Family Support in First Episode Psychosis: News Ideas for Clinicians and Researchers

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Tread softly because you tread on my dreams.

W.B. Yeats

What Principles Guide First Episode Psychosis Family Work?

- Identify and build on common ingredients from effective family programs
- Incorporate recovery attitudes and practices
- Meet people where they are
- Build on participants' strengths
- Develop a collaboration among individual living with the psychosis, relatives, and team

First Episode Psychosis —Clinical Issues

- Participants likely identify with age cohort
- May be hesitant to recognize or acknowledge psychiatric problems
- Influence of social media is important
- Typically not accessing regular medical treatment except for well care; need to be socialized into treatment
- Participants and relatives may be confused about what is happening —need education which incorporates diagnostic uncertainty

First Episode Psychosis—Clinical Issues *con't*

- Developmental challenge is for participant to separate from parents/caregivers but now may need to be more dependent for a time—ambivalence on both sides
- May be missing important developmental milestones—getting a license, money management, going away to college, moving away from parents
- Relatives hold sway and may be ambivalent or discourage participation in treatment (e.g. afraid of medication side-effects, lack of knowledge)

Family Relationships are Important in Mental Health Care

- Brekke and Mathiesen (1995) found that, among persons with schizophrenia not living with their relatives, **those with family contact had better work and overall role performance.** Evert et al (2003) reported a similar positive association between family contact and social role functioning.
- Clark (2001) found, among a sample of persons with severe psychiatric illnesses (over half diagnosed with schizophrenia) and co-occurring substance use disorders, **those with more family contact and/or financial support from their families were more likely to reduce or eliminate their substance use.**
- Prince (2005) found that, three months post inpatient discharge, **individuals with schizophrenia whose families were helped to cope by the treatment team were much more likely to be satisfied with their mental health treatment**.

Family Relationships are Important in Mental Health Care cont'd

- Haselden et al (2019) conducted a study on contact between inpatient staff and family members. When analyses controlled for demographic and clinical factors, **having any involvement between family members and inpatient staff was significantly associated with patients' attending an outpatient appointment by 7 days or 30 days after discharge.**

- Doyle et al (2014) conducted a systematic review of factors predicting disengagement from FEP treatment. Despite differences in definitions and study settings, approximately 30% of individuals with FEP disengage from services. Variables that were consistently found to exert an influence on disengagement across studies were duration of untreated psychosis, symptom severity at baseline, insight, substance abuse and dependence, and **involvement of a family member in tx (Stokowey et al, 2012) or with the client Conus et al, 2010).**

But loving someone newly diagnosed with a psychosis can be hard .

- Families experience considerable subjective burden, e.g., anxiety, worry, grief, sadness
- Families experience considerable objective burden, e.g., expenditure of time and resources
- Families often have significant other burdens
- May have had other (often negative) experiences of psychosis in self or other loved ones

Research on RAISE-ETP NAVIGATE Program

- Randomized controlled trial to compare RAISE-NAVIGATE with the typical kind of care available in local community mental health agencies using existing staff
- Goals of the program went beyond reducing hospitalizations—it emphasized helping individuals **get back to work or school and have a better quality of life.**
- All the NAVIGATE clinicians were typical community care staff but carefully trained and monitored
- The team carefully collected a wide range of outcome data to compare the two treatments over 2 years participation

RAISE-ETP —An Example of Coordinated Specialty Care

- Team-based
  - Shared decision-making
  - Strength & resiliency focus
  - Psychoeducational
  - Motivational enhancement teaching skills
  - Collaboration with natural supports
- Four components
  - Psychopharmacology – COMPASS
  - Individual Resiliency Training (IRT)
  - Supported Employment and Education (SEE)
  - Family Psychoeducation (FPE)
- Can Supplement with Case Management and Peer Support

Inclusion Criteria

- Age 15-40
- SCID confirmed diagnosis:
  - Schizophrenia
  - Schizophreniform disorder
  - Schizoaffective disorder
  - Brief Psychotic disorder
  - Psychosis NOS
- No more than 6 months lifetime antipsychotic medication treatment
- First episode of psychosis

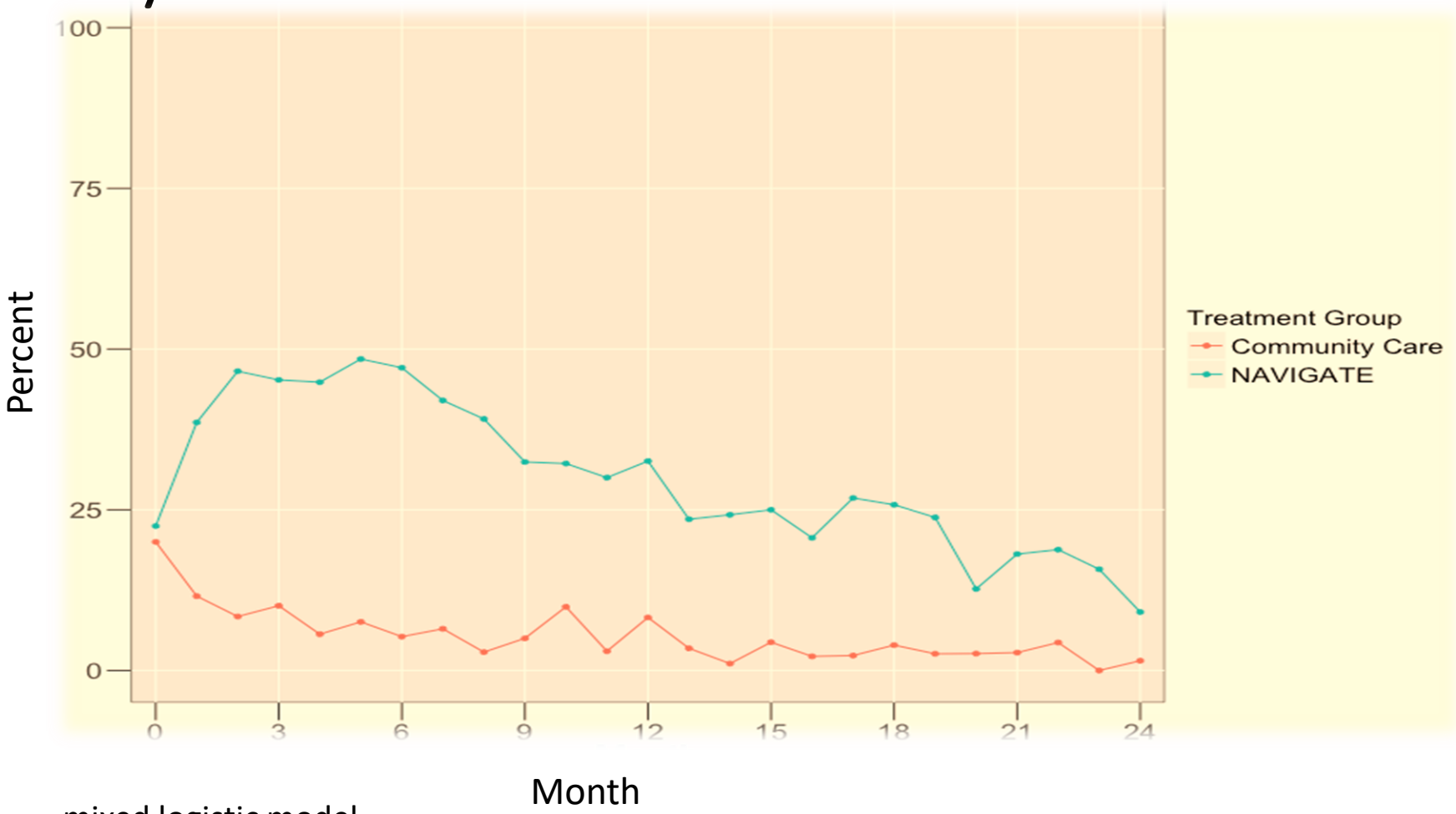
RAISE-ETP Study Design with Cluster/Site Randomization

Conduct the Comparison in Non-academic, United States Community Treatment Settings ETP Sites are in 21 US Contiguous States

Major Study Outcomes Compared NAVIGATE to those Receiving Customary Care

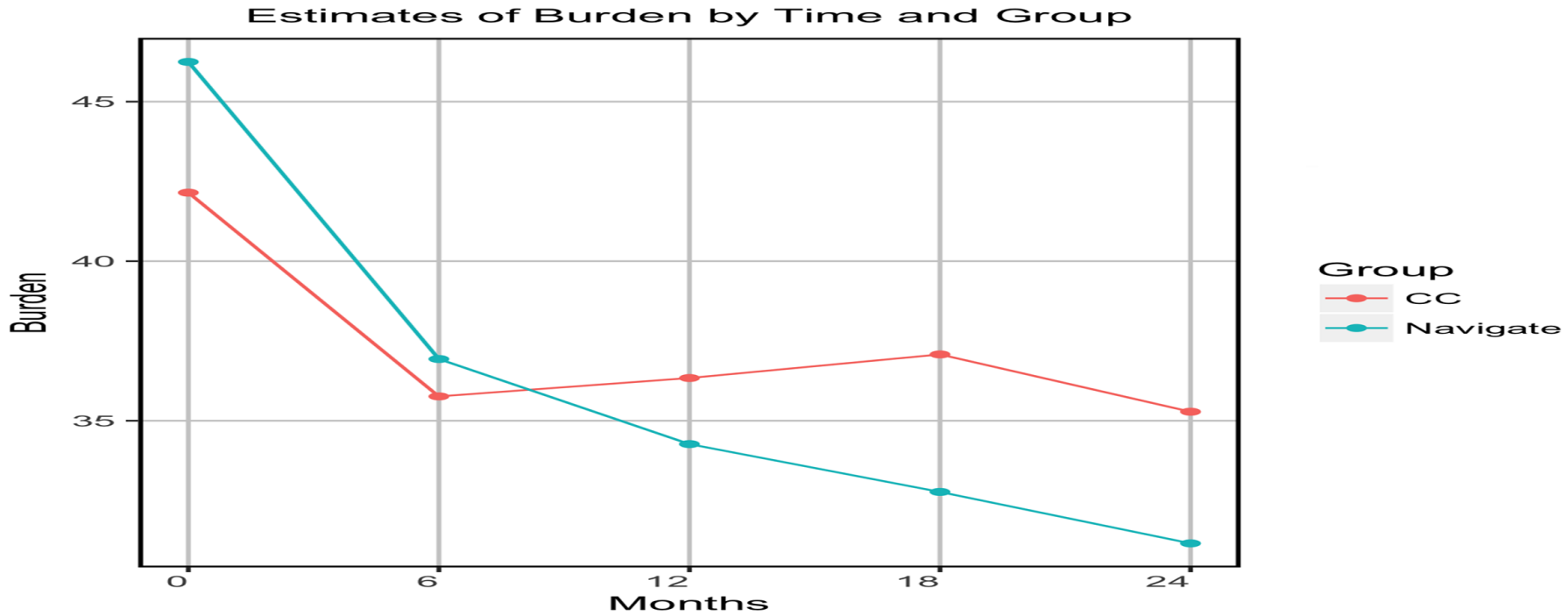
- At 2 years, NAVIGATE participants:
  - Had greater improvements in rates of participation in work or school
  - Had greater reductions in symptoms
  - Had greater improvements in quality of life
  - Were more likely to stay in treatment
  - No differences in hospitalizations

Percent of Sample Whose Family Met with a Mental Health Care Provider by Time Point



mixed logistic model
t= 6.48, p< 0001

Family Burden Scale (Reinhard et al., 1994) Total Score by Time Point Across Both Conditions



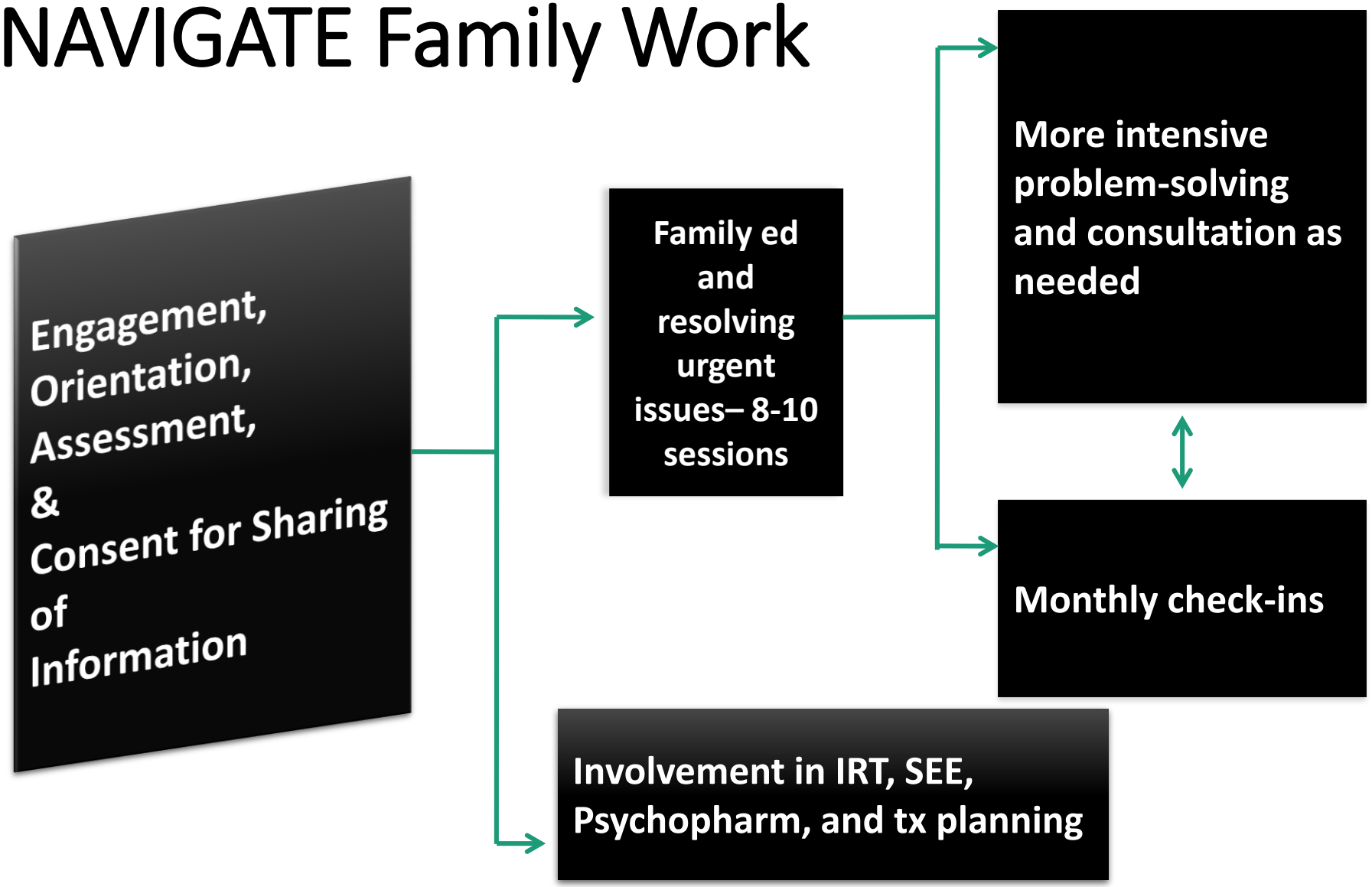
Coefficients	Estimate (SE)
Intercept	41.08 (1.21)***
NAVIGATE	5.27 (1.58)***
Time[1]	-1.47 (0.33)***
NAVIGATE*Time	-1.64 (0.41)***

*p < 0.05, **p < 0.01, ***p < 0.001

[1]Time was square-root transformed

Overview Of NAVIGATE Family Education Components And Organization Of Manual

NAVIGATE Family Work



The NAVIGATE Family Manual: A Tour

- Introduction and overview to family program
- Clinical Guidelines and materials for engagement, orientation, and assessment
- Clinical Guidelines for educational sessions
- Matching Educational Session Handouts (“Just the facts” . . .
- Format for monthly check-ins after education
- Clinical Guidelines for family consultation
- Participant Handouts for family consultation
- MIST—modified intensive skills training
- Discharge Planning

Family Education

- Original Topics (many similar to basic IRT):
  - Facts about Psychosis
  - Facts about Medication
  - Facts about Coping with Stress
  - Facts about Developing Resiliency
  - Relapse Prevention Planning
  - Developing a Collaboration with Mental Health Professionals
  - Effective Communication
  - A Relative's Guide to Supporting Recovery from Psychosis
- In addition, there is an optional handout on substance use and psychosis

Family Education Format

- Family clinician provided factual information necessary to support the person in NAVIGATE and friends/relatives
- Offered in approximately 10 sessions—ideally scheduled weekly
- Client in NAVIGATE invited and must consent to relative involvement in care if over 17
- Client in NAVIGATE given choice whether to attend or not (encouraged but not pushed)
- Individual (rather than multi-family group) format

Recent Updates to the NAVIGATE Family Manual

1. Included a “Healthy Lifestyles” module to mirror IRT and help families support proactive health behavior in clients in NAVIGATE.

2. Added the “Basic Facts about Alcohol and Drugs” module as a standard module for all families. This was done to reflect the high rates of substance use in the original NAVIGATE sample.

3. Updated the information on causes and factors that influence the course of psychosis and schizophrenia-spectrum disorders to include social determinants and personal factors such as a history of trauma.

4. Clarified use of the stress-vulnerability model of schizophrenia more to explain the *course* or *outcome* of the disorder, rather than as a depiction of its causes, as so much more needs to be discovered about the etiology of the illness.

5. Updated the medication information

Preliminary Data on Engagement/Implementation (from therapist contact sheets)

- Some participants had no family or did not want family involved in their care--rough estimate about 30%
- 172/223 (77%) of participants were living with a relative
- 144/223 participants (64.4%) had relatives with at least one post Engagment contact with NAVIGATE team
- About half of participants' relatives (118/223—52%) had at least one educational session;
- Of those who attended family education sessions, they attended approximately 12.5 (sd 10.61)
- Mothers were the primary relatives having contact with the team

Baseline Predictors of Engagement In NAVIGATE Family Services

Variable	Mean (SD) or percent for Those Without Family Engagement N=79	Mean (SD) or percent for Those With Family Engagement N=144
Patient Age	24.39 (5.34)	22.52 (5.03)*
Quality of Life 1- Intimate Relationships with Household Members	3.41 (1.61)	3.94 (1.55)*
Mean Quality of Life Score	2.3 (0.82)	2.5 (0.9)
Mean Calgary Score	0.6 (0.53)	0.48 (0.44)
Mean PANSS Factor Scores		
Positive	3.18 (1.02)	3.04 (0.94)
Negative	2.76 (0.88)	2.86 (0.9)
Disorganized/Concrete	2.8 (0.92)	2.68 (0.96)
Excited	1.84 (0.82)	1.72 (0.73)

*p < 0.05, **p < 0.01, ***p < 0.001

Note: Differences between the two groups were tested using two-sample t-tests and chi-squared tests.

Baseline Predictors of Engagement In NAVIGATE Family Services *con't*

Variable	Mean (SD) or percent for Those Without Family Engagement N=79	Mean (SD) or percent for Those With Family Engagement N=144
Depressed	2.89 (1.17)	2.64 (1.02)
Male	74.5%	79.2%
Latino	17.7%	28.5%
Race		
White	49.4%	68.8%*
Black	39.2%	22.2%
Other	11.4%	9.0%
Living with Family	63.6%	82.5%**
Using Tobacco	62.0%	43.1%**

*p < 0.05, **p < 0.01, ***p < 0.001
Note: Differences between the two groups were tested using two-sample t-tests and chi-squared tests.

Baseline Predictors of Engagement In NAVIGATE Family Services *con't*

Variable	Mean (SD) or percent for Those Without Family Engagement N=79	Mean (SD) or percent for Those With Family Engagement N=144
Using Other Substances	57.0%	52.8%
LOGISTIC REGRESSION		
Coefficients	OR (95% CI)	
Age	0.93 (0.87, 0.99)*	
QLS 1	1.27 (1.05, 1.53)*	
Race - black	0.41 (0.2, 0.79)**	
Race - other	0.49 (0.17, 1.41)	
Living with Fam	0.56 (0.28, 1.15)	
Tobacco Use	0.45 (0.24, 0.83)*	

*p < 0.05, **p < 0.01, ***p < 0.001
Note: Differences between the two groups were tested using two-sample t-tests and chi-squared tests.


THE LATEST RESEARCH SHOWS THAT WE REALLY SHOULD DO SOMETHING WITH ALL THIS RESEARCH

Successful Engagement is the Key--Participant

- We want to link participation in family work to recovery goals
- Many consumers will be wiling to have relatives involved in care
- If the participant is reluctant,
  - Make sure you understand the reluctance—listen carefully
  - Reiterate connection with recovery goals
  - Support ongoing dialogues about the benefits of relative involvement in care if potential participants are initially reluctant
- Shared decision making can be useful
- Activate the participant to invite relative in
- Use all your clinical skills—warmth, genuineness, empathy

Decisional Balance: Should I involve my relatives in TX?

PRO's— Benefits of relative Involvement	CON's— Concerns about relative Involvement
Worry about me less	Invade my privacy
Less arguing	Mother is sick
They might understand what I'm going through	Might be nervous in sessions

Successful Engagement is the Key--Participant

- Shared decision making can be useful
  - Participant has expertise (preferences, personal history)
  - Professional has expertise (science, professional experience)
  - Both share views
  - Work towards compromise

Successful Engagement is the Key-Relative

- “Get your foot in the door” often an important strategy: do whatever you can to help the family feel like you are approachable and have something to offer
- Support ongoing dialogues about the benefits of relative involvement in care if potential participants are initially reluctant
- Make it easy for participants to join—start with an initial meeting, be prepared to use remote modalities
- Use all your clinical skills—warmth, genuineness, empathy
- Problem solve/bring to team urgent issues raised by family—meds, sleep, aggression
- Understand relatives may have a range of responses to psychosis in loved one—disbelief, confirmation of fear, naïve—may need time to process

Clinical Challenges in FEP Work

- Blended families where step-parent was angry about extra burden of illness in “adult” offspring
- Single parents with little support
- Mental illness in multiple family members—esp. parents
- Relatives using drugs or alcohol with consumer
- Relatives reluctant to have consumer take medication because of side-effects or philosophy
- Relatives who had difficulties managing their own situations
- Cultural issues, especially with regard to immigrant families

First Episode Psychosis—Family Research Issues

- Relative critical comments predicts subsequent relapse in 1-2 years in longitudinal follow-up of first episode sample (summarized in Alvarez-Jimenez et al, 2012)—but more EE status instability at beginning of disorder.

- EE study-Carers' criticism at FEP baseline significantly predicted cannabis misuse according to the ASSIST at 7-month follow-up.. Conversely, baseline cannabis misuse was not associated with carers' criticism at 7-month follow-up. **Patients in families with high criticism showed a tendency to increase cannabis misuse over time whereas the opposite trend was observed in those with carers with low criticism**.Gonzalez-Blanch et al, 2015

- Ethnicity/race may play an important role in family engagement in education—RAISE ETP study –community care less successful engaging Hispanic families and NAVIGATE less successful engaging African American Families (Oluwoye et al,: 2018). Or Washington State New Journeys Program (Oluwoye et al, 2020).

- Be careful about comparisons across studies—how is relative participation defined?

Summary

- There is a strong rationale for involving relatives of first episode psychosis in mental health care
- There are unique Issues impacting on family work in recent onset psychosis, but they can be addressed
- Data from the RAISE NAVIGATE family intervention indicate we can involve families in first episode care, although there is variability in uptake
- Factors which may impact negative on engagement in family services—
  - reluctant consumers,
  - older consumers,
  - consumers with less regard for family members, e
  - Ethnic minorities
  - smokers (SES?)

Questions

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