

# Benefits and Changes for Family to Family Graduates

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**Abstract** Family members of people with serious mental illnesses (SMI) need information and support to cope with the considerable stresses they experience. The Family to Family Education Program (FtF) is a structured, peer-led, 12-week information and support self-help class for such individuals. Previous research by Dixon et al. (2004) shows reduced subjective burden and increased empowerment among graduates. The present study sought to understand what processes take place during FtF participation that might lead to these benefits, as a first step in building a conceptual model of how FtF causes its effects, using semi-structured interviews with 31 FtF graduates. Qualitative data analysis suggested that new factual and

emotional information from FtF shifts interviewees' understanding of their situation and that skills acquired through FtF then allow participants to incorporate these new perspectives into more adaptive behaviors. These changes led to both proximal and distal benefits for the FtF participants interviewed. The results are discussed in the context of self-help, stress-and-coping, and trauma recovery theories.

**Keywords** Serious mental illness · SMI · Family support · Psycho-education · Self-help

## Introduction

Family members of people with serious mental illnesses (SMI) often utilize self-help interventions to cope with the challenges they face. One of the most available of these, the Family to Family Education Program (FtF), has been shown to benefit its participants in various ways (Dixon et al. 2001a, 2004). While its creators drew on trauma-recovery and stress-and-coping ideas in designing FtF, no one has examined how FtF actually brings about benefits to participants. Understanding its embedded change processes and how they fit with these theories and/or others not explicitly addressed in its design (e.g., self-help) is important to understanding FtFs value as a community self-help intervention. Therefore, we designed a qualitative, interview-based, exploratory study of FtF graduates to gather their perceptions of the changes they experienced as a result of FtF participation and how those changes came about.

People are usually said to have a "serious mental illness" (SMI) if they experience psychiatric symptoms and distress involving long-term and life-role impairing

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disability (Shinnar et al. 1990). They often receive considerable help from friends and family regarding their illness, its treatment, and its sequelae, especially since the deinstitutionalization movement (Clark and Drake 1994; Dyck et al. 1999; Lehman and Steinwachs 1998; Tessler and Gamache 2000). Loved ones providing such help face considerable challenges. Family members often assume new roles (e.g. informal case management, advocacy, crisis intervention, housing supervision) with limited resources and no professional guidance (Dixon et al. 1999; Marsh and Johnson 1997; Ohaeri 2003). They frequently have to cope with altered family patterns and expectations, financial demands, new pressures, and changed social networks due to both the illness and others' reactions. Not surprisingly, they are at increased risk for psychological distress, including anxiety and depression (Greenberg et al. 1995; Oldridge and Hughs 1992; Perlick et al. 2005). When asked about their needs, such family members ask for information (e.g., about mental illness, services, medications, self-care), help with communication, crisis intervention, problem solving skills, and emotional and practical support (Winefield and Harvey 1994; Johnson 1995; Reid et al. 2005).

#### Family Members and Professional Help

Family members of people with SMI usually look first to the professional mental health providers treating their ill relative for assistance. Yet their needs are rarely met. Although the Schizophrenia PORT (Lehman et al. 1998) and other practice guidelines (American Psychiatric Association 1997; McEvoy et al. 1999) recommend that all family members of persons with SMI should be offered substantial, professionally led, family psychosocial intervention, only a small fraction of such families actually receive any assistance (Dixon et al. 1999, 2001b). Family members are often dissatisfied with the amount and quality of help they do receive (Burland 1998; Pickett et al. 1997; Struening et al. 1995; Koren et al. 1992; Marsh 1992).

#### Family Members and Self-help

Some therefore turn to creating and using self-help modalities (Hatfield 1979; Solomon et al. 1998). Learning from the mental health consumer movement and self-help efforts more broadly, family-member support groups, phone advice and referral lines, printed materials, and family-focused educational programs have proliferated in recent decades through organizations like NAMI, Depression and Related Affective Disorders (DRADA), and the National Mental Health Association (recently renamed

Mental Health America) as well as smaller local efforts.<sup>1,2,3,4</sup>

#### The Family to Family Education Program

The Family to Family Education Program is one of the more widely-available self-help resources for family members of people with SMI and is the subject of this study. It is a free, community based, structured, peer-led, information and support curriculum for family members. Sponsored and disseminated by the National Alliance on Mental Illness (NAMI, formerly National Alliance for the Mentally Ill), FtF was developed in the early 1990s by psychologist and family-member Joyce Burland to address unmet family needs (Burland 1998).

FtF is open to all family members, partners, and friends of individuals who have a SMI; the consumer does not attend. It is currently available in 46 US states plus Puerto Rico, two Canadian provinces, and three regions in Mexico via NAMI affiliate volunteers. There are over 3500 trained volunteer teachers and 300 trainers who train new teachers. To date, an estimated 100,000 family members have completed FtF in the US, plus 1,500 in Canada and 600 in Mexico.

FtF was designed to combine elements of two theoretical models—stress and coping and trauma recovery. Regarding the first (e.g., Lazarus and Folkman 1984), each FtF participant's coping and outcomes are seen as shaped by his/her appraisal of relevant stressors interacting with his/her coping skills and mediating conditions (Solomon

<sup>1</sup> Self-help resources for family members of people with SMI.

<sup>2</sup> NAMI: <http://www.nami.org>. NAMI (the National Alliance on Mental Illness, formerly the National Alliance for the Mentally Ill) is the nation's largest grassroots mental health organization providing education and support for family members of people with SMI. Founded in 1979, NAMI now has affiliates in many communities in every state, extensive consumer resources, and legislative and grass roots advocacy programs. NAMI defines its mission as advocacy, research, support, and education.

<sup>3</sup> DRADA: <http://www.drada.org>. DRADA (Depression and Related Affective Disorders) is a community organization serving individuals affected by a depressive illness, their family members, health care professionals and the general public. It describes its mission as "to alleviate the suffering arising from depression and manic depression by assisting self-help groups, providing education and information, and lending support to research programs" eliminating stigma, and educating the public. It also offers support groups in many communities.

<sup>4</sup> Many other organizations provide excellent resources about mental health/illness, recovery, empowerment and advocacy although they are not focused on assisting family members specifically. These include Mental Health America (<http://www.nmha.org>, formerly the National Mental Health Association) the National Empowerment Center (<http://www.power2u.org>), MindFreedom International (<http://www.mindfreedom.org>), the Depression and Bipolar Support Alliance (<http://www.dbsalliance.org>).

and Draine 1995; Noh and Turner 1987; Joyce et al. 2003). These mediating conditions can include the individual's cognitive style, coping skills, and personality, plus other external stressors and resources (Kramer 1993). Appraisal, coping strategies and some mediating conditions are viewed as modifiable by social support, information, and skill building—forming the rationale for FtF.

Secondly, FtF also recognizes that mental illness and care giving are often traumatic (Burland 1998). In keeping with trauma-recovery models (e.g., Herman 1992), the FtF curriculum is intended to normalize reactions such as shock, disorientation, grief, and need for support. The establishment of safety, gradual incorporation of the trauma, remembrance, mourning, reconnection with ordinary life, and finding meaning in one's experiences are viewed as important for healing (Herman 1992; Burland 1998). While both theories were part of the curriculum's design, there has previously been no research examining whether the effects that FtF has on participants fit with these models.

Additionally, although FtF is presented in a self-help, peer-led format, incorporating self-help theory was not a deliberate part of its design. Each 12-week, structured group is facilitated by two trained peer family-member volunteers (Burland 1995, 1998). In weekly 2–3 h sessions, each with a topical focus, family members receive information about mental illnesses, treatments and medication, and rehabilitation. They also discuss self-care, coping, problem solving, communication and crisis skills, and advocacy strategies. Participants have opportunities to share their stories, exchange support and advice with peers, and gain a fuller understanding of the experience of having a mental illness.

### Research on FtF and the Current Study

Although long popular with family members, FtF has only recently been formally evaluated. Our University of Maryland research team's wait-list control study of FtF's effectiveness (Dixon et al. 2004) indicated that taking FtF is associated with reduced subjective burden, reduced worry, and increased empowerment—consistent with stress and coping models. Participants' understanding of mental illnesses, the mental health system, and self-care also improved. A previous pilot study (Dixon et al. 2001a) showed similar results. This same team recently began a larger, randomized trial of FtF, underway as of Spring, 2006.

These quantitative evaluations, while rigorous and useful, necessarily reduce the experiences of FtF participants to numerical ratings. Therefore, they reveal little about FtF's process—how these beneficial changes come about. Such knowledge would be valuable for deepening our understanding of FtF and similar interventions. Therefore,

in the qualitative study presented here, researchers interviewed people who had recently completed FtF, in order to begin to ascertain the theoretical structures underlying the benefits participants usually accrue from participation.

## Methods

### Overview

We (Stewart and Lucksted) conducted semi-structured interviews with 31 FtF graduates one to three months after their course concluded. We asked FtF participants about their experiences with the class, what if anything from the class they had incorporated into daily life, and any effects they perceived. The University of Maryland IRB approved all recruitment, informed consent, and data handling procedures prior to the study.

### Recruitment

We visited the last class of six different FtF courses across five Maryland locales during the Fall and Winter of 2003. Out of 61 people, 40 gave us their contact information and permission to call and discuss the project further. Of these, two declined when contacted, one was too ill to participate, and five did not respond to our attempts to contact them. Later, one tape was ruined due to electrical interference while recording and the interview could not be repeated, so our final data consisted of 31 interviews.

### Final Sample

Of the final study participants, most ( $n = 23$ ) were women, as is common in FtF and care-giving in general. Over half (19 out of 31) were parents of the ill person about whom they took the class, mostly ( $n = 14$ ) mothers. We interviewed three parental pairs, so our data refers to 28 different families rather than 31. Among the non-parent interviewees, five were spouses of the consumer, four were sisters, one was the consumer's adult daughter, and two had multiple relationships to consumers. They came from Howard, Baltimore, Montgomery, and Anne Arundel counties, and Baltimore city, in Maryland. Most participants indicated that the family member for whom they took FtF had an affective disorder (10 Bipolar, 5 Depression), while four reported their family member as having schizophrenia, three schizoaffective disorder, four gave multiple diagnoses, and two were not sure. Sixteen of the thirty-one interviewees lived with the consumer, nine lived nearby, four lived in a different state, and for two (one parent pair) the consumer was incarcerated (See Table 1).

**Table 1** Demographics

	Female <sup>a</sup> <i>n</i> = 23	Male <sup>a</sup> <i>n</i> = 8	Total <i>N</i> = 31
Relationship to ill relative			
Parent	14	5	19
Child	1	0	1
Sibling	4	0	4
Spouse	2	3	5
Multiple	2	0	2
Consumer's illness			
Bipolar	9	2	10 <sup>a</sup>
Depression	2	2	4
Schizophrenia	3	2	4 <sup>a</sup>
Schizoaffective	3	0	3
Multiple people or Dx	4	0	4
Unclear/Unsure	2	2	3 <sup>a</sup>
Living situation			
Live with	12	4	16
Live near (same state)	7	2	9
Live distant (dif state)	3	1	4
Incarcerated	1	1	2

<sup>a</sup> Adding the figures in columns one and two do not equal "total" because some parents were interviewed regarding the same relative

### Interview Procedures

We conducted the interviews 1–3 months after each participant's class ended. About half were conducted by both interviewers (Stewart and Lucksted) while the rest were conducted by a single interviewer due to scheduling challenges. Interviews ranged from 45 to 90 min. Interviewees gave written informed consent to the interview and its audio-recording, and were offered \$20 in gratuity. Following initial background questions, the interviews focused on three domains. First, we asked interviewees to discuss what about the FtF class was most salient or important to them. Second, we asked about any effects taking FtF had in their lives, ranging from their own thinking and emotions to extended family and community. Third, we explored the change processes involved—whether and *how* did they perceive the elements of FtF as leading to, influencing, or causing the changes they noticed.

### Data Preparation

The interview recordings were professionally transcribed and then checked against the audio-recording for accuracy. During transcription, names and other identifying details were replaced by anonymous placeholders to protect participant privacy while preserving contextual information. The transcripts plus our field notes regarding each interview constituted the body of data for this study.

## Data Analysis

### Overview

We approached data analysis from a constructivist, grounded theory framework (Charmaz 2006) in which data are repeatedly compared with each other and with more abstract conceptual ideas to discern working theoretical understandings of the phenomena under study. We therefore used several analytic techniques to examine the data for what each interview could add to our overall understanding of the change processes involved in FtF participation. Each technique, detailed below, deepened our understanding of the data and of how specific data points (specific interview passages) related to each other and fit with (or did not) larger theoretical concepts. Below we describe the techniques we used in order, noting the analytic function of each.

### Individual Interview Summaries

We first summarized each participant's story according to: (1) Demographics and family context, (2) How they came to know about and contact NAMI and FtF, (3) Most salient facets of the class experience, (4) Any change processes they mentioned, and (5) Effects they noted. We also excerpted factual characteristics from each summary (e.g., relationship between interviewee and ill relative, interviewee gender, etc) in order to describe our sample (see Table 1). These initial steps helped us become acquainted with our sample as a whole and oriented us to the data.

### Cataloging Prominent Aspects of FtF Reported by Interviewees

We next catalogued all the aspects of FtF that interviewees said stood out in their experience. We each separately grouped interviewees' responses to this question and discussed our results until we came to consensus on a single list of meaningful categories: Information, Skills and Strategies, Empathy and Insight, Resources, and Social Support. Although these categories summarized interviewees' perceptions, their mere cataloging does not reveal *why* they were important or whether they played any role in bringing about beneficial changes. Hence, our analysis next sought to discern the effects of taking FtF and then to understand the connections between prominent components and effects.

### Cataloging Effects

We examined the transcripts for what effects interviewees reported FtF participation as having using the same dual

coding and consensus process as above. We settled on eight initial effect categories:

- Improved/increased self care actions
- Sharing helpful class information with others in their family
- Improved well-being (of the person who took the class)
- Improved communication and relationships in the participant's family
- Involvement in NAMI or other support/advocacy activities in order to help others
- Individual advocacy on behalf of ill relative (by the participant)
- Using the strategies learned in class consciously to solve problems or cope more effectively

These categories anchored important end-points of FtF participation that interviewees said they experienced so that our analysis could be grounded in what *these* participants said were the benefits *they* accrued from FtF (rather than our making assumptions based on previous research).

## Change Processes

### *Identifying Change Process “Fragments”*

The two “cataloging” steps described above were necessary to sketch out the beginning and ending markers of FtF change processes. Our next step was to discern how the prominent elements of FtF and the effects of participating in it were connected. We wanted to analyze the data in ways that both preserved each individual's details and yet allowed us to discern larger patterns of change processes across interviews, if any existed. Therefore, going through each transcript, we diagrammed each instance in which an interviewee described any change because of FtF. This resulted in more than 250 separate diagrammed statements, herein termed “fragments”. For example (→ means “led to”): *class information on family impact → better understanding of sibling issues → not blame sister as much for resentment towards ill brother.*

### *Grouping Fragments into Working Categories*

To help us see how these individual fragments might fit together across interviews in theoretically meaningful ways, we grouped them into 14 working categories. For example, *problem-solving parts of FtF curriculum → interviewee feeling better prepared for crisis → the interviewee feeling less anxious* was a common type of fragment with different interviewees discussing diverse crisis and anxiety details. In typical qualitative analysis fashion (Miles and Huberman 1994), we could then consider the meanings, variations, and roles of each working

category by closely examining its many exemplars. This also helped us see higher order concepts within each category and relationships between categories. Since these were rough intermediate working categories, we are not including a list of all 14 here but they are available from the authors.

### *Emergence of a Single Model*

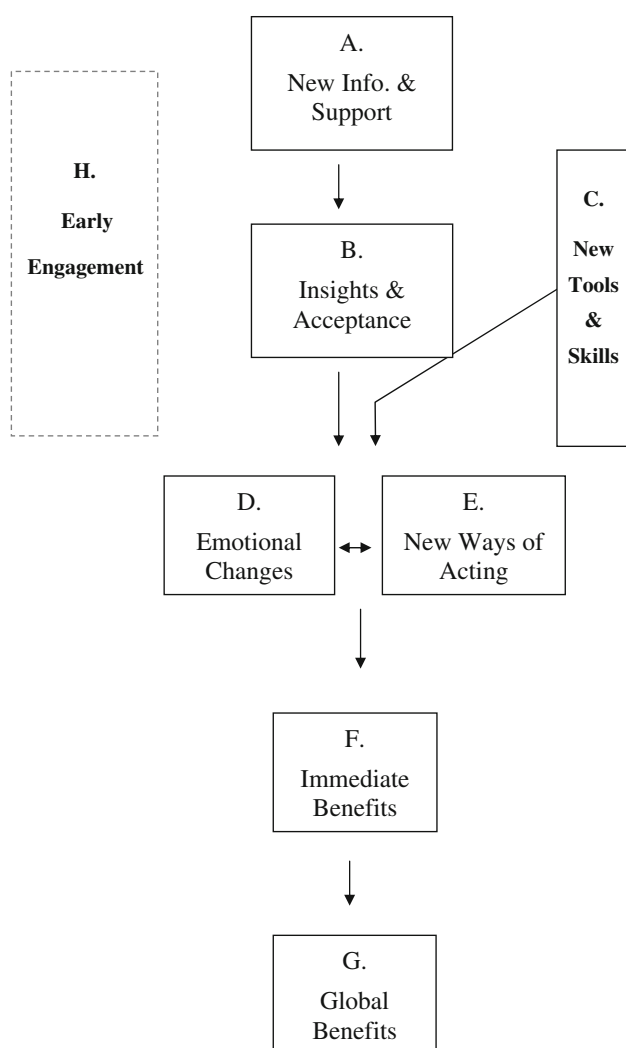
We did not set out to create a unitary change diagram across all interviews. Rather, we considered that there might be multiple parallel processes occurring or different chains of events for different sub-groups of participants. However, while examining the working categories of diagrammed fragments, we found a high degree of commonality across interviews and many interconnections between fragment groups. On this basis, conceptualizing a single overall stream of change set in motion by taking FtF seemed the best fit with the data. We then pieced together the interlinked fragment groups, refining the fit and our understanding through repeated comparison with the raw data. This strategy is in keeping with grounded-theory tenets (Charmaz 2006) of building theory bottom-up from the data so that it is grounded solidly in the participants' experiences before comparing it to any pre-existing outside theory (in this case trauma or stress-and-coping theory, addressed in the Section “Discussion”).

### Checking Back on Earlier Steps

We also looked back at the initial “prominent aspects” and “effects” catalogs as well. The meanings they captured remained important and fit with the emerging change process diagram. Yet, because the analyses that followed their early creation had refined our understanding of the data, we could now better see why certain aspects of FtF were important to interviewees, what had led to the effects mentioned, and how the various effects related to each other. This led us to adjust and rename some of these initial ideas as we incorporated them into an overall schematic. We iterated theory-building and data examination in these ways until we were confident that the final version (see Section “Results”) depicted a working model that was both true to the individual interviews in this study and conceptually useful.

## Results

We have organized this study's results into a schematic (Fig. 1) of how interviewees depicted FtF as catalyzing change in their thinking and lives and organized this section according to the Figure's labeled boxes. Boxes A and



**Fig. 1** Flow of change in FtF

B depict new information and insights that interviewees described having gained from FtF. Box C represents skills taught within the FtF curriculum, which interviewees described as tools with which to put new ideas into practice. Subsequently, box D represents new ways of feeling and E represents new ways of behaving that result from the confluence of A, B, and C. The boxes marked F and G represent the immediate and specific, and the more global, outcomes of this overall process, respectively. Box H depicts early engagement factors. Each is explained below, followed by a final section on “time regret” that does not appear in Fig. 1.

#### New Information & Support

Interviewees said that FtF gave them several types of important new information. First, for many, the factual information about mental illness, diagnosis, treatment, medications, and side effects was partly or completely new.

For some, it corrected previously held misinformation. For example, one father said: *I pretty soon began to realize that Bipolar is treatable, can be managed in... 60% to 80% of the cases. I didn't know that before, and that was very encouraging.* Second, interviewees said that realizing one is not alone and that others can lend real support was important new information for them:

You hear yourself talk and when it comes out of your mouth and you know it's out in the open and the room doesn't come crashing down upon you, then you feel safe because you were able to go public with it. And after you get it out there it's like there's a new fresh air... It is liberating... And you hear that there are other people in this room—other people who have similar problems and experiences in dealing with their family members.

Even just finding commonality was a shock for some:

I don't know what I had expected to see when I came to that class. My thought was, “all these people look normal.” I'm not sure what I expected because they are family members. I looked around and said “Um, that lady looks really nice.” And I think the reality of it all, that all of us had the same type of problem...that was an eye-opener.

Interviewees also valued the information they gained about first-person experiences of living with a mental illness. Some had never had in-depth conversations with their ill relative or other consumers about living with SMI:

It makes you have a different understanding of what the consumer is going through. I see it much differently then I used to. Much differently. I feel that I am a lot more tolerant and understanding and I tend not to get as angry.

#### Insights & Acceptance

As evident in the quote above, interviewees told us that new information often changed their thinking. They attributed these insights to a combination of the new information presented plus seeing themselves, their ill relative, and their family reflected in the stories and experiences of others. For some, these insights were subtle, especially among those who were well informed before coming to FtF. Others experienced profound realizations. Some said they had previously denied their relative's illness entirely, or had not understood that certain symptoms were outside his or her control:

Somehow reading about and talking about all the negative symptoms of a disease turned my attitude around in dealing with [my son] because, you know,

I'm a type-A personality... And I would just get frustrated,...and I would just be real hard on him. Somehow, I just got more of a sympathetic view towards him and his difficulties... I lost a lot of my negativity... and I think it was taking the NAMI class ... [Interviewer: What do you think happened?] Well, I think that it was the information about how common these symptoms are...I mean, that thought had never entered my mind.

These insights were not always comfortable. Interviewees said they shook and sometimes dismantled the frameworks through which they previously made sense of their relative's illness and its impacts. New insights unsettled their expectations and assumptions about the present and the future, about what is helpful, and about what they can and cannot control. For example, one person realized the necessity of pacing one's self for a long struggle, and another realized that her younger sister might not ever meet her expectations. Several commented on the difficult but useful realization that many things are outside their control and that expectations must be adjusted or let go.

#### Tools/Skills

Interviewees described specific skills that the FtF curriculum teaches and how they combined with the new information and resulting insights. That is, they experienced FtF as offering new tools to help them implement new ideas, allowing them to more effectively engage with their life situation. Repeatedly, interviewees said they felt "better equipped" to handle situations in their lives after completing the class. For example:

The communications skills really helped us not to fight as much. [Before] it was a constant fight with her [ill sister]... Everything would turn into an argument and we couldn't really figure out why. And then when we started looking at the communication skills and learning all of the other stuff in the Family-to-Family course we really shifted gears and changed our perspective and I would say changed our expectations even... Instead of isolating her and her always feeling like we were blaming her and that everybody was against her, she truly, she even said she started to feel like we were really supporting her and that we were on her side.

Our analysis of the transcripts showed that the combination of A (new information), B (insights), and C (new skills) blended together to form two types of effects—emotional and behavioral. These effects are described below. Interviewees described them not as one causing the other, but rather as mutually affecting each other. This is

reflected in their side-by-side position and double-ended arrow in Fig. 1.

#### Emotional Changes

Interviewees described feeling better because of their new understanding, tools, and skills. They reported less despair and hopelessness, less fear about the next crisis or challenge, less anxiety, anger, guilt and blaming, and more hope, confidence and feelings of strength and competence. They experienced these feelings as a benefit even in negative situations:

Literally, the next two days after I had that communication class, [my daughter] called me up and bawled me out. And I tried everything and it didn't work (laughter) but I felt better for having tried it. Because sometimes nothing's going to work no matter what you do—[but] I had something to try.

A few said or implied that these changes also raised *negative* emotions. Some now wondered if their relative's illness was diagnosed correctly; others felt daunted by the complexity of mental illness as they came to understand it better. Several described feeling frustrated and motivated to learn more about promising treatments that their relative was not receiving.

#### Behavior Change and View of Control

The processes depicted in steps A–D usually resulted in FtF participants changing the ways they treat themselves (e.g., self care, self blaming), their ill relative, and others in their family and surroundings. Behavioral changes also included how they solve problems and interact with mental health providers. For example, one participant credited FtF with leading her to ask better questions of her husband's psychiatrist; another told of celebrating Christmas differently after taking FtF because he had learned more about things that were destabilizing to his ill son. Yet another said that taking FtF had led her to speak up more about mental illness and stigma to relatives, friends, and acquaintances.

Many of these individual behavioral changes had a common theme of shifting what the person tries to control. This often involved letting go of "trying to control everything" (a phrase used by many). For others, it meant letting go of specific things they now realized were "not mine to change," or recognizing a new possibility. Paradoxically, accepting certain things as beyond one's control helped interviewees see other areas where they *could* have positive impact. For example:

He stands on the steps in the rain and it's bothering me. Are you okay? "Sure." Why are you standing out

there in the rain? It's cold. He said "I just want to be by myself for a while." I said okay. But that wasn't enough and I [started to go] back [to talk to him again] and then I thought about what they said [in class] about once your family members go down the street or whatever [you can't control what happens] and then I said [to myself]... "If he stands out there long enough, he'll get wet. He'll get cold. He'll come back in the house or he will turn into an icicle. That's not very likely." So, I didn't, you know...I stopped worrying.

Another person said: *It helped me to see there is nothing I can do to solve the problems she has, but there are ways I can help.*

### Communication

One of the most repeated examples of behavioral change was improved communication between interviewees and their ill relatives. As reflected in some of the quotations above, many interviewees said that before taking FtF they argued frequently and did not communicate well. They described FtF as offering new *information* (e.g., that SMI can make certain kinds of communication hard to process), combined with new *tools and skills* that improved their communication. Interviewees said that as a result they saw difficult situations in a new light:

Like instead of like yelling at him and everything,—I learned this in one of the sessions, to start it with "I". You know, like, "I need you to do this for me, I need you". And when I tell him that way, he's doing it more.

Communication improvements extended to other family relationships as well. Participants spoke of being more understanding of others, using the same techniques to disagree effectively with other relatives, and being more open in discussing issues related to mental illness. Similarly, they described improved communication with mental health and other professionals.

### Self Care

Taking care of one's self was a second prominent category of new behaviors and shifting understandings of control. Interviewees said that through FtF they understood that it is important to take care of one's self while one is helping others. For many, a desire to solve or control *everything* and feeling guilty when they could not had previously stood in the way of self care. Interviewees also cited FtF as teaching specific ways to take care of one's own needs as a caregiver, such as setting limits, knowing that it is alright to

have one's own preferences and comfort count for something, carving out personal time, and delegating certain responsibilities. For example:

[Before] I could say "no"... but then I would let him talk me into it. ...the class helped because I [now] have this information about dealing with [his] bipolar and addiction and the dual diagnosis and all of that...I guess it helped me see that I can't help anybody else except myself. [Later:] The class helped me know that I need to go to sleep, I need to get my rest—in order to...deal with this and not be stressed...

### Immediate Benefits

As in the examples above, interviewees experienced the emotional and behavioral changes sparked by FtF participation as positive. No one mentioned feeling harmed by their experiences in FtF. Many spoke of relief and sometimes happiness as they saw new ideas and techniques pay off practically and emotionally. Interviewees often described two tiers of benefits—immediate benefits directly related to their family and SMI and then more global benefits caused by the immediate benefits. Immediate benefits included:

- More effective coping and problem solving and more confidence
- Feeling less tension, stress, exhaustion, anger, frustration
- Better relating to ill relative and others
- Noticing their ill relative seemed less tense relating to them
- Deepening acceptance

Regarding immediate benefits, one interviewee said:

I think a lot had to do with the Family-to-Family course... When crises have occurred since then we have been able to handle them a lot more efficiently... as opposed to [before]—It was almost like a crisis would occur and we would escalate it by our reaction. But now I think that we are a lot calmer and a lot more accepting of, you know. And maybe there was a little bit of denial on our part too, earlier on, like "this can't be happening." And now, [we say] "okay, this is happening and we're accepting it and let's...what's a proactive way we can handle this?"

Interviewees also described ongoing developments in acceptance over time. Certain initial elements of acceptance were important at the beginning, but interviewees made clear that accepting the realities of a loved one having SMI is both an ongoing process and a beneficial outcome of taking FtF. Thus, they describe deepening

levels of acceptance—such as accepting the long term nature of their relative’s illness, one’s inability to control large portions of the experience, and the likelihood of future hard times—as freeing in that they lessen frustration, allow one to minimize wasted effort, and lead one to concentrate on feasible goals.

### Global Benefits

Interviewees’ accounts depict these immediate benefits as facilitating broader benefits. Many emphasized that they still experience tragedy, despair, anger, and frustration, but that their overall lives are better as a result of the changes in information, perspective, skills, and behaviors they gained through participating in FtF. Across interviews, these global benefits comprised four themes:

- Increased quality of life for one’s self and sometimes also for their ill relative and others
- Increased feelings of empowerment and having the ability and confidence to speak up and change things that are possible to change
- Increased activity level, using more active coping styles, mobilization, advocacy
- Decreased depression, despair, and stress related symptoms

A few examples include:

The NAMI program actually saved our marriage. As a matter of fact, may even have saved my wife’s life. Gaining insight into the illness has given me the strength to keep working on the relationship. Learning what I know about depression has helped me make better decisions when my wife is getting symptomatic. Emotionally I feel a lot stronger, a lot better. That’s the word I want to use.

I just don’t think my parents knew how to handle it [her sister’s illness] well and they didn’t know what steps to take and so bringing them to NAMI was huge for me and for them because it just showed them there’s a million things we can be doing that we’ve never even thought about doing before.

Such global benefits, as well as the immediate ones and the emotional and skill changes discussed earlier do not end when the FtF course ends and may not be fully develop by the end of the course. To the contrary, many interviewees described benefits as still unfolding at the time of their interview, one to three months after the class had ended.

### Early Engagement

Participants come to FtF through numerous routes, most often word-of-mouth from people who have previously

taken FtF, FtF teachers, or NAMI affiliate volunteers/staff. Some interviewees credited the encouragement and sometimes even a little persuasion they received from these people as important to getting them “in the door”. Many interviewees mentioned initially feeling uncertain about the class’ value and concerned about the time commitment of 12 weeks.

Three factors stood out regarding why they returned, each giving participants some immediate beneficial feeling that drew them back. First, many interviewees mentioned tremendous relief in realizing they are not alone—in having the chance to talk with others who *get it*. This in itself was enough to bring some people back. Second, some said they felt less crushed by their own situation as soon as they heard others’ stories, often finding them much worse:

The first thing I remember about the first meeting is that I met people whose stories were much more tragic than my daughter’s story... I guess that is one of the effects of taking the class, you realize that things could be a lot worse in some cases. That in itself is therapeutic in a way. I mean it’s, “there but for the grace of God go I.”

Participants said that such comparisons made them feel thankful for what they do have and made them think that *if others can cope with that, I can cope with this*. Participants returned to gain more of these mutual assistance benefits.

Third, some participants said that the information and support offered in the initial class(es) convinced them that the course would be useful and therefore was worth their time and emotional investment. One person said:

I think that [attending] was an effort to do, but once you see the other people—the class instructor, how it is handled, you are more reassured with every class that you go to. And I think two or three classes into it you look forward to going and look forward to that support and just feeling better about yourself and your ability to go.

In this initial study, we were not able to discern further details of how or whether these early engagement processes meshed with the overall process of change summarized in Fig. 1. Therefore, in Fig. 1 “Early Engagement” is depicted as parallel with the overall early steps, but no specific connection is posited. These limitations are further considered in the Section “Discussion” of this paper.

### Time Regret

It was clear across interviews that not everyone benefited in the same ways from FtF. An important factor in this difference was the amount of time between when an interviewee initially began experiencing their relative’s

mental illness and when s/he entered FtF (ranged from 1 to 30 years in our sample). Interviewees who had been dealing with their relative's illness for a short amount of time usually did not know as much about the topics covered in the FtF curriculum before taking the class. Therefore, more of the curriculum was new and revelatory for them.

In contrast, family members who had been coping and care-giving for decades told stories of having to figure things out on their own (e.g., by trial and error, asking doctors, reading) long before they knew about FtF. One person said: *You have no choice. You have two choices. Either develop some skills or go crazy yourself.* Therefore, while uniformly positive about FtF, the benefits these participants described were mostly incremental—adding detail, correcting small misconceptions, validating things about which they had been unsure, and adding skills. Across these individual differences, many interviewees who came to FtF later expressed what we came to call “time regret”—avidly wishing they had had earlier access to the FtF curriculum. Two examples are offered below:

I think I cried when I saw the FtF class description. We'd been going without this information so long, and it seemed like something that could really help.

Well, you know, this is my great regret that I didn't find it long ago...I guess I heard about NAMI through my church and in a sense I felt, well, I'd been through so much by that time that I didn't need this, you know. And in a sense that's true. I'd learned an awful lot by that time. ... but having just finished the course, I realize there were a lot of holes in my knowledge which NAMI offers—the course is so thorough. And I only wish I'd had that from the beginning.

This emergent theme of “time regret” is not part of the overall process sketched out in Fig. 1 but rather a factor that shaped interviewees' individual trajectory through it. Thus, it is not depicted in Fig. 1. Its implications are considered in the Section “Discussion”.

## Discussion

### Overview

As the first qualitative examination of the change processes in FtF, the results of this study shed useful light on the mechanisms through which the FtF serves as a self-help modality, an intervention utilizing stress and coping and trauma and recovery conceptual models, and a community resource. Additionally, this research indicates that the beneficial change processes central to self-help theory are also at play even though they were not an explicit part of

FtFs construction. At the same time, this study's limited sample and single sample methodology require us to consider its results tentative and incomplete. Strengths and weaknesses are discussed below, including ideas for applications and future research.

### Evaluating Figure 1

The grounded theory data analysis approach used in this study seeks to “uncover” explanatory theory that emerges from the data itself by building conceptual ideas from comparisons of data across participants (Charmaz 2006). The change processes summarized in Fig. 1 were robust in the interview data and, as discussed below, fit with stress/coping, trauma, and self-help theories. Yet, the model in Fig. 1 remains incomplete. One indication of its limitations is our inability to integrate the “early sustenance” theme into the main flow of the model. This study focused on experienced change and outcomes rather than engagement or retention. Therefore, we did not have the data to evaluate whether “early sustenance” fits into the proposed model, whether its not fitting belies a critical shortcoming of the schematic, or whether it is most usefully considered as part of a separate and parallel process that participants experience.

Further, we used a linear set of boxes and arrows in Fig. 1 to clearly depict the study's main results via a schematic. Yet, interviewees' experiences were less like a single line and more like the eddies of a river with diverse streams of change mixing in unique and varying ways for each individual. Also, this study asked interviewees to reflect retrospectively from a vantage point of one-three months post-FtF participation. Thus, their retrospective perceptions of change might have differed from what they experienced in vivo during the course.

Finally, we chose semi-structured interviews and qualitative analyses as the most appropriate methods for understanding FtF change processes. Our study was not intended to necessarily employ a participant sample representative of any larger population but rather to delve deeply into conceptual understanding of a specific group of participants. Therefore, we cannot directly assess the generalizability of results. Yet the emergence of a robust series of change processes that fit with relevant theories suggests that these study results may indeed hold for FtF participants more broadly, helping to explain *how* programs like FtF benefit participants.

### Integration of Results with Self Help Theory

The benefits and change processes reported by interviewees fit with classic principles of mutual assistance. These include the benefits of a supportive peer group to lessen isolation, the normalization of meeting others who share

one's challenging life situation, the exchange of practical information and coping strategies, and social support (Kryouz et al. 2002; Norcross 2000). Although there is little research on *structured* peer-led programs like FtF, research on support groups for family members of people with a variety of serious illnesses show similar outcomes (e.g., Pickette et al. 1998). Similarly, peer programs run by and for people with SMI may show benefits in areas such as social functioning and problem-focused coping (Yanos 2001), empowerment, and reduced distress (Nelson et al. 2006). In these respects, FtF seems consistent with other self-help interventions.

#### Integration of Results with Stress and Coping Principles

Our study's results indicate that stress and coping principles are components of the FtF mechanisms experienced by participants. First, FtF seems to reduce participants' distress by offering information that enables them to re-appraise stressors in more adaptive ways. For example, some participants developed a better understanding of their ill relative's troubling behaviors (Provencher and Fincham 2000) or developed new ideas about what to try to change. Second, the curriculum teaches specific and relevant skills such as communication, problem solving, and self-care, which interviewees reported improve their active coping repertoire. Third, FtF normalizes the powerful emotions that accompany being a family member of someone with SMI and offers both support and assistance with effective emotional coping strategies (Lazarus and Folkman 1984). Thus, study results indicate that the integration of stress and coping theory (Burland 1998) into FtFs curriculum is reflected in participants' experiences and outcomes.

#### Integration of Results with Trauma and Recovery Models

Study results similarly indicate that interviewees benefited from the trauma-recovery principles underpinning FtFs design. Interviewees appreciated FtFs acknowledgment that the distress and disruption they experience is traumatic. Additionally, their accounts of change can readily be seen as steps towards integrating the trauma of a loved one's mental illness into their own and their family's lives. For example, some said that before their participation in FtF they alternated between denying aspects of their situation and being overwhelmed by it (analogous to numbing and flooding). They attributed FtF with helping them move to steadier ground where they neither denied their loved-one's illness nor permitted it to define their life. This included improving their ability to attend to their own needs and set limits on care-giving while staying attentive to their family and its challenges.

#### Integration of Results with Previous FtF Research

Additionally, study results add to our understanding of the findings of the previous quantitative wait-list control study (Dixon et al. 2004) of FtF in ways that integrate all three of the theoretical models discussed above. In our study, study participants' discussions of feeling "better equipped", more confident, and having "more options" to solve problems all fit logically with the increases in empowerment measured in the quantitative evaluations. Interviewees also said that exchanging support, seeing results in light of the new skills they had gained, and shifting their expectations lifted their spirits, gave them hope, and made their care-giving roles and family's situation feel more manageable. These processes fit with the quantitative study's results indicating decreased subjective burden and depression.

#### Time Regret

A number of participants who enrolled in FtF years after their relative first became ill avidly wished they had found the program and learned the skills it offers much earlier in the history of their family-member's illness. This represented a theme we called the "time regret". The "time regret" concept was unknown to us before this study and was not an a priori part of FtFs theoretical design. Rather, it emerged from participant interviews as an important and complex issue in the processes through which participating in FtF benefits family members. Once it came to our attention in the data, we sought out other related research, intending to put our results in the context of previous work. However, despite considerable effort, we were unable to locate relevant examples in the social science literatures. This concept merits future, additional study due to its considerable practical implications, which we touch on in the section below.

#### Immediate Applications

This study's findings have potential practical applications to FtF as a program and community resource. First, knowing about its embedded change processes helps to flesh out the growing evidence of FtFs effectiveness. For example, being able to explain not only that the program benefits people but *how* it works may help potential attendees feel more comfortable participating in FtF. It could also help FtF teachers feel more valuable and assured of their role and health care professionals feel more confident about recommending FtF to families.

Secondly, emergence of the poignant "time regret" theme underscored concerns expressed by FtF program leaders (Personal communications 2004, 2005) about the

importance of making FtF available to family members early in their relative's illness. This study's results may be useful in supporting their efforts to do so. Thirdly, FtF teachers and others may be able to use this study's findings to offer interested parties some detail about what to expect if they participate in the program. Additionally, "early engagement" factors identified in this study may assist in enhancing participant retention.

#### Future Research

We intend to test and further develop the initial model developed in this study in future work. For example, we may seek to interview FtF participants at various points *during* the course of the program to examine the change process *in vivo* rather than retrospectively. We also hope to carry out mixed-methods and quantitative evaluation of the current model's components and their relationships to specific outcomes for both family members and consumers.

Additionally, given the resonance of this study's results with the self-help, stress and coping, and trauma literatures, it would be wise to integrate current knowledge in those areas into future FtF research. For example, the broader body of self-help research might aid in clarifying the function of the "early engagement" and "time regret" factors in the processes of change that occur through FtF participation. Research on self-help leadership succession and how peer leaders/teachers benefit from experience in leadership roles may be useful to FtFs sustenance and development as a community resource for family members of people with SMI.

#### Conclusion

This qualitative interview study investigated the processes through which participants in the FtF gained benefits that have been documented in previous work (Dixon et al. 2004) such as decreased emotional distress and increased empowerment. The current study's results suggest that these benefits accrue because the FtF curriculum and format give participants new information, emotional and practical support, new frameworks for understanding, and new skills which, in combination, allow participants to respond to challenges in new ways. These new ways include shifts in what they try to control or influence, making different behavioral choices, increases in self-care, and changed expectations. As a result, although many participants emphasized that they still experience tragedy, despair, anger, and frustration, graduates described immediate benefits from FtF participation including enhanced coping, more confidence, less tension and frustration, better family communication, deepening acceptance, and more

hope. They further described these immediate effects as leading to more global benefits including enhanced quality of life, decreased distress, amplified energy to take action, and increased feelings of empowerment. These change processes are in keeping with self-help, stress and coping, and trauma-recovery theories and literature. Thus this study, while limited, adds to our knowledge about FtF as a resource for family members of people with mental illnesses and to our understanding of how structured, self-help interventions operate to benefit participants.

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