

Is Family to Family Education an Evidence-Based Practice?

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Outline

- What is an evidence-based practice?
- Including families in the care of persons with schizophrenia and other mental illnesses: What are established evidence-based practices?
- Why can't we just stop here? Implementation challenges of current EBP's
- Moving the field forward: Families helping families

What an EBP is NOT

- The intervention you believe in
- The intervention someone is paid most to do
- The intervention that is necessarily done all the time
- The intervention found to work in three case reports by an enthusiastic and talented clinician

"Evidence Based Practice is the integration of best research evidence with clinical expertise and patient values."

Institute of Medicine

Research Evidence

- Hierarchy of Evidence
 - Anecdotal reports
 - Open (pre-post) trials
 - Controlled (but not randomized) trials
 - Randomized trials
- Standard for "EBP" shifts with different evaluators
- PORT requires randomized trials with independent replication

Questions About EBP

- What if a randomized trial is unethical?
- How representative of the population to receive a treatment is the population under study?
- What is the magic of .05? (An x% chance that an improvement is due to chance alone)
- How to integrate the values and preferences of patients and families?

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Reminders of History

- Fromm-Reichman (1948) asserted that individuals with schizophrenia are "painfully distrustful and resentful of other people due to the severe early warp and rejection" they encountered in relationships, "mainly in a schizophrenogenic mother."

What is Best Practice?

- Schizophrenia PORT treatment recommendations
- Patients who have on-going contact with their families should be offered a family psychosocial intervention which spans at least nine months and which provides a combination of:
 - education about the illness
 - family support
 - crisis intervention
 - problem solving skills training.

Lehman AF, Kreyenbuhl J, Buchanan R, Dickerson F, Dixon L, Goldberg R, Green-Paden L, Tenhula W, Boersescu D, Tek C, Sandson N, Steinwachs D. The Schizophrenia Patient Outcomes Research Team (PORT): Updated Treatment Recommendations 2003. *Schizophrenia Bulletin*. 2004; 30 (2): 199-217

What is family psychoeducation?

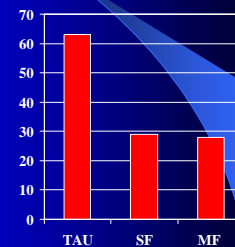
- It is not one model, but a group of programs that share certain characteristics
- Professionally created and led
- Offered as part of an overall clinical treatment plan for the ill individual
- Last nine months to five years
- Usually is diagnosis-specific
- Focus first on consumer outcomes, although family well-being is essential as an intermediary outcome.

What is family psychoeducation?

- Differing formats (multiple-family vs. single-family sessions vs. mixed)
- Different type of participation of the consumer
- Different locations (clinic-based, home, family practice or other community settings)
- Variable emphasis on didactic, cognitive-behavioral and systemic techniques.

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

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



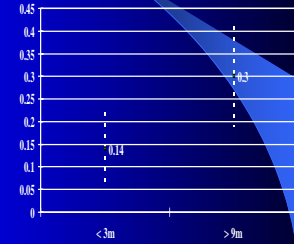
McFarlane, W. R., Dixon, L., Lukens, E., Lucksted, A. (2003). Family psychoeducation and schizophrenia: a review of the literature. *Journal of Marital and Family Therapy*, 29(2), 223-245.

Key outcomes of Family Psychoeducation (2004 Cochrane Review)

- Family intervention reduces relapse
 - N=723, 14 RCTs
 - RR 0.72; CI = 0.6 – 0.9
- Family intervention improves compliance with medication
 - N=369, 7 RCTs
 - RR = .74, CI = 0.6 – 0.9

Meta-analytic Results: Length of Intervention as Moderator of Effect Size

- Length: moderator of effectiveness
- However, critical ingredient is not intensive skill training
 - Treatment Strategies Study SFM = AFM



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%.

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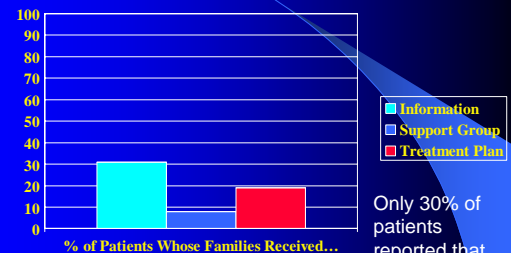
What is Standard Care? Medicaid Claims Proportion of Study Population with at Least One Outpatient Mental Health Service (N=6066)



Dixon et al., *Psychiatric Services* 1999;50:233-238.

Schizophrenia PORT

Receipt of Family Services: Patient Field Study (N=539)

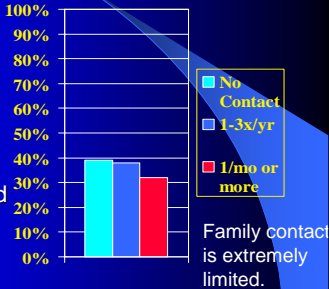


Only 30% of patients reported that families received even education

Dixon et al., *Psychiatric Services* 1999;50:233-238.

Baltimore Community Mental Health Center Study

- Random sample of 214 clients with SZ and Affective Disorder
- 19-item survey of primary therapist
- Frequency, type and focus of clinician-family contact



Dixon et al., *Psychiatric Services* 2000;51:1449-1451

Taking Stock

- Ordinary practice does not include family psychoeducation
- Can we make efforts to disseminate family psychoeducation?
- Short answer: With great difficulty, at considerable expense, for relatively few families

EBP Toolkit Project

- FPE model was implemented in 3 of 8 EBP states at 4 of the 52 sites (two sites dropped out at year 1)
- "High" fidelity was reached (FPE fidelity scale mean >4) at two of the sites; the other sites reached "medium" fidelity (between 3.0-3.9 FPE fidelity scale means)

Toolkit Project (Laura Coots, PC)

- A total of 45 clients were served by FPE over the course of the project at these 4 sites out of over 2000 clients project-wide; small n of sites implementing, but also relatively low penetration as a practice (as compared to ACT, for example)
- FPE practice can be implemented quite discretely in small programs with small number of staff trained

Toolkit Project

- FPE required a great deal of front-loaded work including engagement process / getting interested families, 3-5 single family joining session, and day-long educational workshop
- Experience suggested that there was a GREAT deal of enthusiasm by clients and family members in terms of satisfaction with the groups -- those who stuck with it really liked it

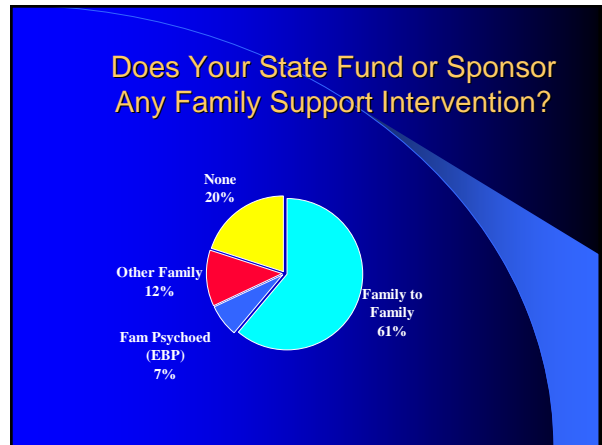
New York State Family Psychoeducation Initiative

- Implementation of FPE statewide
- Abandoned for different "consultation" model



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- ## Another View of Standard Practice: A State Survey of Services Provided to Families of Adults with Severe Mental Illness
- Five question survey distributed to State Mental Health Authorities
 - 88% Response Rate
 - Collaboration with the National Association of State Mental Health Program Directors
- Dixon L, Goldman HH, Hirsch A: State policy and funding of services to families of adults with serious and persistent mental illness. *Psychiatric Services* 1999;50:551-552.



- ## Family-To-Family
- Dr. Joyce Burland
 - 1991 F2F was began in Vermont
 - 1998 F2F became a NAMI sponsored program
 - Currently offered in 48 states, Canada, Mexico and
 - Based on a trauma / recovery model

- ## Time Frame
- Meets once a week for 12 consecutive weeks
 - Meets each week for 2 ½ hours
 - Usually meets in the evenings, when more family members are likely to be available

Who Takes The Course?

- Relatives of individuals diagnosed with:
 - Schizophrenia
 - Major depression
 - Bipolar disorder
 - Borderline personality disorder
 - Panic disorder
 - Obsessive-compulsive disorder
 - Co-occurring addictive disorders

Who Teaches The Course?

- Volunteer family member graduates of the Family-to-Family course
- Family member teachers receive an intensive training on the model
- The NAMI Education Program is highly manualized for uniform delivery
- The format is combines didactic and interactive skills workshops

Helping Families Cope with Trauma

- The basic focus in the course is on the family member, not the ill person
- Encouraging families to regain the primacy of their own lives
- Expressing anger and grief: the crux of self-care
- Teaching empathy as the means of gaining acceptance of loss
- Because the facilitators are family members they can help each other let go

Curriculum In Family Education

- Problem-solving skills workshop
- Medication review
- Inside mental illness, learning about mental illness from the consumer perspective
- Communication skills workshop
- Self-care, learning about family burden and managing negative feelings

Curriculum In Family Education

- The vision and potential of recovery
- Advocacy
- Review, sharing and celebrating the journey together

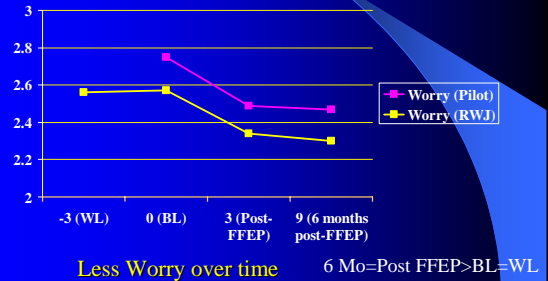
FFEP and Family Psychoeducation

Dimension	FFEP	Family Psychoeducation
Target	Family, then Patient	Patient, then Family
Duration	12 weeks	9 months +
Leader	Family members	Clinicians
Diagnosis	Broad	Schizophrenia, but expanding research base
Research Base	Growing evidence of improved family well-being	Very extensive evidence of relapse reduction

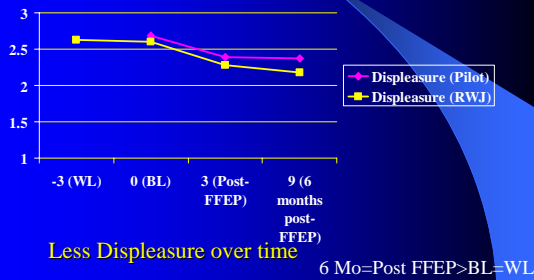
Evaluations of FFEP

- Study 1: Uncontrolled pre-post pilot with six-month follow-up
- Study 2: Prospective waiting list control study
- Study designed by collaboration between UM team and NAMI
- Assessments at waiting list, baseline, post-FtF, & 6-months post-FtF via interview
- Trained family member research interviewers

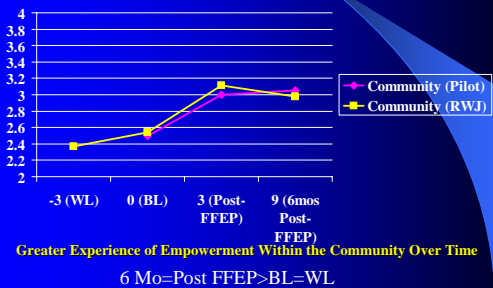
Results: Affective Response Module of Family Experience Interview



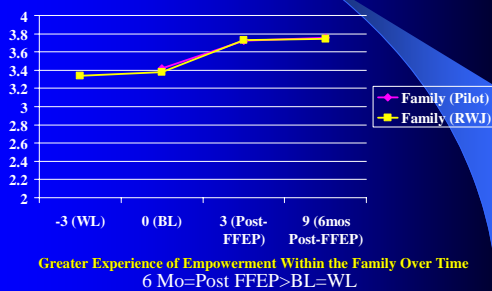
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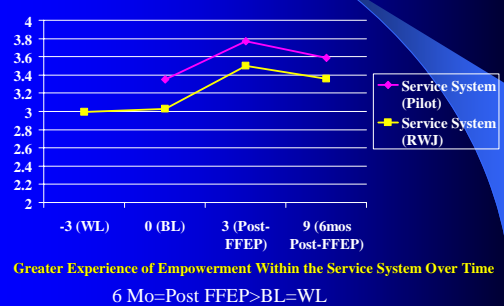
Results: Family Empowerment Scale: Community



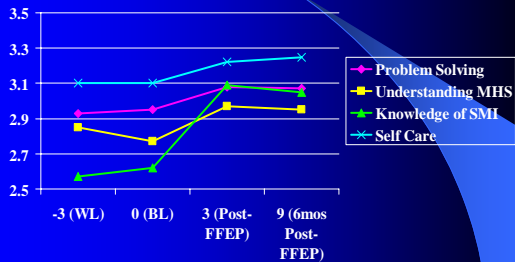
Results: Family Empowerment Scale: Family



Results: Family Empowerment Scale: Service System



Results: FMQ and FTF Scales



Greater Experience of Empowerment Within the Community Over Time

6 Mo=Post FFEP>BL=WL

Results: Family to Family Questions

- Same change pattern observed for:
 - I understand the causes of mental illness
 - I understand the medications used to treatment mental illness
 - I understand the symptoms of mental illness
 - I have realistic expectations
 - I know who to turn to for help when feeling upset
 - I know how to advocate for better treatment
 - I know how to communicate my concerns

Results: Family to Family Questions

- Same change pattern observed for:
 - I worry about what the future will bring
 - Trying to deal with my relative makes me feel helpless
 - I can set firm limits with my relative
 - I know my relative is doing the best he/she can
 - Being in a peer family group makes me feel safer
 - I can challenge authority figures when I need to
 - I can identify the support that I need

Current Study of FFEP

- Randomized Controlled Outcome Trial, funded by NIMH over 4 years
- Working with 4 Maryland NAMI groups
- Family member, Family system, and Consumer outcomes
- Interviews at baseline, post FtF, and 6months after the completion of FtF.

Is Family to Family an EBP? Other Evidence

- RCT of Journey of Hope in Louisiana
- 8-week Family Education program
- 462 family members of adults with mental illness randomized to immediate JOH (N=231) or to nine-month waiting list (N=231)

Pickett-Schenk et al. Improving knowledge about mental illness Through family-led education: the JOH, Archives of General Psychiatry 2008, 59, 49-56

Results

- Significantly increased knowledge of mental illness
- Significantly reduced need for information
 - Coping with positive symptoms
 - Coping with negative symptoms
 - Problem management
 - Basic facts about causes and treatment
 - Community resources
- Significantly increased satisfaction with caregiving

Pickett-Schenk et al. Improving knowledge about mental illness Through family-led education: the JOH, Archives of General Psychiatry 2008, 59, 49-56
Pickett-Schenk et al. Changes Archives in caregiving satisfaction and information needs...American Journal of Orthopsychiatry 2006, 76, 4, 545-553.

Family Interventions

- Persons with schizophrenia who have ongoing contact with their families, including relatives and significant others, should be offered a family intervention that lasts at least six to nine months. Such interventions have been found to significantly reduce rates of relapse and re-hospitalization.
- Key Elements:
 - illness education
 - crisis intervention
 - emotional support
 - training in how to cope with illness symptoms.

Family Interventions

- A family intervention that is shorter than six months, but at least four sessions in length, should be offered to persons with schizophrenia who have ongoing contact with their families. Possible benefits for patients include reduced psychiatric symptoms, improved treatment adherence, functional and vocational status, and treatment satisfaction. Key elements include
 - education,
 - training
 - support.

The selection of a family intervention should be guided by collaborative decision making among the patient, family and clinician.

What About Clinical Care? New Approach Must

- Address consumers' concerns regarding family involvement
- Promote consumers' control of care
- Educate consumers regarding benefits of family involvement and participation in care
- Work toward promoting utilization of EBP and its precursors of basic family involvement

The Family Member Provider Outreach Model (FMPO)

- A recovery-oriented program to promote family participation in treatment
- A collaboration between Lisa Dixon, MD, MPH, (VISN 5) Shirley Glynn, Ph.D. and Amy Cohen Ph.D. (VISN 22)
- Based on services delivered by a mental health professional who has a family member with mental illness

FMPO Intervention Goals

- Promote consumers' empowerment in decisions about involving "family" in care
- Increase consumers' and family members' satisfaction with mental health care and family relationships
- Increase rates and numbers of clinician-family contacts
- Increase rates of participation in Family Psychoeducation

Phase 1: FMP & Consumer

- Help the consumer make an informed decision about whether or not to include family in his/her treatment.
- Identify how the family can become more productively involved in his/her care.
- Activate the consumer to promote this participation him/herself.

Decisional Balance Exercise

Good Outcomes from Having Family More Involved in Care

relatives might feel calmer if they know the doctor,
might be able to manage medication better,
relatives might be able to help me more if I have a symptom flare-up,
relatives might be able to help me reach some of my goals

Bad Outcomes from Having Family More Involved in Care

might risk privacy,
might feel too controlled,
might lead to more fights

FMPO Phase Two: Family Phase

Goals:

- Increase family knowledge about mental illness, treatment, and resources for family support (e.g., NAMI)
- Encourage families to interact with consumers' regular treatment team
- To strengthen family members' ability to support the consumer's treatment and recovery

FMPO Summary

- Consumers with serious mental illness should play an active role in:
 - making choices about involving their family in treatment
 - engaging family as partners in treatment
- FMPO is a promising recovery-oriented approach to promote family participation in treatment.

Final Points

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