

Outcomes of the peer-taught 12-week family-to-family education program for severe mental illness

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Objective: Family-to-Family Education Program (FFEP) is a 12-week course for family members of adults with serious mental illness (SMI). This study evaluates the effectiveness of FFEP for several family member outcomes.

Method: The FFEP enrollees on a ≥3-month waiting list were eligible; 95 consenting family members agreed to four interviews (waitlist, pre-FFEP, post-FFEP, and 6 months post-FFEP) regarding subjective and objective burden, empowerment, and depression. Mixed effects ANOVA models tested hypotheses of decreased burden and increased empowerment after FFEP.

Results: The FFEP was associated with reduced subjective burden ($P < 0.01$) and increased empowerment ($P < 0.01$) without changes in objective burden. Knowledge about SMI, understanding the mental health system, and self-care also improved. There was no significant decay at 6-month followup.

Conclusion: This study provides evidence that FFEP is helpful to relatives of persons with SMI by reducing subjective burden and worry, and increasing empowerment, knowledge about SMI, understanding the mental health system, and self-care.

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Introduction

Family members play important roles in the lives of many adults with serious mental illnesses (SMIs) (1) and across diverse contexts often report feeling overwhelmed, frustrated, alone, thirsty for practical knowledge, and abandoned by people from whom they usually seek support (2–6). They also often report dissatisfaction regarding their interactions with the mental health system (4, 7–12). Families and consumers seek information about mental illness and its treatments, relevant resources, coping, communication and problem-solving skills (4, 6).

Family psychoeducation, a clinical approach to assisting families and persons with schizophrenia, is considered an evidenced based practice for reducing client hospitalization (13, 14). Family psychoeducation programs are professionally created and led, offered as part of an overall clinical

treatment plan for the ill individual, last 12 months to 3 years, are usually diagnosis-specific, and focus first on patient-outcomes with family well-being considered an important intermediary outcome. Family psychoeducation has not been widely available to family members due to dissemination and adoption obstacles on numerous levels (13, 15–17).

In part to fill this gap, family- and peer-based education programs have emerged as important resources for family members of persons with severe mental illness. One such program that is widely disseminated is the Family-to-Family Education Program (FFEP), sponsored by the National Alliance for the Mentally Ill (NAMI). FFEP (formerly called Journey of Hope) was developed in 1991 by NAMI member Joyce Burland, a psychologist and family member of two people with SMI (18). Well-trained family-member volunteers teach this 12-week program using a

highly structured, scripted manual. In weekly 2–3 h sessions, attendees receive information about mental illnesses, treatments, medication, and rehabilitation. They also learn self-care, mutual assistance and communication skills, problem-solving strategies, advocacy, and develop emotional insight into their responses to mental illness (19). FFEP classes are held in the community and are open to anyone with a family member who has serious and persistent mental illness, whether or not the ill person is receiving treatment. The model is based on theories of stress and coping, trauma recovery, adaptation and support; family-member well-being is the primary outcome of concern (19).

To date, FFEP is offered in 45 USA states plus Puerto Rico, two Canadian provinces (British Columbia and Ontario), and three regions in Mexico. It has over 3000 volunteer teachers and 250 trainers of new teachers, with plans to continue international expansion. In each locale it is supported by a combination of grass-roots donations and/or municipal mental health funds. The program is free to participants. So far, in the USA an estimated 80 000 family members have participated in FFEP classes nationally, 1500 in Canada, and 300 in Mexico (J. Burland, personal communication, August 2003). In each locale, some attendees are later trained to teach the program and a few of these receive still more training to become trainers of future teachers, allowing the model to sustain itself.

In contrast with family psychoeducation, which has an extensive research base documenting its effectiveness for a variety of outcomes, rigorous studies documenting the effectiveness of peer-based family education have been limited. A 1997 program evaluation of FFEP in three states found that participants were highly satisfied and reported increased knowledge of mental illness, improved management of their ill relative's behavior, and increased awareness of the mental health system (20). Drop-out rates were low (20%), and attendees report improvements in their knowledge and ability to cope effectively with the challenges of mental illness in their family (20). Others have noted that families seem to like the stable, predictable structure of each class meeting (21). Additionally, we have recently reported an uncontrolled pilot study of FFEP in which participants had decreased subjective burden of illness and increased empowerment at the conclusion of FFEP, and these benefits were sustained 6 months post-FFEP termination (22). However, these and other evaluations of FFEP (23) have used naturalistic designs without any comparison group, making their results difficult to evaluate.

Aims of the study

This study conducted a controlled evaluation of the effectiveness of the FFEP. We hoped to replicate the results of our pilot, i.e. that family members of persons with severe mental illness would have reduced subjective burden of illness and increased empowerment after participation in the FFEP program. We also assessed whether specific subgroups of family members were more likely to benefit from FFEP.

Material and methods

Overview

This study recruited family members who signed up for FFEP and were on a waiting list for at least 3 months before a class became available. Consenting subjects were assessed at four time points: waitlist (3 months before FFEP), baseline (at the beginning of FFEP), immediately after FFEP, and 6 months after FFEP was completed. In Maryland, current resources allow NAMI-Maryland to conduct two rounds of classes each year (spring and fall) with multiple classes across the state during each round. Participants for this study were recruited from the 15 classes held between February–November, 2000 on the USA east coast, in six different Maryland counties and the city of Baltimore.

Recruitment and Consent

Individuals learn about FFEP's availability through word-of-mouth from FFEP 'graduates', NAMI publicity, and clinician referrals. For this study, anyone contacting the state NAMI-MD office or a local affiliate and expressing interest in FFEP was given basic information and then referred to Bette Stewart, NAMI-MD's FFEP state coordinator. She then called each person to (i) engage them in anticipation of the FFEP class and waitlist, and (ii) if they would be waiting 3 months or more, to describe this study and ask if they were willing to be contacted by research staff and to consider participating. If yes, she forwarded their contact information to the research staff who called and presented the study. Written informed consent was obtained from all study participants in full accordance with the standards of the University of Maryland Institutional Review Board that approved the study. Because FFEP class start dates are not publicized, potential enrollees did not know when the next class would be available before they called. Therefore, the waiting time for FFEP is

virtually randomly determined; persons meeting the 3-month wait-list criterion for this study constitute a virtually random subset of people signing up for FFEP.

Assessments

The Caregiver Interview included modules from the Family Experience Interview Schedule (FEIS) (24) which has well established reliability and validity. Among several other information, FEIS modules included the following that were used in this paper: Background (demographics and level of involvement with ill relative); Client Background (ill relative's demographics and mental health history); and Affective Response (worry and displeasure). The worry subscale consists of seven items that ask respondents to rate their level of concern on different aspects of their ill relative's life. All items are rated on a 0–7 scale with lower scores indicating less worry. The displeasure subscale has seven items that measure emotional distress or displeasure on a 1–4 scale with lower scores indicating less displeasure.

We also used modified versions of the CES-D to assess depression (25) and self-esteem and mastery scales developed by Pearlin [Family Impact Survey (FIS)] (26). The Depression scale is comprised by 14 items that measure the extent to which respondents experienced depressive symptoms during the previous week. The sum of the item scores is the scale score which can range from 0 to 42 with lower scores indicating less depression. The self-esteem scale is made up of 10 items that assess positive and negative self-feelings. Respondents rate the items using a 1–4 scale with higher scores indicating greater self-esteem. Then mastery scale is a 7-item scale with two items measuring sense of mastery and five items tapping pessimism or lack of control. Respondents rated the items on a 1–4 scale with higher scores indicating greater sense of mastery.

Finally, we included the Family Empowerment Scale (27) which has three subscales: family (12 items), community (10 items) and service (12 items) system empowerment. The items were rated on a 1–5 scale with higher scores indicating greater sense of empowerment.

As part of our effort to perform a truly collaborative evaluation of the effectiveness of this family-delivered and created program, we thought it was essential to include family-created measures. Therefore, Dr Burland created two inventories that were used to evaluate the program. The first, the Family-to-Family Scale (FTF), has been used extensively in post-program evaluations of the

FFEP. The second, the Family Member Questionnaire (FMQ), was created expressly for this study. She was invited to include items that she felt the FFEP was specifically targeted at changing. Both instruments are made of a series of statements with a 1–4 scale indicating level of agreement with each. A total of 39 statements comprise the FMQ and 15 items make up the FTF.

Each interview lasted 30–45 min and was conducted via telephone. Participants were paid \$10 for their time. All interviewers were trained research assistants familiar with FFEP and who identified as having a mentally ill family member. Having data collectors who are members of the participants' population group has been found to set participants at ease, allow data collectors to better understand participant questions and responses, and improve participation and data validity (e.g. 28) (of note, research interviewers were NOT research subjects in this study). The Center for Mental Health Services Research has a well-established data collection unit that utilizes a rigorous training protocol. Each interviewer was thoroughly oriented to the interview format and instruments and then sat in on five or more interviews, completing the data forms in parallel with an experienced interviewer (from the pilot study). Inter-class correlations and percentage of agreement were over 90% in all cases for all questions, with many being perfect (100%).

Fidelity Study. To ensure that participants received the intervention we described, we conducted a fidelity study within this larger study. During two rounds of FFEP classes (March–November 2000) four experienced FFEP teachers acted as observers to rate 23 different FFEP class meetings. They were oriented to the purpose and format of the observations, and were paid \$20 for each that they completed, with each observer responsible for three to nine ratings over the course of the round. Fidelity ratings were based on a check-list form created for this study (available from authors) in consultation with Dr Joyce Burland (FFEP creator) to capture 22 essential elements of FFEP and record their presence or absence; for example: Are class meetings being held every week, rather than alternating weeks or some other schedule? (i) Did the class meeting adhere to the FFEP curriculum for this week? (ii) During the class meeting, did the teacher(s) answer all questions, or turn many of them back to the whole group for consideration, answers, and discussion?

Method of analysis. Mixed effects regression analysis was used to address the hypothesis that

family members of persons with SMI would improve (i.e. have reduced subjective burden, increased empowerment) after participation in FFEP. Separate analyses were conducted on the dependent variables including subjective burden of illness, objective burden of illness, empowerment, depression, self-esteem, mastery, knowledge of SMI, understanding of mental health system, and self-care. A key advantage of this analytic technique over the fixed effects model is that it does not require discarding data for those subjects without complete data, and therefore results in more appropriate estimates of the treatment effects and their SE (29).

SAS PROC MIXED was used to conduct the analyses. A random intercept was used in the model to capture correlation across time points. To obtain adjusted means at each time point, variable time was entered as categorical assessment point vs. as continuous elapsed time. For each outcome, after conducting a global *F*-test for change across time, pair-wise comparisons of adjusted means between all time points was conducted using two-tailed Tukey's test.

A second regression model was developed for each outcome to assess whether there were differential effects of the program for different demographic and diagnostic subgroups. This time, analyses were performed without the 6-month follow-up since our focus was on improvement, not on sustained change over time. Six demographic variables [gender, race (Caucasian vs. non-Caucasian), relation to family member (parent vs. other), age, education (less than High School or High School degree or greater) and urban vs. county residents], and one clinical status variable (major depression vs. Schizophrenia) were tested singly in separate analyses. Age and gender did not have significant differential effects on the dependent variables.

Finally, to determine whether there was differential benefit from the program for the subgroups, interaction terms were added to the model between each subgroup designator and Time and again tested with a global *F*-test. The final full model consisted of four subgroup variables (age and gender were dropped), time, and the four subgroup \times time interactions. Tukey's pairwise comparisons between pairwise time points was conducted on adjusted means within subgroups when significant interaction effects were found by the global *F*-tests.

All 95 participants were used in all analyses that focused on the demographics. Analyses that focused on diagnosis of mentally ill relative used 86 participants who have relatives diagnosed with either schizophrenia or major depression.

Sample. Of the 157 people asked to consider participation in the study, 155 assented to being contacted by the researchers. A total of 102 turned out to be eligible for the study. The large majority of those who were considered ineligible did not take the class. Of those 102 eligible subjects, 95 (93%) consented to participate. Seventeen people dropped out over the course of the study (two at baseline, four at post-FFEP and four at 6-months post-FFEP). A small number of subjects had data missing from individual time points. Given the high consent rate and the relatively low drop out rate, the sample could be considered reasonably representative of persons who participate in the FFEP programs and possibly those like it. What is unknown is how these family members compare with others who do not choose to enroll in family education curricula.

Results

Data reduction and psychometric properties of FMQ and FTF Scales

To analyze data from these instruments efficiently, reduction methods were employed. To reduce the numbers of FMQ items, the first author (LD) and two co-authors (AL, LP) each independently grouped FMQ items into face-valid subscales. Through a consensus building, iterative process, five candidate FMQ subscales were derived. Cronbach's alpha was calculated for each subscale to assess internal consistency. Results indicated modest to strong reliability ranging from 0.59 (understanding mental illness) to 0.75 (understanding of mental health system). The other subscales and their alpha coefficients were 'worry/sadness' (0.72), 'burden/displeasure' (0.63), and 'empowerment/coping with relative's illness' (0.71). For 'worry/sadness' and 'burden displeasure', lower scores indicate less worry and less displeasure. For the other three subscales, higher scores indicate greater sense of empowerment, greater understanding of mental health system, and higher level of knowledge of SMI.

The FTF items were reduced through the application of principal components factor analysis using varimax rotation. Factor analysis yielded two subscales which account for 57.5% of the variance of the FTF scale. Determination of an acceptable factor solution was based on the following criteria: (a) all items load substantially (factor coefficient ≥ 0.40) on only one factor; and (b) the items cluster together in a meaningful fashion. The two scales were termed 'knowledge about SMI' and 'self-care'. The first subscale

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explains 42.7% of the variance while the second accounts for 14.8%. After establishing the factor structure of the FTF subscales, reliability was assessed. Internal consistency reliability was high for both scales ($\alpha = 0.86$ and 0.87 for, respectively). For the FTF subscales, higher scores indicate greater self-care and greater knowledge about SMI. The original FMQ and FTF instruments, and the items comprising each derived subscale, are shown in the Appendices A1 and A2.

All subjects who consented were included in the analysis (see Table 1 for study subject characteristics). Participants' self-reported *subjective burden* was significantly reduced after attending the FFEP (Table 2). This is indicated by the reduction in the displeasure adjusted mean score from the waitlist and pre-test to post-test and leveling-off at 6-month follow-up on the FEIS. A similar pattern was discernible in the worry scale mean scores suggesting that the FFEP reduced the 'worry' of relatives. In contrast, participation in FFEP did not alter objective burden of illness (measured by the FEIS supervision and activities of daily living scales).

Level of empowerment in all three domains (community, family, and service) was greatly enhanced among participants of FFEP on the empowerment scale. Improvement in empowerment was most dramatic in the community

Table 1. Demographics of FFEP participants ($n = 95$)

	n (%)
Gender	
Male	26 (27.4)
Female	69 (72.6)
Race	
White	69 (72.6)
Non-white	26 (27.4)
Marital status	
Ever married	89 (93.7)
Never married	6 (6.3)
Education	
High School and below	26 (27.4)
More than High School	69 (72.6)
Relationship to ill relative	
Parent	56 (59.6)
Child	7 (7.5)
Sibling	14 (14.9)
Spouse/partner	7 (7.5)
Other kin	9 (9.6)
Non-kin/friend	1 (1.1)
Diagnosis	
Schizophrenia	40 (43.5)
Major affective disorder	46 (50.0)
Other	6 (6.5)
Age: mean (SD)	52.2 (12.9)

domain. Depression symptoms significantly improved from waitlist and pre-test to the 6-month follow-up. The relationship of improved depression scores to the FFEP is not as clear with

Table 2. Adjusted mean values and SE of outcome variables at each time point

Outcome measures	Waitlist ($n = 95$)	Pre ($n = 85$)	Post ($n = 79$)	6-Month ($n = 78$)	F-value† (D.f. = 3, 230)	Significant difference‡
Subjective Burden Scale						
Displeasure	2.65 ^a (0.09)	2.61 ^a (0.10)	2.29 ^b (0.10)	2.18 ^b (0.10)	15.15***	Post, 6 month < w, pre
Worry	2.63 ^a (0.08)	2.62 ^a (0.09)	2.40 ^b (0.09)	2.30 ^b (0.09)	10.97***	Post, 6 month < w, pre
Objective Burden Scale						
Activities of daily living	0.84 ^b (0.09)	1.00 ^a (0.09)	0.85 ^b (0.10)	0.89 ^b (0.10)	3.39*	Post, w < pre
Supervision	0.30 ^a (0.05)	0.31 ^a (0.05)	0.25 ^a (0.05)	0.25 ^a (0.05)	0.89	None
Empowerment Scale						
Community	2.40 ^b (0.07)	2.54 ^b (0.08)	3.10 ^a (0.08)	2.98 ^a (0.08)	48.90***	Post, 6 month > w, pre
Family	3.39 ^b (0.06)	3.41 ^b (0.06)	3.75 ^a (0.06)	3.74 ^a (0.06)	18.53***	Post, 6 month > w, pre
Service	3.04 ^b (0.09)	3.06 ^b (0.09)	3.53 ^a (0.09)	3.36 ^a (0.09)	19.86***	Post, 6 month > w, pre
Depression	9.87 ^a (0.68)	9.33 ^a (0.71)	8.61 ^{ab} (0.73)	7.07 ^b (0.73)	4.40***	6 Month < w, pre
Self-esteem	3.34 ^a (0.04)	3.34 ^a (0.05)	3.39 ^a (0.05)	3.40 ^a (0.05)	1.26	None
Mastery	2.96 ^{ab} (0.05)	2.87 ^b (0.05)	2.89 ^{ab} (0.05)	3.01 ^a (0.05)	3.73**	6 Month > pre
FMQ Scale						
Empowerment	2.93 ^b (0.03)	2.95 ^b (0.04)	3.08 ^a (0.04)	3.07 ^a (0.04)	7.90***	Post, 6 month > w, pre
Worry	3.16 ^a (0.05)	3.12 ^a (0.05)	2.96 ^b (0.05)	2.91 ^b (0.05)	12.32***	Post, 6 month < w, pre
Burden	2.44 ^a (0.05)	2.41 ^a (0.05)	2.26 ^b (0.05)	2.25 ^b (0.05)	9.96***	Post, 6 month < w, pre
Understanding SMI	3.12 ^b (0.04)	3.10 ^b (0.04)	3.24 ^a (0.04)	3.08 ^a (0.04)	5.84***	Post > w, pre, 6 month
Understanding of MHS	2.85 ^b (0.05)	2.77 ^b (0.05)	2.97 ^a (0.05)	2.95 ^a (0.05)	7.54***	Post, 6 month > w, pre
FTF Scale						
Knowledge of SMI	2.57 ^b (0.05)	2.62 ^b (0.05)	3.09 ^a (0.05)	3.05 ^a (0.05)	53.82***	Post, 6 month > w, pre
Self-care	3.10 ^b (0.04)	3.10 ^b (0.04)	3.22 ^a (0.04)	3.25 ^a (0.04)	8.00***	Post, 6 month > w, pre

Mean values with common letters are NOT significantly different at 0.05 level.

Numbers inside parentheses are SE of the adjusted mean values.

* $P < 0.05$ ** $P < 0.01$ *** $P < 0.001$.

† Global F-value for Time from mixed model Multiple Regression Analysis.

‡ w, Waitlist; pre, pre-test; post, post-test; 6 month, 6-month follow-up

Table 3. Adjusted mean values and SE of outcome variables at each time point by subgroup

Outcome variable	Subgroup	Waitlist	Pre	Post	F-value†	Significant difference‡
Knowledge of SMI	White	2.49 ^b (0.11)	2.61 ^b (0.10)	3.17 ^a (0.10)	4.19* (2, 138)§	Post > w, pre
	Non-white	2.79 ^a (0.11)	2.78 ^a (0.12)	3.03 ^a (0.12)		None
Worry	Parent	2.73 ^a (0.13)	2.75 ^a (0.13)	2.78 ^a (0.13)	6.03** (2, 138)§	None
	Non-parent	2.39 ^a (0.16)	2.39 ^a (0.16)	2.13 ^b (0.17)		Post < w, pre
Empowerment-family	Parent	3.55 ^a (0.11)	3.61 ^a (0.09)	3.69 ^a (0.10)	3.17* (2, 139)§	None
	Non-parent	3.49 ^b (0.11)	3.43 ^b (0.12)	3.90 ^a (0.12)		Post > w, pre
Empowerment-service	Parent	3.36 ^a (0.13)	3.39 ^a (0.14)	3.53 ^a (0.14)	3.73* (2, 137)§	None
	Non-parent	3.01 ^b (0.16)	2.99 ^b (0.17)	3.55 ^a (0.17)		Post > w, pre

Adjusted mean values with common letters are NOT significantly different at 0.05 level.

† Global F-value for subgroup × time interaction from mixed multiple regression analysis.

‡ w, Waitlist; pre, pre-test; post, post-test.

§ Numbers inside parentheses are numerator and denominator degrees of freedom, respectively.

this pattern since the post-FFEP rating did not differ from the pre-test. Self-esteem and mastery scale scores did not change over the intervention.

FFEP Scales

Participants also showed improvement on all FMQ and FTF subscales as shown by a clear pattern of significant improvement from pre- to post-test. In addition, such improvement was sustained at 6-month follow-up based on all subscales with the exception of FMQ knowledge.

Subgroup analysis

Significant subgroup by time effects suggesting differential subgroup benefits, are summarized in Table 3. Race had a significant differential effect on knowledge of SMI. Tukey’s test on the adjusted means revealed improvement among whites but not among non-whites. Relation to ill family member emerged as a powerful determinant of change on three outcomes: worry, family empowerment and service empowerment. Non-parents showed significant improvement on all three scales while parents did not. Diagnosis of ill relative, education and urban vs. county residence did not have significant differential effects on benefits.

Fidelity

Ratings were made for 22 characteristics fundamental to the FFEP model. Raters recorded at least 85% compliance on 18 of 22 items; 10 of these were 100%. Those that fell below 85% were (i) presence of non-family attendees (17/23 = 84% non-compliance); (ii) teachers turning Qs back to the group (17/22 = 77% non-compliance), and (iii), presence of resource person (5/21 = 24% non-compliance).

Discussion

This study strengthens the available evidence that the NAMI-sponsored FFEP meets its stated goals of reducing subjective burden, increasing empowerment, increasing knowledge of the mental illness and the mental health system, and increasing self-care among family members of people with SMI. These outcomes did not change throughout the waiting list period and then showed improvements from the beginning to the end of FFEP.

Further, it is especially noteworthy that gains revealed at the end of the brief FFEP were sustained for 6 months after completion of the program. FFEP is a very popular program in the three countries where it is offered (Canada, USA, Mexico). This study replicates the results of our uncontrolled pilot study of FFEP (22), and within the constraints of this study’s non-randomized design, these provide the strongest evidence available that FFEP has important salutary effects on the family experience of SMI. These positive findings corroborate the high esteem in which it is held by graduates and suggests that efforts to continue its expansion within countries and internationally are well spent.

The reductions in depression scores over the program are also noteworthy. FFEP participants show reduced depression over the time of their participation in the study. The mean scores improved steadily over each time point, although the post-FFEP assessment did not differ significantly from the pre-FFEP assessment. Statistical analysis showed that the 6-month score was significantly lower than the waitlist and pre-FFEP time periods. Several interpretations of these data are possible; the pattern of change makes direct and immediate attribution to FFEP less compelling. It is possible that the effects of FFEP on depression were not immediately

observable, such that reduced depression was apparent only after 6-months. It is also possible that just the intention to participate in FFEP as opposed to the program itself resulted in reduced depression scores. Nevertheless, it is striking that participants became less depressed over the study period.

That FFEP did not change objective burden of illness is not surprising. The FFEP is not directly targeted at altering the behavior and needs of the ill individuals within the FFEP families. This contrasts with family psychoeducation models that include the ill family member and directly target clinical outcomes and behaviors. Family psychoeducation models are thus more likely to reduce objective burden of illness for family members.

That mastery and self-esteem scales did not change is also worthy of mention. We used measures of global self-esteem and mastery, not targeted to the domains of coping with mental illness. Therefore, the lack of change likely reflects that FFEP did not enhance participants' overall self-view, but does not address possible changes in mastery or self-estimation regarding the specific domains addressed by FFEP. Unfortunately, such specific measures were not available.

The subgroup analyses allow consideration of ways in which FFEP may be modified to enhance its impact for diverse participants. Every subgroup examined did benefit on most of the measures. Therefore, subgroup differences should not be interpreted to indicate that some participants received no benefit from FFEP. For example, while showing similar benefits on many variables, white participants showed significant gain in 'knowledge of SMI' while non-white participants improved only slightly and did not reach statistical significance. Examination of mean scores reveals that non-whites started at a higher baseline level of knowledge, perhaps suggesting a ceiling effect. It is also possible that something in the FFEP curriculum better addressed the needs of white family members in this one area of information. The possible explanations will have to be evaluated in future work.

Similarly, non-parents showed significant increase in their self-rated empowerment at the family and mental health service levels, whereas parents' mean scores increased very little (non-significant). Non-parents also showed improvement (significant decrease) in their worry scores that parents did not. On all three measures, parents start at a higher level, taken together, this could indicate that non-parents are particularly in need of what FFEP offers in this area, that parents'

particular needs are not being as well addressed, or a measurement ceiling effect.

Overall, this study provides a solid first step on the way to recognition of FFEP as an evidence based practice for assisting family members. Our findings must be replicated with other samples in other locations, using similarly rigorous methods and a random assignment design. One concern with this design is that the family members who were willing to participate in the program after waiting for 3 months may differ from those who might drop off the waitlist. However, our results were quite similar to our pilot study which did not require a wait list. The impact of a telephonic interview as opposed to a research interview conducted in person is unknown. Researchers also need to determine whether the outcome variables we chose are sufficient to capture FFEP's efficacy, and what other effects of participation should be investigated. We are now undertaking a qualitative study of FFEP participants to obtain a richer understanding of the quantitative results obtained here. Similarly, future research should inquire about FFEP's effectiveness among various (independent variable) sub-groups of participants, such as demographics and the participant's relationship to the ill person. Finally, it is plausible that FFEP benefits patients by changing the attitudes and behaviors of family members. This would be another avenue of future investigation.

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Appendix A1. Family Member Questionnaire (FMQ) Scales and items*

Empowerment

1. I feel useful when I help my ill relative.
2. I can listen empathetically to my ill relative without getting upset over the beliefs s/he is expressing.
3. I can set firm limits with my ill relative over those things which are important to me.
4. I can identify the support I need to keep going in this life hardship.
5. I can trust my instincts when I feel my ill relative is in danger of relapse.
6. I can have a full and happy life despite the sadness I sometimes feel about my relative's illness.
7. I am sure there is a way to solve problems when they come up.
8. Taking action when I need to is therapeutic for me.

Worry

1. One of the hardest things about dealing with my ill relatives is that his or her problems are so unpredictable.
2. I worry about what the future will bring for my ill relative.
3. Sometimes, trying to deal with my ill relative's problem makes me feel helpless.
4. One of the hardest things about my ill relative's problem is worrying about whether or not the worst symptoms will occur again.
5. I worry about the effect of stigma and discrimination on my relative's future life prospects.
6. I feel sad when I think about the shattered dreams mental illness has caused my ill relative.

Burden

1. Sometimes, I feel that my ill relative is not really mentally ill but instead is just being lazy or uncooperative.
2. I feel that my ill relative tries to manipulate me.
3. If I do not help my ill relative, no one else will.
4. I wish my ill relative would show better grooming and personal hygiene.
5. I feel embarrassed by my ill relative's behavior.
6. My family and I often have disagreements about my involvement with my ill relative.
7. I can never plan to do things with other people unless I first stop and think about whether or not my ill relative will need me.
8. Sometimes, I'm not sure where my ill relative fits in as part of the family.
9. I feel that my ill relative is too dependent on me.
10. I wish I could get more help for my ill relative from other members of my family.

Family-to-family education program for severe mental illness

Appendix A1. (Continued)

Understanding of mental illness

1. I recognize how much courage it takes for my ill relative to cope with such changed life circumstances.
2. I know that any serious and persistent illness can cause a gap in the normal adult development of the person suffering from it.
3. I am certain that having a mental illness is not my relative's fault.
4. I know that my ill relative is doing the best s/he can.
5. I can understand my ill relative's perspective when s/he wants to quit taking medication.
6. I recognize that mental illness has robbed my relative of many valuable skills s/he used to have.
7. I realized that my relative's lack of energy, drive and will is a symptom of severe and persistent mental illness.
8. I am certain my relative is suffering from a biological illness of brain.

Understanding of Mental Health System (MHS)

1. I can count on the mental health system to collaborate with me as a family member in the treatment of my relative.
 2. I am willing to do whatever is needed to protect my ill relative when s/he needs hospitalization.
 3. I can challenge authority figures when it is necessary to get assistance for my ill relative.
 4. I am able to get mental health professionals to respond to my concern about my ill relative.
 5. I am able to get the information I need from mental health professionals.
-

* Response options and scoring scheme applied to all items: strongly agree, 4; agree, 3; disagree, 2; strongly disagree, 1.

Appendix A2. Family-to-Family (FTF) Outcome Survey Scales and Items*

Knowledge of SMI

1. I understand the causes of mental illness.
2. I understand the medications used to treat mental illness.
3. I know who to turn to for help when I am feeling upset about my ill relative.
4. I know how to advocate for better treatment for my ill relative.
5. I have information about the different mental health programs currently available for persons with severe mental illness.
6. I know how to communicate my concerns about my ill relative with his/her mental health treatment provider (e.g. social worker, care manager, or doctor).
7. I have realistic expectation of what my ill relative can and cannot do.

Self-care

1. I do not feel alone because I know that there are other families with problems just like mine.
 2. I get along with my ill relative.
 3. I plan to participate in activities to lower stigma and discrimination against people with mental illness in my community.
 4. I have a happy outlook on life in general.
 5. I feel guilty about my relative's illness.
 6. I take time for myself to take care of myself and do the things I enjoy.
-

* Response options and scoring scheme applied to all items: strongly agree, 4; agree, 3; disagree, 2; strongly disagree, 1.

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