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Caregiver Positive and Negative Appraisals: Effects of the National Alliance on Mental Illness Family-to-Family Intervention

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Abstract

The 3-month long Family-to-Family intervention (FTF) has been shown to increase empowerment, knowledge, and coping, and to reduce distress among caregivers of people with serious mental illness. We sought to determine the influence of FTF on caregivers' appraisal of their caregiving experience. Family members of individuals with mental illness who sought enrollment in FTF (N=318) were randomly assigned to FTF or a waitlist condition. Positive and negative appraisals were measured using the Experiences of Caregiving Inventory (ECI) at baseline and 3 months later; 259 participants completed both assessments. Regression analyses found significant increases in positive appraisal but no significant decreases in negative appraisals for those in the FTF condition. In the context of overall benefits from taking FTF, these relationships reflect the FTF curriculum's emphasis on positive coping (e.g., strength and empowerment) and the potential value of strategies that help caregivers increase positive appraisal.

Keywords

Family-to-Family; Caregiving; Appraisal; Serious Mental Illness

Substantial literature has identified burdens associated with being a caregiver for a person with a serious mental illness (SMI) and the resulting risks of emotional distress and even

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medical and psychological illness (Vella and Pai, 2013; Drapalski et al., 2008; Jenkins and Schumacher, 1999). Family members in such roles benefit from programs providing information and support (Chen and Greenberg, 2004; Drapalski et al., 2008; Jenkins and Schumacher, 1999; Dixon et al., 2010). The peer-run Family-to-Family (FTF) program is the most widely available such resource in the U.S. designed to meet the needs of family members of adults with mental illness. FTF is a free, community-based, education and support program offered nationally by the National Alliance on Mental Illness (NAMI) through its local affiliates. In a randomized controlled trial, FTF reduced caregiver distress and increased caregiver empowerment, knowledge, problem-focused coping, emotion-focused coping, and family functioning (Dixon et al., 2011). These outcomes were maintained through a 9 month follow-up period (Lucksted et al., 2013).

The stress-appraisal-coping framework is an important foundation of the FTF program. It posits that perceived stress is a combined consequence of existing stressors, one's appraisal of those stressors, and one's coping abilities (Lazarus, 1966). How one assesses (appraises) stressors and their circumstances is believed to shape the types and intensity of distress one experiences. Ample research has borne this out regarding caregiver distress. For example, Hesse and Klingberg (2014) found that when caregivers attributed control over stressors to their ill relative, they felt distressed due to feelings of *anger* toward him/her. However, when they attributed stressors as due to factors under *their own* control, they felt distress due to *anxiety* regarding the ill person. More broadly, a 2010 review of a sociocultural stress and coping framework concluded that research robustly supports the core cognitive model linking caregiver appraisal (of stressors regarding their ill relative's problems) to caregiver distress-related health outcomes (Knight and Sayegh, 2010). This research supports a thesis central to FTF's development: while caregivers may have limited ability to reduce their objective burden (concrete, measurable stressors), FTF participation may alter their *appraisal* of those stressors, with important implications for their coping and levels of distress.

Negative appraisals (e.g., perceptions of stigma, of losses connected to caregiving) and positive appraisals (e.g., perceptions of good relations, of positive experiences involved in caregiving) are distinct and important components of the caregiving experience. While studies of caregivers for other conditions (i.e., Alzheimer's disease and breast cancer) have found a significant impact of intervention on negative appraisals of caregiving (Mittelman, Roth, Haley, & Zarit, 2004; Northouse, Kershaw, Mood, & Schafenacker, 2005), successful interventions for caregivers of relatives with SMI appear to uniquely impact positive appraisals. For example, Szmukler and colleagues (1996b) examined the impact of a six-session family member counseling protocol on both positive and negative appraisal and found that relatives in the intervention group reported a more positive relationship with their ill relative as a result, but no differences regarding the negative aspects of caregiving or coping. In addition, Gleeson and colleagues (2008, 2010) conducted a randomized trial of a 3-year cognitive-behavioral relapse prevention intervention for young adults with first episode psychosis and their core family member(s) versus clinical services as usual. Family aspects of the package involved assessing relationships, burdens, and coping; psychoeducation regarding relapse prevention; communications training; and problem

solving. Family members in the intervention group showed greater improvement in positive appraisals regarding caregiving experiences, their relationship with their ill relative, and overall more positive subscale scores on the Experiences of Caregiving Inventory (ECI) than controls. Similar to the study by Szmukler and colleagues (1996b), there were no significant differences on negative attribution ECI subscales (Gleeson et al., 2010). Of note, in a non-intervention study, Trute and colleagues (2010) reported that mothers' positive appraisal of the impact of their child's disability on the family accounted for 35% of the variance in family adjustment, while negative appraisal did not make a significant unique contribution. Thus, there is evidence that positive and negative appraisal operate independently with respect to family experience and stress. Further, previous work suggests that family interventions can reduce distress by increasing family members' *positive* attributions around caregiving while negative appraisals are not reduced. Therefore, we hypothesized that participating in the FTF program would a) increase positive appraisals and b) not impact negative appraisals among family members seeking support, compared to those in the wait-list control condition via secondary analysis of data collected in the parent randomized FTF trial.

Methods

The NAMI Family-to-Family program is a 12-week, family-member-led course offered by NAMI affiliates for free across the U.S. It is open to any family member, partner, or close friend of an adult with mental illness; the ill person does not attend. FTF is designed to help family members improve their well-being and coping capacities, and to better understand the experiences of their ill relative(s), the nature of mental illness, various aspects of treatment, and their own emotional reactions and conflicts. A more complete description of the program can be found on the NAMI FTF website (NAMI: Family-to-Family, n.d.).

The parent randomized controlled study of FTF (Dixon et al., 2011) was conducted in Maryland regions served by five NAMI affiliates (Baltimore Metropolitan, Howard, Frederick, Montgomery, and Prince George's Counties) under University of Maryland Institutional Review Board approval. During the study period, all family members interested in taking FTF were asked to also consider study involvement. Individuals were eligible if they were 21 to 80 years of age, desired enrollment in FTF regarding a family member or significant other with mental illness, and spoke English.

Each consenting participant completed a 60-minute structured baseline telephone interview and then was randomly assigned either to take FTF immediately (intervention) or to wait at least 3 months before taking it (control). In both cases, study participants attended existing FTF courses in their communities. Three months after randomization (i.e., after the FTF group completed the program), a research assistant blind to the participant's study condition conducted a second structured 60-minute telephone interview. Participants were paid \$15 for each interview.

Among the measures comprising the parent study interviews, the Experiences of Caregiving Inventory (ECI) is a measure of respondents' appraisal of caregiving experiences in the past

month. Findings of the ECI have not yet been reported because the impact of FTF on appraisal were considered secondary hypotheses.

The ECI is comprised of 66 items on a 5-point Likert scale from 0 (never) to 4 (nearly always). The first 52 items are prompted with, “During the past month how often have you thought about...” and the last 14 (i.e., the Difficult behaviors and Negative symptoms subscales) are prompted with, “During the past month how often have you thought about [him] her being...” The 66 items are separated into groups of 5 to 8 items and are summed to create 10 subscales: eight measure negative appraisal regarding caregiving, and two measure positive appraisals. Negative subscales are: *Difficult behaviors* (e.g., “Behaving in a reckless way”), *Negative symptoms* (e.g., “Not interested”), *Stigma* (e.g., “The stigma of having a mentally ill relative”), *Problems with services* (e.g., “Dealing with psychiatrists”), *Effects on family* (e.g., “How family members do not understand the illness”), *Need to provide back-up* (e.g., “Having to support him”), *Dependency* (e.g., “Unable to do the things you want”), and *Loss* (e.g., “He thinks a lot about death”). Positive subscales are: *Positive personal experiences* (e.g., “I have learnt more about myself”) and *Good aspects of relationship* (e.g., “He is good company”). The ECI has demonstrated good validity and reliability in samples of caregivers of adults with SMI (Szmukler et al, 1996a).

We used multilevel regression models (SAS, version 9.2, PROC MIXED procedure) to test whether participation in FTF led to changes in positive and negative appraisals of caregiving. The models tested for significant changes over time by using the score at the three-month assessment as the dependent variable and condition (FTF or waitlist) as the primary independent variable, with baseline ECI score and class as covariates. In addition, for the FTF condition, we assessed whether class attendance was a moderator of change for positive and negative appraisal.

Results

Of the 322 individuals who consented to the parent study, four were administratively withdrawn, leaving a total of 318 who completed the baseline interview and were randomly assigned to FTF ($n = 160$) or the waitlist condition ($n = 158$). Of these, 259 (133 FTF, 126 waitlist) completed a 3-month follow-up assessment. Study participants averaged 53 ± 10.6 years old, and were primarily female ($n = 196/259$, 77%) and Caucasian ($n = 186/259$, 72%). Sixty-six percent were college graduates ($n = 171/259$) and 73% ($n = 185/259$) had incomes greater than \$50,000. They were primarily parents of the consumer ($n = 154$, 60%), but children ($n = 19$, 7%), siblings ($n=32$, 12%), partners/spouses ($n = 27$, 10%), and other kin ($n = 25$, 10%) were also represented in the sample.

Objective burden of caregivers was measured in three ways. First, for 80 of 194 participants (2 had missing data), their family member with a mental illness had been admitted to a psychiatric hospital in the past 6 months. Second, in terms of assistance in daily living, caregivers reported 1.09 ($SD = .96$) on a scale from 0 to 4, with higher scores indicating that the family member provides more assistance to the consumer regarding daily living tasks. Last, in terms of supervision, caregivers reported a .47 ($SD = .06$) on a scale of 0 to 4, with higher scores indicating that the family member provides more supervision of the

consumer's potentially problematic behaviors. More demographic details of participants (including comparisons of the FTF and wait-list control conditions) can be found in Dixon et al. (2011).

The regression analyses showed that participation in FTF significantly increased family members' positive appraisal (ECI Positive Scale) from baseline to 3 month follow up, compared to controls, accounting for 44% of its variance ($t(101) = 3.60, p < .001$; Table 1). Increases in both subscales comprising the ECI Positive Scale—*Positive Personal Experiences* and *Good Aspects of Relationship*—contributed significantly (Table 1). In contrast, family members' negative appraisal (ECI Negative Scale) was not significantly affected by FTF participation ($t(101) = -.43, p = .67$). The number of FTF sessions attended did not significantly predict the change in any ECI scale.

Discussion

This study found that participation in the NAMI FTF program increased caregiver endorsement of positive caregiving appraisals but did not reduce their endorsement of negative caregiving appraisals, compared to controls. These findings add detail to our initial report which denoted that FTF significantly reduced caregiver distress and increased family functioning as well as caregiver knowledge, coping, and empowerment (Dixon et al., 2011).

Why FTF would affect positive but not negative appraisal deserves consideration. Results from Szmulker and colleagues (1996b) suggest that relatives completing the counseling intervention felt they understood their ill relative's situation better, which improved their relationship despite negative aspects that were unchanged. Similarly, family participants in the Episode II trial (Gleeson et al., 2010) reported "an increase in perceived opportunities to make a positive contribution to the care of their relative" (p. 474), which the authors posited contributed to their increased ECI Positive scale scores. This meshes with findings by Bauer and colleagues (2012) that caregivers cite personal growth as a main benefit of caregiving. Gleeson and colleagues (2010) also speculated that their intervention's recognition of family members' personal strengths related to caregiving may have played a role.

Further, the FTF curriculum emphasizes strengths, increasing one's personal resources, empowerment, and making a difference (for self, family, ill relative) where one can. In keeping with the studies above, such emphases may simply have more impact on positive appraisal. For example, FTF provides family members with information and encouragement to engage in self-care and to build rewarding experiences into their lives to counteract stressors. It also includes information and exercises to increase participant empathy for the ill person's experiences, urges participants to value and lean on their connections with others in the class, and encourages them to focus on creating realistic positive changes rather than railing against stressors outside one's control. Thus, FTF participation may, in part, constitute a "Positive Personal Experience" and help participants be more aware of "Good Aspects of [their] Relationship" with caregiving and their ill relative (both ECI Positive subscales).

Differences in construction of the Positive versus Negative ECI scales may also account for some portion of our findings. Most Positive scale items focus on caregivers' thoughts about themselves (e.g., "[I] have discovered strengths in myself"), while most Negative scale items tap perceptions of ongoing external stressors (effects on family, dealing with services) including negative perceptions of the ill family member (dependence, difficult behaviors). Thus the Positive scale is more internally focused than the Negative. Respondents may be more able or likely to sense (and therefore report) changes in themselves than in external situations, leading to more change in the Positive scale. However, we did not have the data to evaluate this possibility.

Reasons for the lack of moderation between FTF sessions attended and changes in positive appraisal are unclear. Perhaps joining FTF is itself empowering. Given the internal focus of the Positive ECI scale, becoming at all involved with FTF may increase self-efficacy attributions. At the same time, it is possible that the spread in attendance was not diverse enough to lend itself to adequate statistical analyses. Future close examination of the precise mechanism of change regarding positive appraisals would help interpret this finding and be useful broadly.

A limitation to consider is that our participants, consisting of family members seeking the help and resources FTF offers, are from one geographic location and are overall well educated (two-thirds college graduates) with almost three-quarters of the sample above U.S. median income. Consequently, they are likely not representative of caregiving family members more broadly, and the study results might not be generalizable to all people who attend FTF. Further, caregivers reported relatively low need for providing supervision for problematic behaviors and for assisting with tasks of daily living. Thus, it is possible that results also might not be generalizable to participants who report a higher objective burden.

Nonetheless, our findings add to other studies demonstrating positive appraisal and coping impacts of family-based interventions regarding caregiving (e.g., Bauer et al., 2012; Pickett-Schenk et al., 2006; Gleeson et al., 2010; Szmukler et al., 1996b). This documents that, even in the presence of significant ongoing stressors, caregivers can experience positive aspects of the caregiving experience and the relationships involved, as well as feelings of personal growth and mastery related to making positive contributions to their relative's recovery (Bulger et al., 1993; Chen and Greenberg, 2004). Helping family caregivers develop these positive attributions and experiences may be an important and under-utilized avenue for improving their coping and decreasing family caregiver distress, augmenting efforts to increase coping skills and reduce stressors and negative attributions.

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Table 1

ECI Positive and Negative scores for FTF vs Control condition participants

	Score Range	Baseline		3 month Follow-up		Regression Result					
		Control (N=155)		Control (N=126)		β(SE)	d.f	t	p		
		FTF (N=158)	M ± SD	FTF (N=133)	M ± SD						
ECI Subscale											
Difficult Behavior	0-32	16.9 ± 6.9	16.1 ± 6.7	14.5 ± 7.0	14.0 ± 6.7	100	100	-.10(.75)	-.14	.891	-.018
Negative Symptom	0-24	13.9 ± 5.6	14.1 ± 4.7	12.2 ± 5.5	12.2 ± 5.1	100	100	-.02(.61)	-.03	.974	-.004
Stigma	0-20	6.1 ± 4.0	6.2 ± 4.2	5.4 ± 3.7	6.0 ± 4.0	101	101	-.46(.37)	-.1.24	.216	-.161
Problem w Service	0-32	14.6 ± 7.3	13.3 ± 7.0	13.0 ± 6.7	11.5 ± 7.0	101	101	.52(.70)	.74	.460	.103
Effect on Family	0-28	12.3 ± 5.9	12.0 ± 5.5	11.2 ± 5.4	10.9 ± 5.7	101	101	-.17(.56)	-.29	.770	-.040
Need to Provide Back-up	0-24	12.0 ± 5.3	11.6 ± 5.0	11.3 ± 5.2	10.6 ± 4.9	101	101	.21(.45)	.46	.644	.058
Dependency	0-20	10.5 ± 4.2	10.7 ± 4.2	9.1 ± 4.0	9.4 ± 4.4	101	101	-.27(.39)	-.69	.490	-.087
Loss	0-28	12.2 ± 5.2	12.3 ± 5.3	10.3 ± 4.5	10.7 ± 4.9	101	101	-.34(.48)	-.71	.477	-.095
Positive Personal Experience	0-32	17.8 ± 5.9	17.3 ± 5.5	19.0 ± 6.0	16.5 ± 6.2	101	101	2.13(.59)**	3.59	<.001	.469
Good Aspect of Relationship	0-24	13.2 ± 4.5	13.4 ± 4.4	14.1 ± 4.3	13.2 ± 4.4	101	101	.98(.46)*	2.12	.036	.295
ECI Overall Scale											
Positive	0-56	31.0 ± 9.1	30.8 ± 8.2	33.1 ± 8.7	29.7 ± 9.3	101	101	3.16(.86)**	3.60	<.001	.470
Negative	0-208	98.3 ± 32.6	95.9 ± 30.7	86.8 ± 31.7	85.3 ± 31.0	101	101	-1.05(3.03)	-.43	.671	-.046

Note.

* p < .05,

** p < .001