset of psychosis and family involvement in help-seeking as determinants of duration of untreated psychosis
Haselden et al., 2019. Family involvement in psychiatric hospitalizations: Associations with discharge planning and prompt follow-up care
Oluwoye et al., 2020. Family experiences prior to the initiation of care for first-episode psychosis: A meta-synthesis of qualitative studies.
Importance of Family Members

• Family contact is associated with better work performance.
• Living without a family member at discharge and lack of family involvement is a predictor for disengagement.
• Family engagement increases service user engagement.

Brekke & Mathiesen, 1995. The effects of parental involvement on the functioning of noninstitutionalized adults with schizophrenia
Conus et al., 2010. Rate and predictors of service disengagement in an epidemiological first-episode psychosis cohort
Stowkowy et al., 2012. Predictors of disengagement from treatment in an early psychosis program
Oluwoye et al., 2022. Taking a look at how family member engagement influences service user engagement in New Journeys: A coordinated specialty care program
Black/African American families with no prior contact with a mental health provider had lower QoL.

Oluwoye et al., 2020. The impact of early family contact on quality of life among non-Hispanic Blacks and Whites in the RAISE-ETP trial
REACHING EARLY INTERVENTION SERVICES
Stages of Engagement

FAMILY ENGAGEMENT

Continuous Engagement During Care
10-50% of family members are engaged in CSC
Family Engagement in RAISE-ETP

Oluwoye et al., 2022. The unique pathways to coordinated specialty care for Black families navigating early psychosis: A preliminary report
Rates of family engagement

Early Psychosis Intervention Center (EPICENTER)

• 22% participated in individual family psychoeducation
• 44% participated in group psychoeducation.

Breitborde et al., 2015. The Early Psychosis Intervention Center (EPICENTER): Development and six-month outcomes of an American first episode psychosis clinical service
Rates of family engagement

OnTrackNY

- 84% had contact with CSC providers at 3 months
- 41% of service users requested conditional or no family involvement

Jones et al., Clients’ preferences for family involvement and subsequent family contact patterns within OnTrackNY early psychosis services
Rates of family engagement

• 70% participated in at least one individual family psychoeducation
• 39% attended psychoeducation in the first month
Rates of engagement in New Journeys

Oluwoye et al., 2020. Understanding differences in family engagement and provider outreach in New Journeys: A coordinated specialty care program for first episode psychosis
Stages of Engagement

FAMILY ENGAGEMENT

Initial Engagement
Pathways to Care

Continuous Engagement
During Care

South Southwest MHTTC
First Episode Psychosis
Conference 2022
Re-envisioning FEP Services with Youth & Young Adults
EARLY CONTACT LINKED TO BETTER OUTCOMES

NEGATIVE EXPERIENCES LEADS TO LACK OF ENGAGEMENT

ENGAGEMENT INCREASES ENGAGEMENT
BARRIERS TO FAMILY ENGAGEMENT
Barriers to engagement

I. Stressors and Obstacles that Compete with Treatment
II. Treatment Demands and Issues
III. Perceived Relevance of Treatment
IV. Relationship with the Therapist
V. Critical Events
I. Stressors & Obstacles

During the course of loved ones’ treatment I experienced a lot of stress in my life.

I. Stressors & Obstacles that Compete
II. Treatment Demands & Issues
III. Perceived Relevance of Treatment
IV. Relationship with the Therapist
V. Critical Events
II. Treatment Demands & Issues

Scheduling of appointment times made it hard to attend
III. Perceived Relevance of Treatment

My loved one has a new or different set of problems
IV. Relationship with the Therapist

The therapist did not seem confident that treatment would work for my loved one.
V. Critical Life Events

Interruptions in Treatment
(e.g., placed in inpatient)

Family Dynamics & Other Family Issues
(e.g., family substance use)

Household Changes
(e.g., changes in medical insurance)

I. Stressors & Obstacles that Compete

II. Treatment Demands & Issues

III. Perceived Relevance of Treatment

IV. Relationship with the Therapist

V. Critical Events
Summary of Family Member Needs

- Treatment relevance - family member needs and expectations
- Relationship building - consistency
- Stress management, flexibility
- Treatment demands – clarity and involvement

ENGAGEMENT
FAMILY MEMBER PERSPECTIVES ON HOW CAN WE IMPROVE ENGAGEMENT
Theme I: Support

SUPPORTIVE INTERACTIONS

POSITIVITY

WORKING WITH COLLEGES/UNIVERSITIES & EMPLOYERS
Theme II: Knowledge

EDUCATING COMMUNITY ORGANIZATIONS

UNDERSTANDING SIGNS & SYMPTOMS

AVAILABLE RESOURCES & SERVICES IN THE COMMUNITY
Theme III: Communication

VALUED AND LISTENED TO BY CLINICIANS

BILINGUAL STAFF
Theme IV: Access

AVAILABLITY OF SERVICES

TIMELY REFERRALS
WHAT OTHER RESOURCES CAN BE USED?
Current Efforts

- Family Peers to address continuous engagement in CSC
- Family Motivational Engagement Strategies (FAMES) to improve continuous engagement in CSC
- Family Peer Navigators to improve initial engagement and access to care for Black/African American families

Oluwoye et al., 2020. Developing and implementing a culturally informed FAmily Motivational Engagement Strategy (FAMES) to increase family engagement in first episode psychosis programs: Mixed methods pilot study protocol
TRANSFORMATION
TRANSFORMATION I want to see...

- Services that address the needs of family members
- Improved navigation between systems of care
- Community-informed resources and support
- More diversity in the workforce