

Enhancing Family Support in Recovery From Serious Psychiatric Illness--What's New? What Works???"

Minneapolis, MN

3/1/17

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SAMHSA Core Tenets--Recovery

- Emerges from hope
- Is person-driven
- Occurs from many pathways
- Is holistic
- **Is supported by peers and allies**
- **Is supported through relationships and social networks**
- Is culturally based and influenced
- Is supported by addressing trauma
- **Involves individual, family, and community strengths and responsibility**
- Is based on respect

A Brief Case Example



Rationale & Evidence Base for Family Involvement in Care



So what kinds of disorders are we talking about?

- ▶ Adults
- ▶ Many axis I disorders have an evidence-base for family interventions
 - ▶ Schizophrenia
 - ▶ Schizoaffective disorder
 - ▶ Bipolar illness
 - ▶ Other psychotic disorders
 - ▶ PTSD
 - ▶ Depression with a significant impact on functioning
 - ▶ May have co-morbid, but not primary, substance use

Less research support for personality disorders

Why Involve Relatives in Care ?

Family relationships are important to support recovery

- ▶ 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.
- ▶ Fleury et al, (2008) found that individuals with smi who reported more contact with family had better medication adherence and shorter hospital stays when hospitalized than those without family contact
- ▶ Gold (2013) found that, among participants with smi in a supportive employment program, those with employment *and at least weekly contact with family*, reported the highest quality of life

Why Involve Relatives in Care ?

Contact between the treatment team and the family has beneficial effects

- ▶ Prince (2005) that, three months post inpatient discharge, individuals with schizophrenia whose families were helped to cope with their illnesses by the treatment team were much more to be satisfied with their mental health treatment.
- ▶ Stowkovey et al (2012) found that family participation in a comprehensive first episode program decreased attrition at 30 month follow-up

But loving someone with a serious and persisting psychiatric illness can be hard

• • •

- ▶ Families experience considerable subjective burden, e.g., anxiety, worry, grief, sadness
- ▶ Families experience considerable objective burden, e.g., expenditure of time, resources
- ▶ Families often have significant other burdens



Common Negative Effects of Caregiving

- ▶ Anxiety
- ▶ Depression
- ▶ Increased susceptibility to illness
- ▶ Potential exposure to violence
- ▶ Marital discord
- ▶ Economic & time investment





“He’s fine as long as I take my medication.”

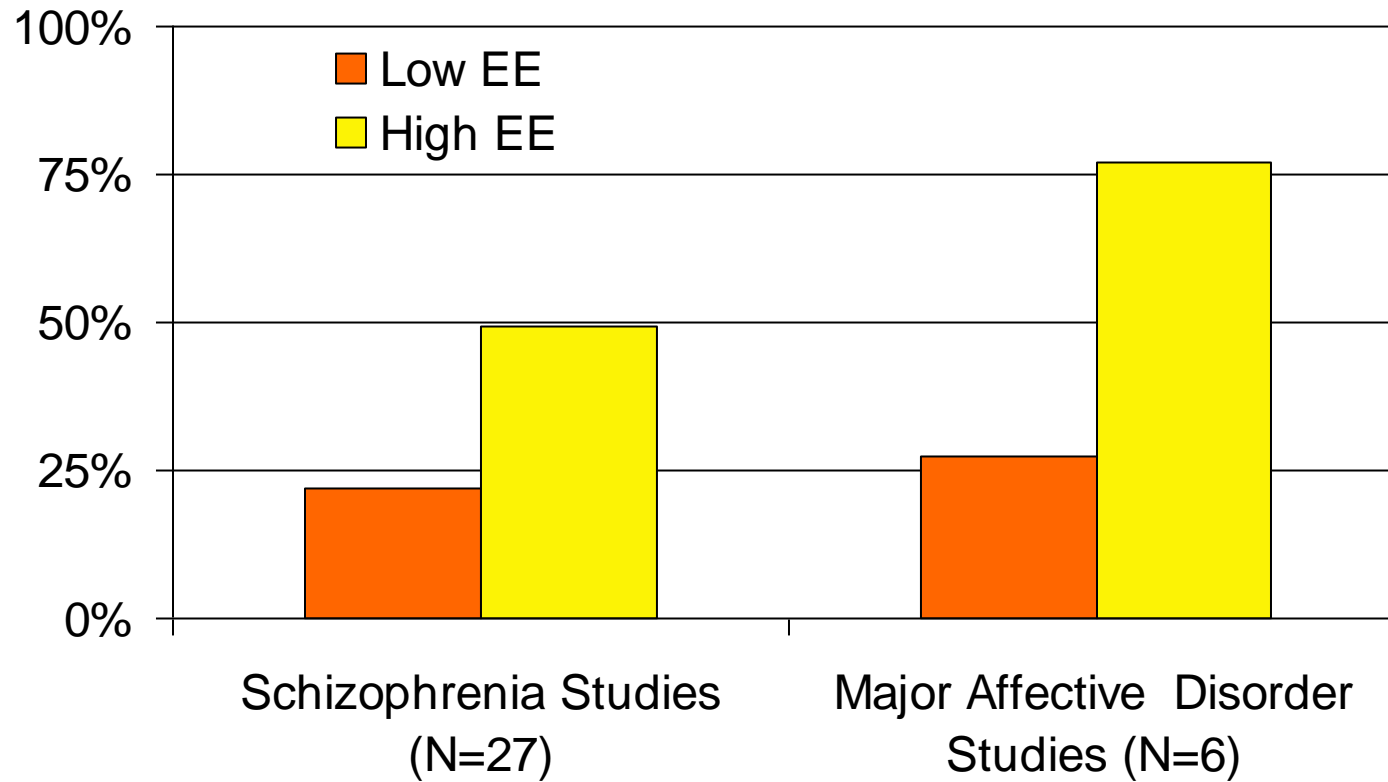
Expressed Emotion

- ▶ Assessed in a semi-structured relative interview (CFI) at time of consumer exacerbation.
- ▶ Scored for presence of critical comments, hostility, warmth, positive comments, and emotional over-involvement (content and tone).
- ▶ Hi EE-high critical comments; high emotional over-involvement.

Expressed Emotion (cont.)

- ▶ First identified in England in mid '50's.
- ▶ Found in relatives around the world
- ▶ Hi EE predominant in western cultures.
- ▶ EE predicts relapse at 9-12 months (across 27 studies)
low EE-22%, high EE-52%
- ▶ Likely reflects high stress and limited resources

Family Stress and Relapse



Positive Effects of Caregiving

- ▶ Living one's values (ACT)
- ▶ Close, rewarding, meaningful relationships
- ▶ Increased empathy with others' suffering

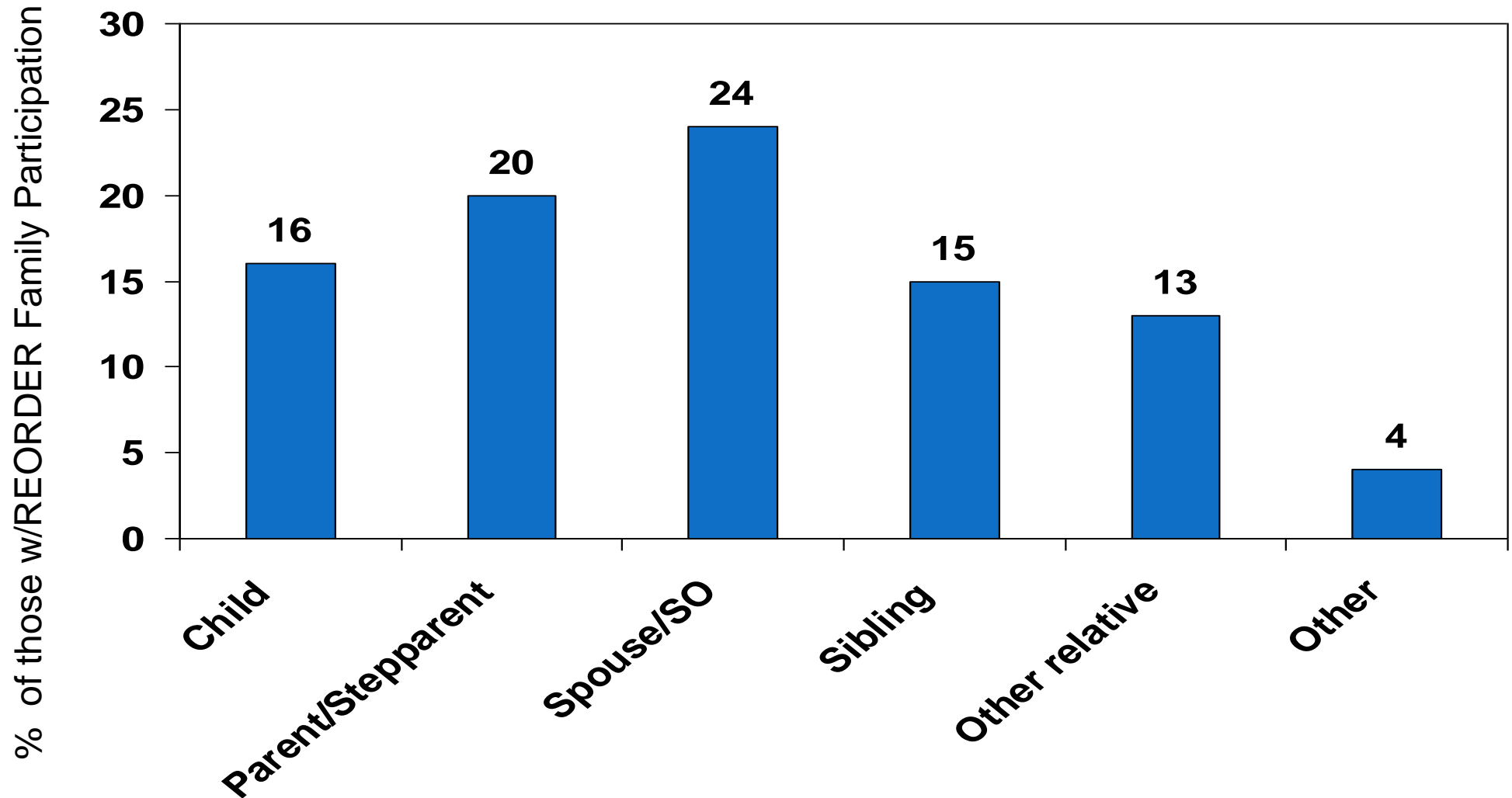


So what services and information would you want a relative to have if you were diagnosed with a serious mental illness?

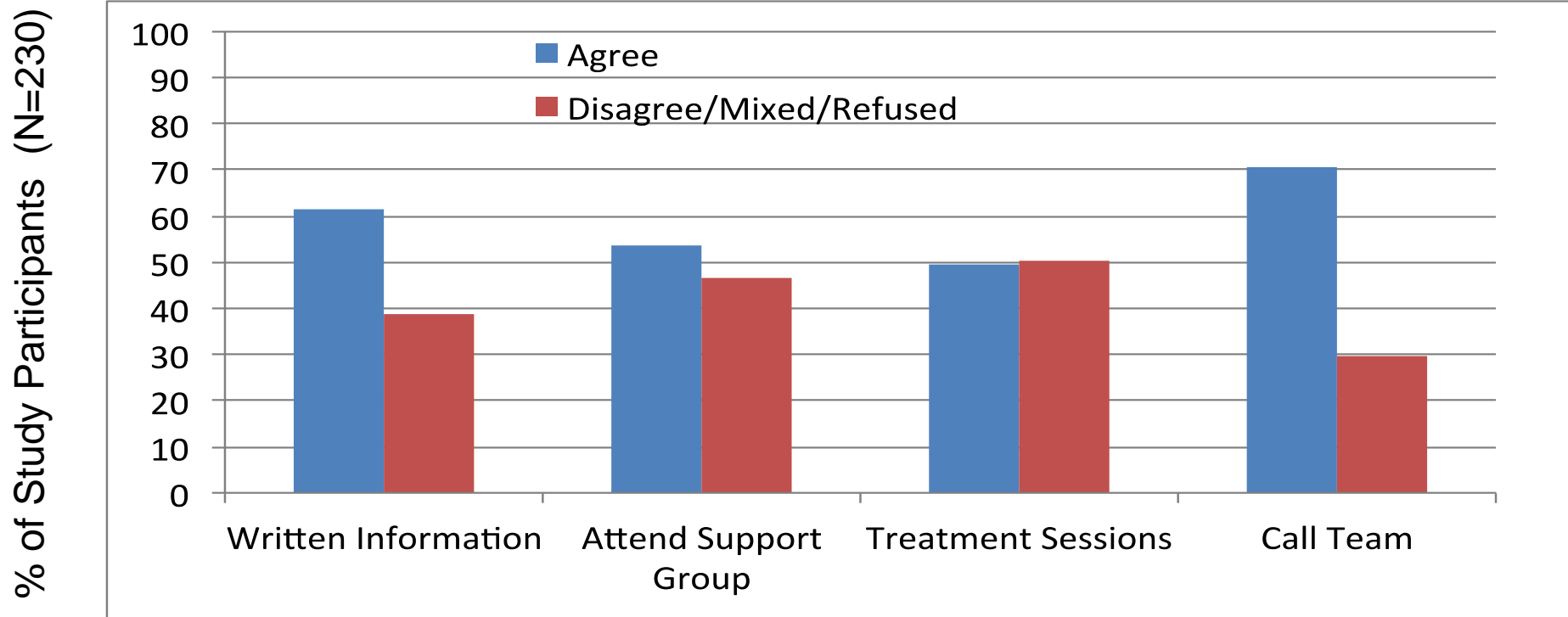
Baseline demographics

	REORDER (N=111)		ETAU (N=115)	
	n/	%	n/	%
	Mean ± SD		Mean ± SD	
<u>Demographics</u>				
Male	92	83	s98	85
Age (Yrs)	51.8 ± 9.5		51.2 ± 8.7	
Diagnosis				
Schizophrenia	37	33	32	28
Schizoaffective Disorder	16	14	14	12
Bipolar Disorder	49	44	53	46
Depression with psychotic feature	6	5	10	9
Psychotic disorder NOS	3	3	6	5
Currently Married	23	21	20	17
White	44	40	38	34
Spanish, Hispanic Or Latino	5	5	3	3
Lives with family	57	52	42	37

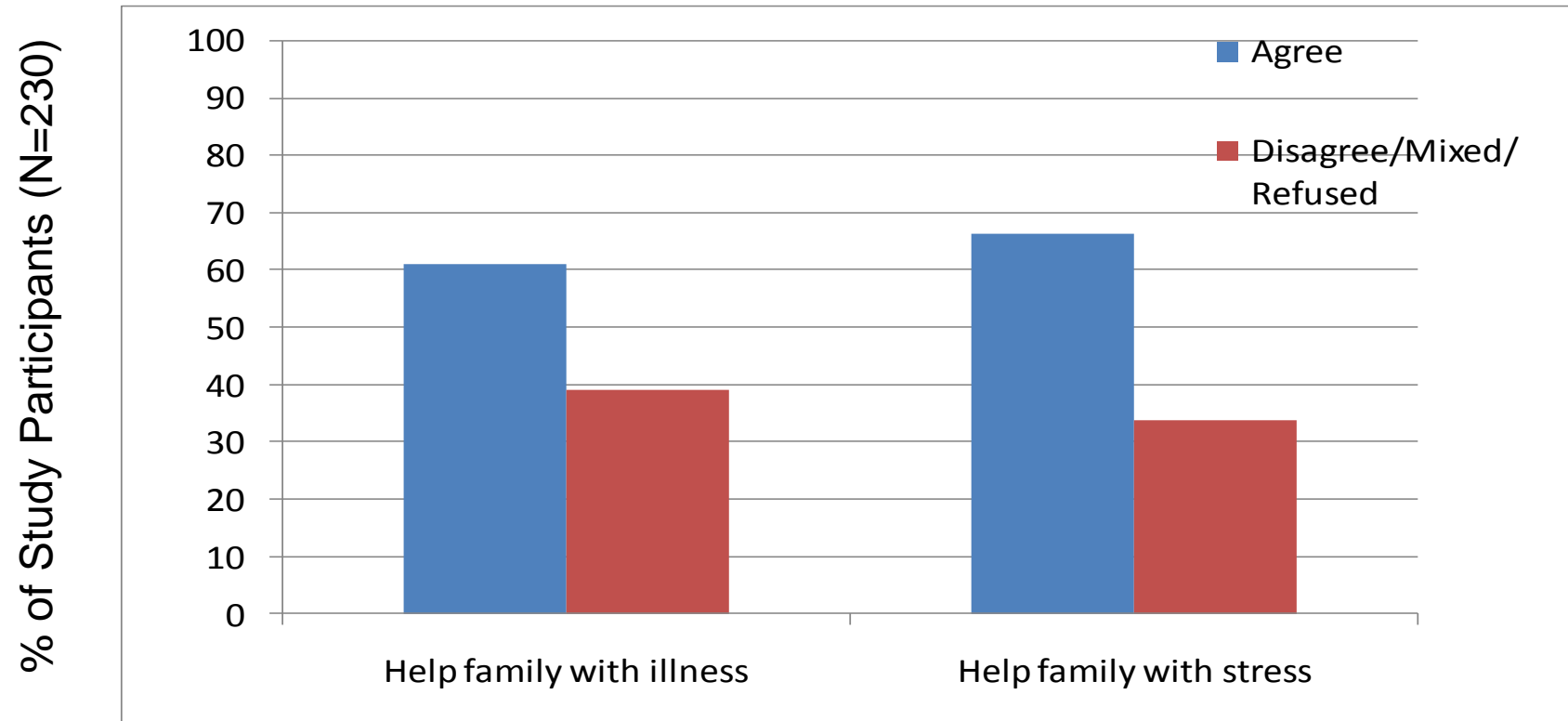
Relationship to Consumer of Primary Person Participating in Family Sessions



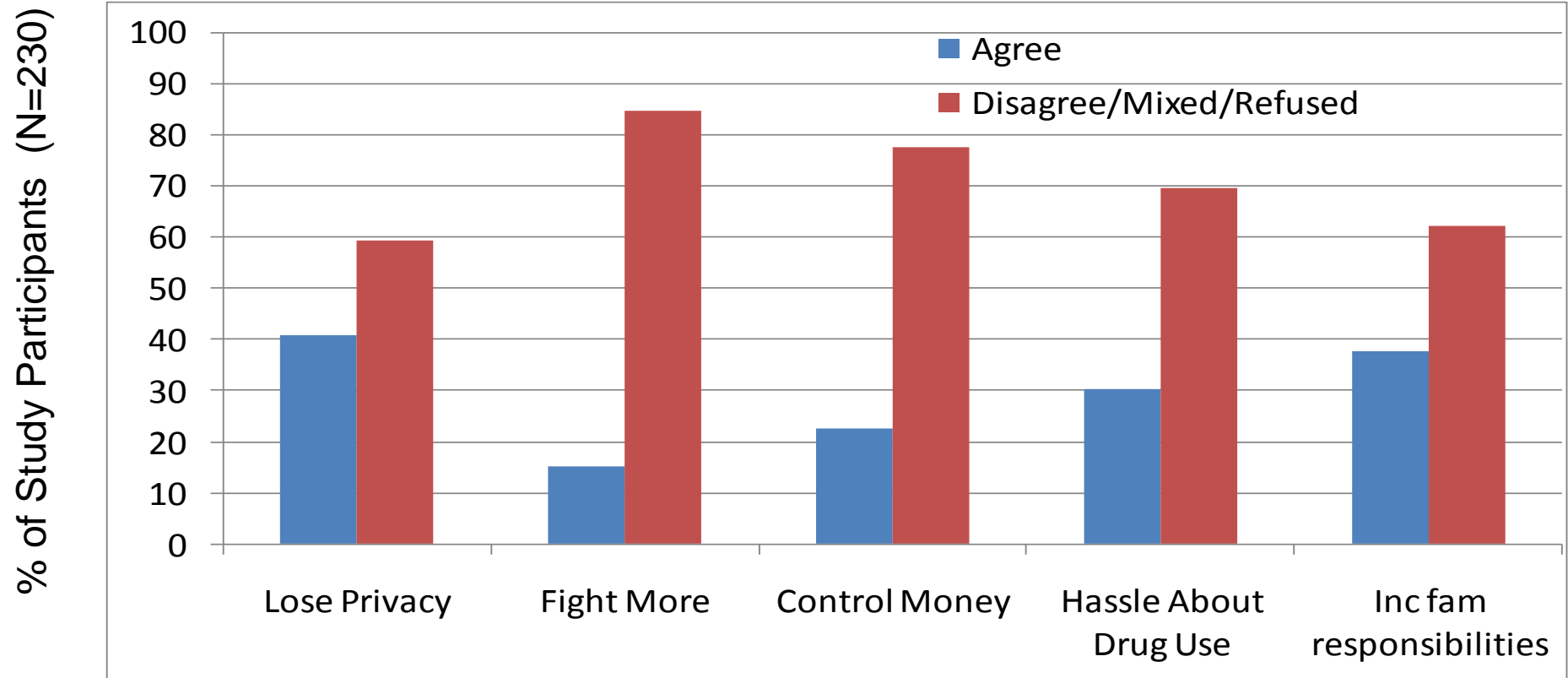
Consumer Preference for Family Involvement in Care



Consumer Perceptions of Benefits of Family Involvement



Consumer Perceptions of Barriers to Family Involvement



Types of Family Involvement Care Tailored to the Needs of Specific Consumers and Their Loved Ones

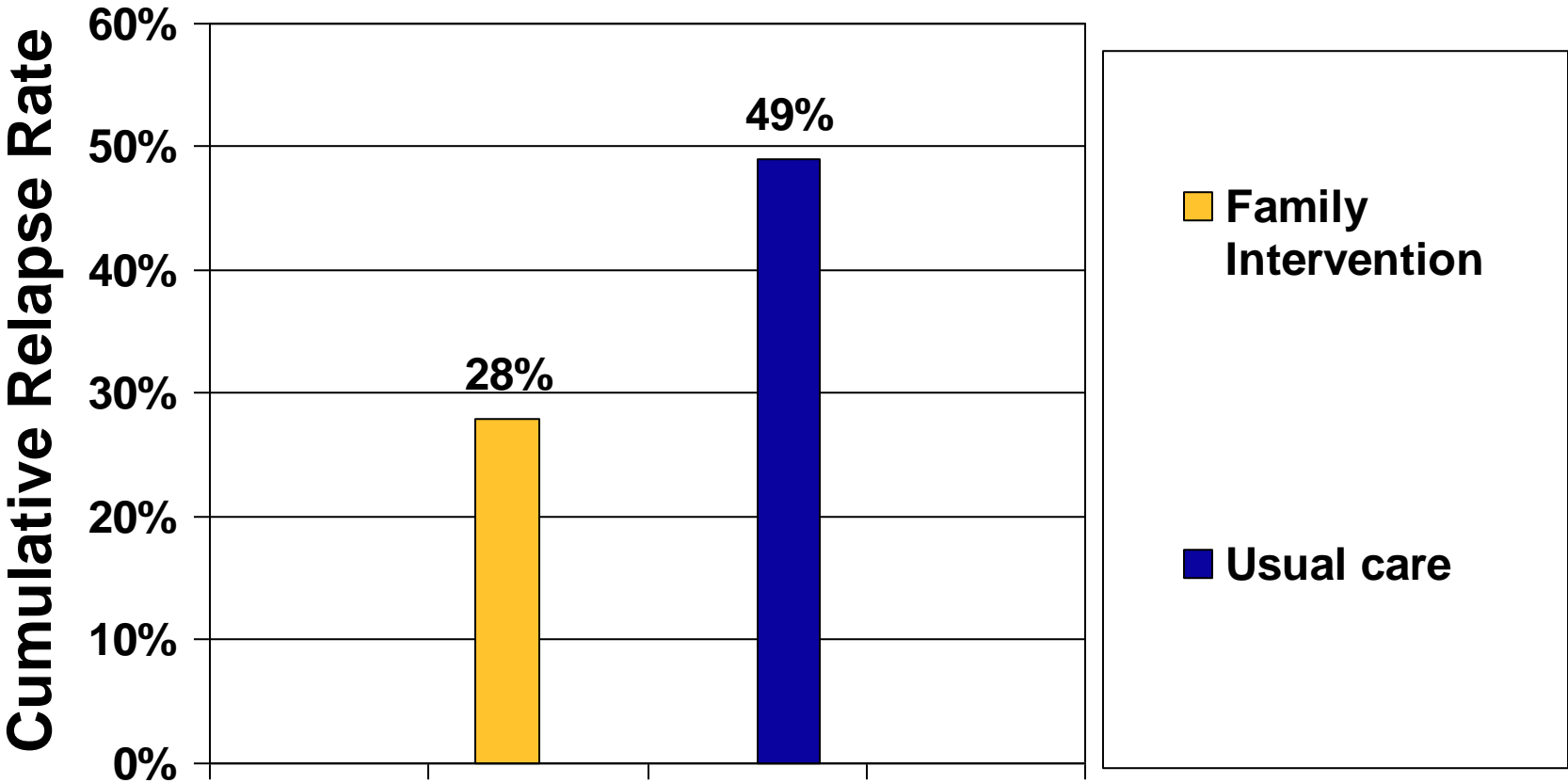
- **Contact With Treatment Team-**
 - Meet team;
 - invitations to attend team meetings;
 - relative orientation to agency services;
 - involving relatives in services (e.g. inviting them to a meeting with the supported employment team)
- **Family Consultation—**
 - Brief series of targeted meetings based on a needs assessment
- **Family Illness Education (Family Psychoeducation)—**
 - Provision of factual information—
 - Can involve referrals to Family Peer Led Support and Education Programs (NAMI Family-to-Family)
- **Intensive Family Interventions—**
 - Evidence-based Interventions Behavioral Family Therapy;
 - Multiple Family Group Therapy

Evidence for the Efficacy of Family Psychoeducational Interventions for Serious and Persisting Psychiatric Illnesses

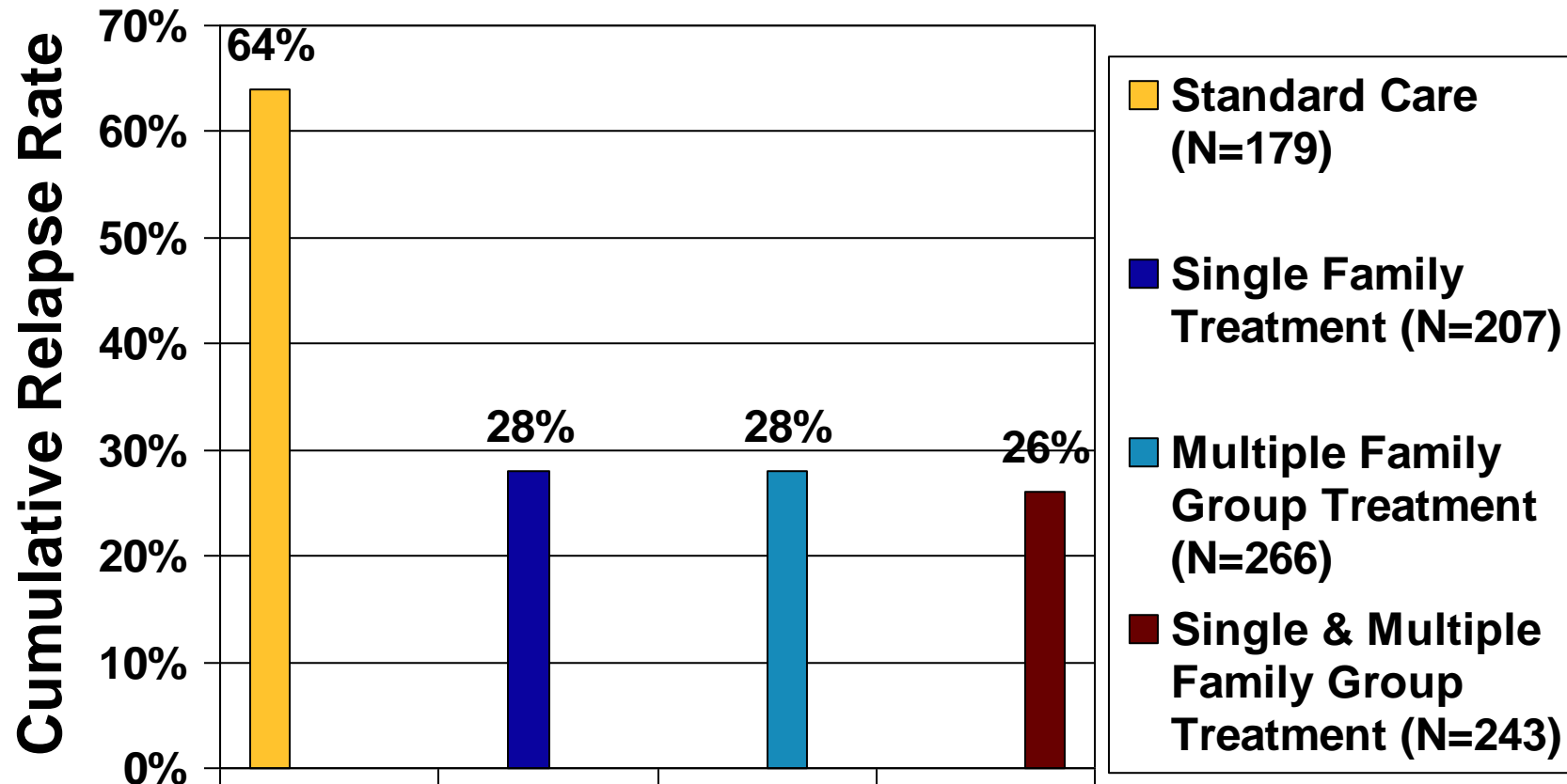
Research on FPE

- ▶ Single-family & multiple-family family programs standardized and empirically validated
- ▶ Outcome studies report a reduction in annual relapse rates for medicated, community-based people of as much as 50% by using a variety of educational, supportive, and behavioral techniques
- ▶ Defining features of an evidence-based family FPE
 - ▶ At least 6 months of regular meetings—weekly to biweekly
 - ▶ Involves illness education and *skills training* (communication and problem-solving); not just the provision of factual information
 - ▶ May or may not involve conjoint sessions with consumer
 - ▶ Includes instruction on coping with symptoms, relapse prevention, and work on personal goals

Mean Relapse Rates-18 Studies Comparing Relapse Rates in Family Intervention to Usual Care (n=895)¹

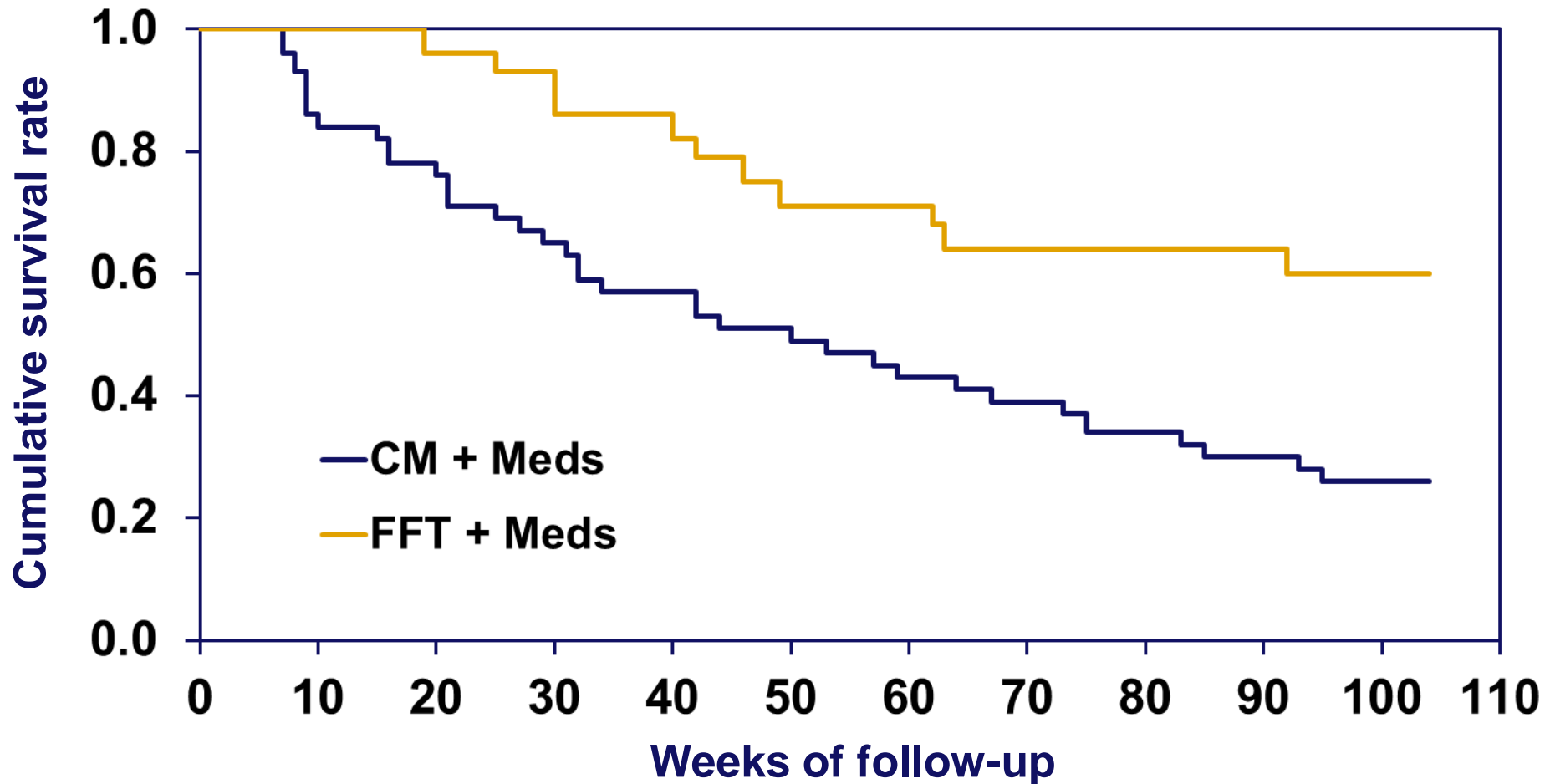


Combined Results of Family Intervention Programs on 2-year Cumulative Relapse Rates in Schizophrenia (11 Studies)



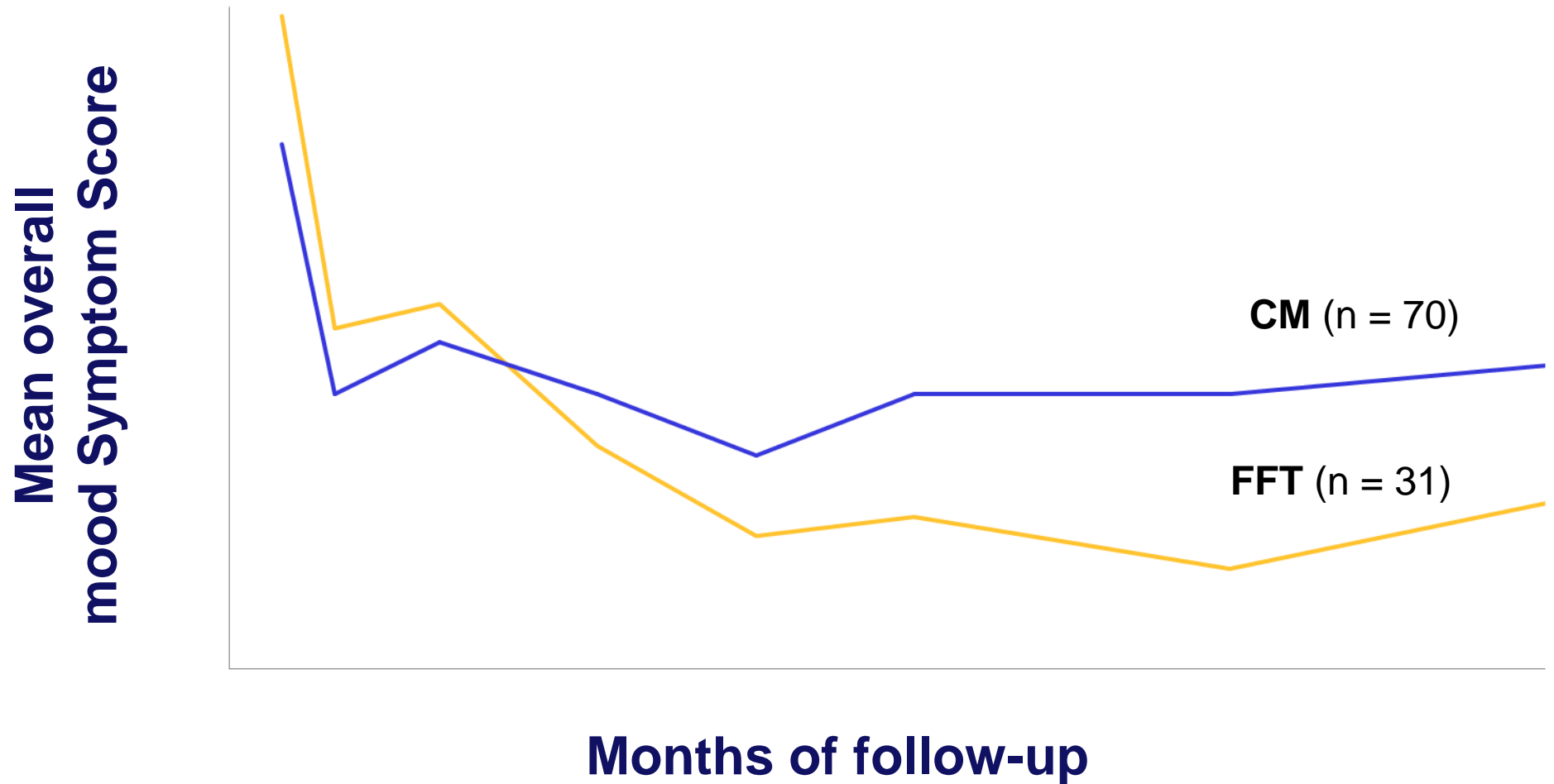
FFT + Medication Delays Relapse More than Crisis Management + Medication

(N = 101)



CM vs. FFT $\chi^2 (1) = 8.71, p = .003$; FFT, mean survival = 73.5 weeks; CM, 53.2 weeks.
Miklowitz DJ, et al. *Arch Gen Psychiatry*. 2003

FFT & Medications Improve Mood Symptoms More Than Crisis Management and Medications: 2-Year Follow-Up



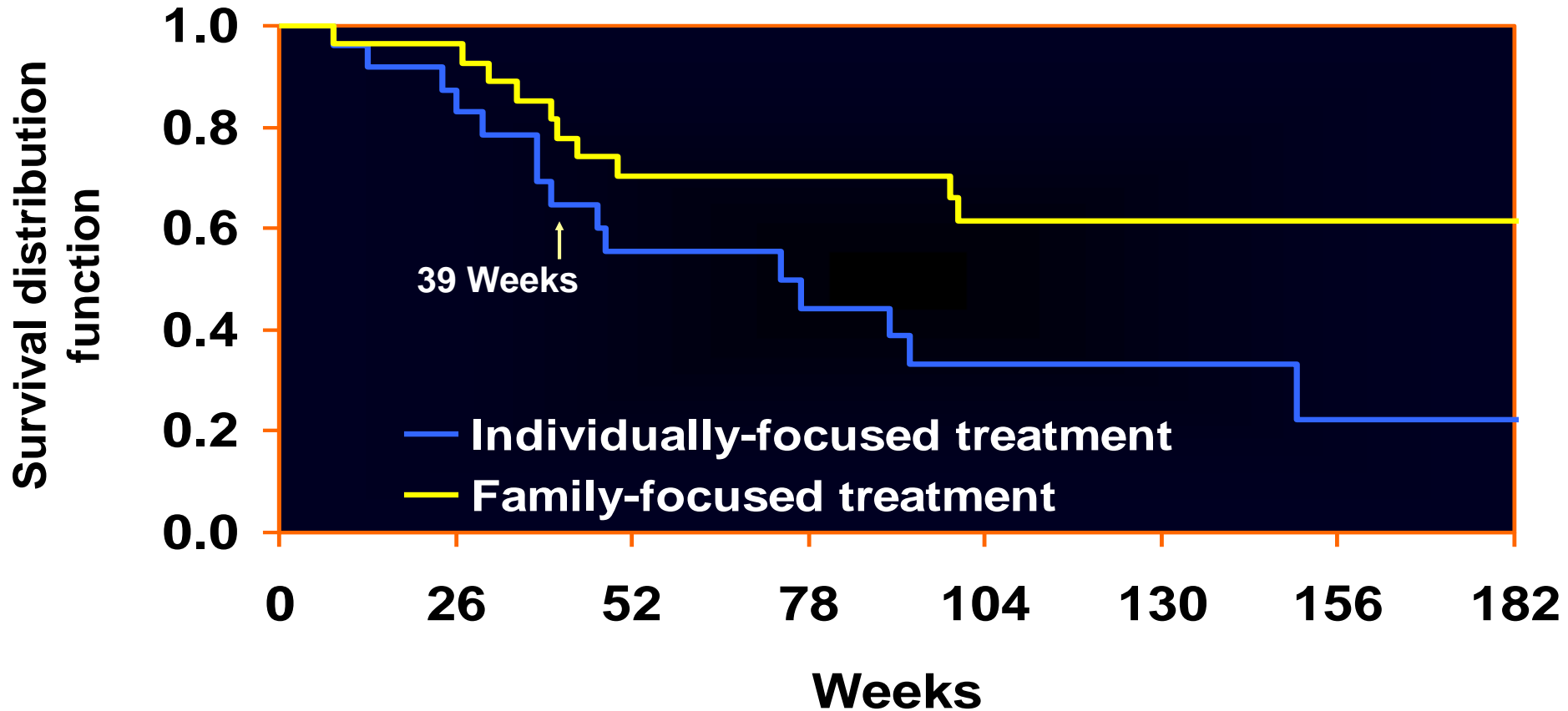
Repeated Measures ANOVA: Treatment * Time $F(7,549) = 2.81, p = .007$
Miklowitz DJ, et al. Arch Gen Psychiatry. 2003.

Key outcomes of Family Psychoeducation (2012 Cochrane Review)

- ▶ Family intervention may decrease the frequency of relapse (n = 2981, 32 RCTs, RR 0.55 CI 0.5 to 0.6, NNT 7 CI 6 to 8), although some small but negative studies might not have been identified by the search.
- ▶ Family intervention may also reduce hospital admission (n = 481, 8 RCTs, RR 0.78 CI 0.6 to 1.0, NNT 8 CI 6 to 13) and encourage compliance with medication (n = 695, 10 RCTs, RR 0.60 CI 0.5 to 0.7, NNT 6 CI 5 to 9) but it does not obviously affect the tendency of individuals/families to leave care (n = 733, 10 RCTs, RR 0.74 CI 0.5 to 1.0).

Greater Persistence of Effects of Family vs. Individual Therapy: Time to Rehospitalization

UCLA FFT Study (N=53)



$X^2(1) = 3.87, P < .05$

Rea, Tompson, Miklowitz et al. J Consult Clin Psychol. 2003.

Key outcomes of Family Psychoeducation (2012 Cochrane Review)

- ▶ Family intervention also seems to improve general social impairment and the levels of expressed emotion within the family.

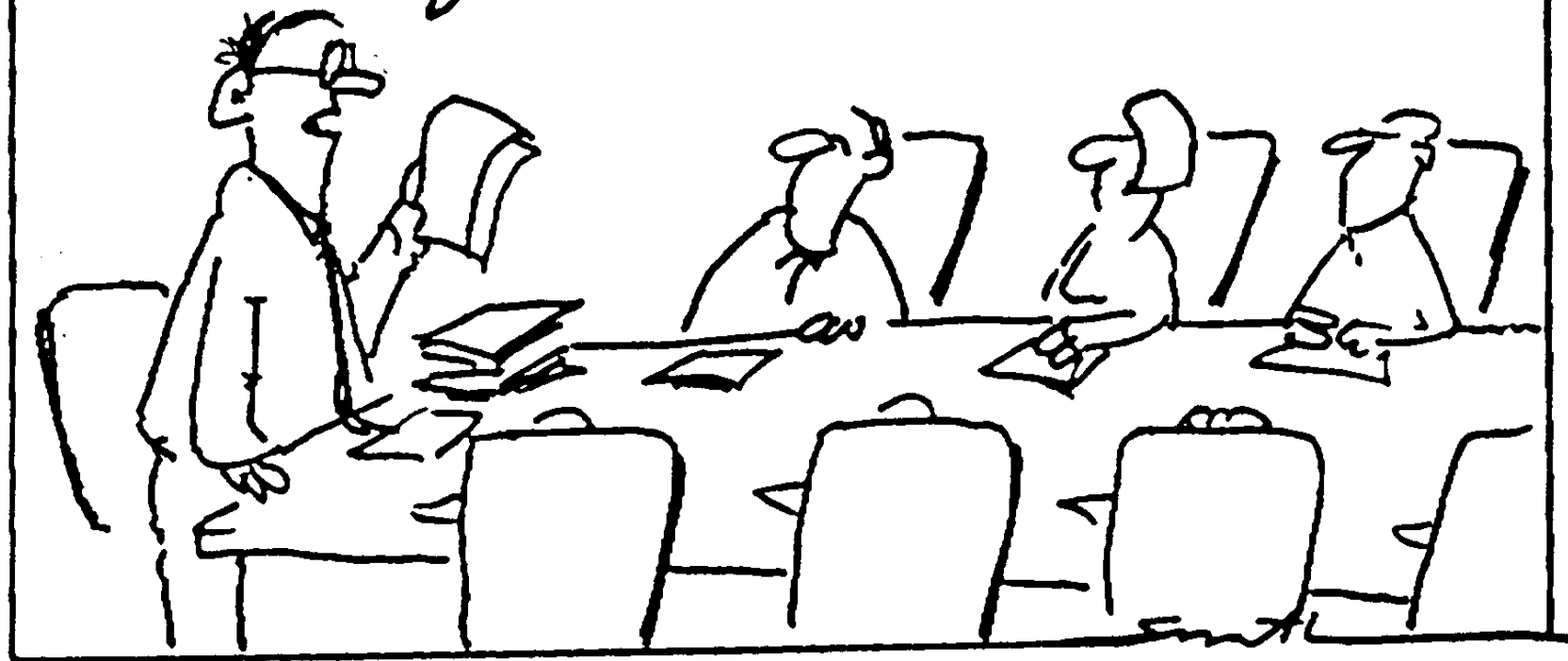
Summary of Evidence Supporting EBP

- ▶ Relapse rates in schizophrenia can be reduced by 20% if relatives are included in treatment.
- ▶ If programs last six months or more, relapse rates are reduced by 30% to 50%.

Who Can Benefit from FPE?

- ▶ Clients living with or in regular contact with family members (> 4 hours contact per week)
- ▶ Wide range of family relationships (e.g., parents, siblings, spouses, children)
- ▶ Relatives who want to help the client re-integrate into the community
- ▶ Families where the primary issue is grounded in the consumer's illness –we are *not* proposing FPE to deal with issues like blended families, anticipated divorce, divorce, problems with child rearing

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



Overview of the Family Services Continuum

← Continuum of Family Services →



Continuum of Family Services

Family Friendly Agency

- ▶ Activate the consumer to consider family involvement in care (shared decision-making)
- ▶ Detailed inquiry about social network part of initial and regular reviews (not just cursory)
- ▶ Rooms large enough for family meetings
- ▶ Clinicians trained in obtaining ROI with skill
- ▶ Routine provision of information about NAMI to consumers and relatives
- ▶ Involving family members in care is the default position—invitations to team meetings, orientation to agency services, involvement in evidence-based activities as appropriate
- ▶ Evening and/or weekend hours

Engaging the Family

Engagement

- ▶ Activate the consumer—shared decision-making
- ▶ Provide an array of services to meet consumer and relative need
- ▶ Home based sessions can help
- ▶ Often engagement is most likely at time of crisis or hospitalization
- ▶ Be kind and compassionate
- ▶ Motivational Interviewing can be useful
- ▶ Needs assessments can help

Continuum of Family Services

Family Education (FE)

- ▶ Treatment team provides factual information necessary to support the veteran and partner
- ▶ Offered in many formats, regularly scheduled and conducted over time including:
 - ▶ By professionals
 - ▶ By trained family members (e.g., NAMI Family-to-Family Education Program)—issue here is no access to consumer treatment team

Principles of Illness Education

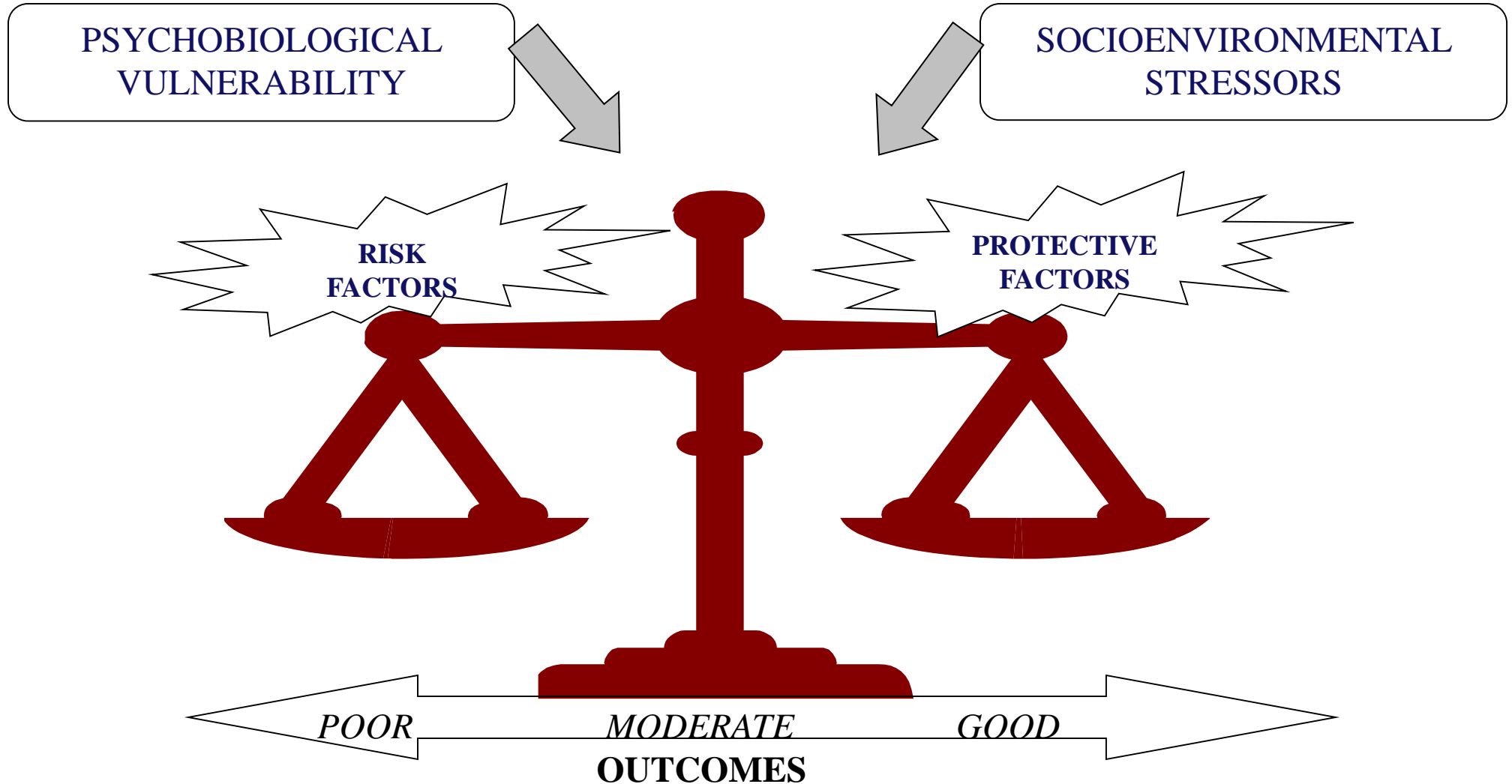
- ▶ Education is interactive
- ▶ Use multiple teaching aids
- ▶ Connote consumer as the “expert”
- ▶ Elicit relatives’ experience and understanding
- ▶ Avoid conflict and confrontation
- ▶ Education is a long-term process
- ▶ Evaluate understanding, especially of any at home assignments
- ▶ Review materials as often as possible
- ▶ Listen more than you talk
- ▶ NAMI, NIMH good sources of info

Typical Content & Order of Education Sessions

- The Stress-Vulnerability Model of Psychiatric Disorders & Relapse Prevention
- Illness Specific Education
- Medication (*Understanding Antipsychotic Medications, Understanding Antidepressant Medications, or Understanding Mood Stabilizing Medications*)
- Recovery from Mental Illness
- Helping a Relative who has a Serious Psychiatric Illness
- Other Education
 - Collaborating with the treatment team
 - Substance Use
 - Infectious Disease
 - Etc.

Etiology

Decrease blame/guilt/stigma
Increase knowledge for informed decision making



An Example: NAMI's Family to Family

FAMILY-TO-FAMILY EDUCATION CURRICULUM

- CLASS 1:** PRINCIPLES, GOALS, LEARNING ABOUT FEELINGS
- CLASS 2:** SCHIZOPHRENIA, MAJOR DEPRESSION AND MANIA; CRITICAL PERIODS
- CLASS 3:** TYPES AND SUBTYPES OF BIPOLAR DISORDER; DIAGNOSES OF PANIC DISORDER AND OCD
- CLASS 4:** BASICS ABOUT THE BRAIN AND "BIOLOGY OF RECOVERY"
- CLASS 5:** PROBLEM SOLVING WORKSHOP
- CLASS 6:** MEDICATION REVIEW
- CLASS 7:** EMPATHY WORKSHOP; DEFENSIVE STRATEGIES TO PROTECT SELF-ESTEEM
- CLASS 8:** COMMUNICATION SKILLS WORKSHOP
- CLASS 9:** "RELATIVE GROUPS" EXPERIENCE AND SELF-CARE
- CLASS 10:** REHABILITATION AND RECOVERY
- CLASS 11:** FIGHTING STIGMA; ADVOCACY

Continuum of Family Services

Family Consultation (FC)

- ▶ Family meets with mental health professional as needed to resolve specific issues related to the veteran's treatment and recovery
- ▶ Intervention is brief; typically 1 – 5 sessions for each consultation
- ▶ Provided on as needed or intermittent basis
- ▶ If more intensive ongoing effort is required, family can be referred to Family Psychoeducation
- ▶ Family Institute at the University of Rochester has a great program

Connecting

Explain goal: Get to know each other & understand family

- ▶ Casual conversation
- ▶ Explain the purpose and process of the consultation as it relates to the consumer's recovery
- ▶ Family tells their story, with an emphasis on current experiences
- ▶ Demonstrate empathy and understanding
- ▶ Recognize and reinforce strengths including personal, cultural and social resources
- ▶ Appreciate and incorporate family's cultural values and beliefs

Define and Prioritizing Wants/Needs

Explain goal: Prioritizing Wants/Needs

- ▶ Consultant shares perspectives
- ▶ Elicit reactions of family members
- ▶ Merge perspectives on shared views
- ▶ Include how the family supports the consumer's treatment goals
- ▶ Create list of family wants/needs
- ▶ Prioritize list with family to identify first steps

Planning and/or Providing Next Steps

- ▶ Explain goal: Figure out best way to address family wants/needs
 - ▶ Share ideas about ways to help family

Further consultation	Family psychoeducation	Share “Family Guidelines
Share info.About resources	Family support at agency	Problem-Solving Approach
Consultant is available prn	Education at agency	NAMI referral/Support Group
Consultant provide education	Other	NAMI referral/Education

- ▶ “Check in” with family and revise plan (if necessary)
- ▶ Set next meeting time OR say goodbye

Re-Connecting

- ▶ Casual conversation
- ▶ Get reacquainted and prepared for meeting
- ▶ Explain consultation to any new family members
- ▶ Restate the purpose based on outcome to the prior consultation
- ▶ Acknowledge their presence as a strength reflecting their commitment for the family member

Defining & Prioritizing Wants & Needs

- ▶ Review family' s wants & needs
- ▶ “Check in” with family to confirm wants, needs & agenda
- ▶ Layout the steps for addressing the family wants & needs

Providing the Family with Education, Support & Referral

Education

- ▶ Basic information on their loved ones mental health condition
- ▶ Guidance on how family members may support their loved ones treatment & recovery
 - ▶ Use of Family Guidelines
 - ▶ Problem-Solving Strategies
- ▶ Provide practical information to assist family members to navigate the mental health system

Providing the Family with Education, Support & Referral cont' d

Support

- ▶ Demonstrate an understanding of the family experience
- ▶ Serve as an advocate for family members
- ▶ Acknowledge the strength of family members

Referral

- ▶ Provide information regarding community services such as NAMI, the Mental Health Association and other resources
- ▶ Directly promote a linkage for the family member to a community

Ending the Consultation

- ▶ “Check in” with family – ask whether wants/needs/goals have been satisfied
- ▶ Express appreciation to family and recognize strengths
- ▶ Say goodbye

Continuum of Family Services

Family Psychoeducation (FPE)

- ▶ Type of evidence-based Family Therapy
- ▶ Focuses on developing coping skills for handling problems posed by mental illness in a member of the family
- ▶ Can be used in single family format (e.g., Behavioral Family Therapy) or multi-family group (e.g., Multiple Family Group Therapy)

Behavioral Family Therapy

- ▶ Structured approach to working with families with a family member diagnosed with a psychiatric disorder
- ▶ Accepts the biological basis of specific psychiatric disorders
- ▶ Views the family as having an important influence on the course and outcome of the disorder
- ▶ Builds on strengths
- ▶ Goal is to galvanize the family to support consumer recovery

Behavioral Family Therapy nice family therapy session

Major Focus of BFT:

- ▶ Develop a basic knowledge of relative' s disorder
- ▶ Improve communications skills
- ▶ Foster ability to solve problems and achieve goals

Behavioral Family Therapy

- ▶ Consumer & family attend together
- ▶ Behavioral
- ▶ Weekly → Biweekly → Monthly
- ▶ Typical course of treatment is 9-12 months



Behavioral Family Therapy Includes Six Components

- ▶ Engagement—one extended or 2 reg sessions
- ▶ Orientation—one session
- ▶ Assessment
(individual session with each participant)
- ▶ Education about mental illness and its treatment - 4-6 sessions
- ▶ Communication skills training - 3-6 sessions
- ▶ Problem-solving skills training - 6-12 sessions
- ▶ Work on specific problems
(as needed)

Guiding Principles for the Behavioral Family Therapist

- ▶ Promote an open sharing of information among participants
- ▶ Develop a problem-solving orientation
- ▶ Reduce negative affect in the family
- ▶ Instill hope for change
- ▶ Generalize skill use through out of session assignments

Format of BFT

- ▶ Individual family sessions
- ▶ Relatives and consumers included
- ▶ “Open door” policy for reluctant participants
- ▶ 45-50 min sessions
- ▶ Sessions conducted on a “declining contact basis”
- ▶ Focus is on learning new information and skills, not fostering insight-behavioral orientation
- ▶ Out of session assignments are important

Intensive Family Intervention: Goals

- ▶ To **establish** a working alliance between the treatment team and family members
- ▶ To provide education to family members about responses to disorder
- ▶ To enhance family coping skills through:
 - ▶ Improved communication
 - ▶ Teaching problem solving skills

Relapse Prevention Worksheet

_____ has a risk of reexperiencing symptoms
of _____ (specify disorder)

The earliest **OBSERVABLE signs that symptoms are flaring up are:**

The circumstances that tend to make symptoms worse include:

Plan to be implemented when warning signs flare up:

Doctor's Name: _____ **Phone:** _____

Therapist or Case Manager's Name: _____ **Phone:** _____

Family Services Funding Issues

- ▶ Most insurers cover conjoint therapy sessions with a parity dx (90847) ; often do not include relative alone sessions (90846)—these two codes do not have a duration element
- ▶ Can use 90834 and 90837 when inviting family members in for occasional sessions—these have a duration element
- ▶ Can use 90887 for family support/education interventions

Questions

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