Stigma and families of individuals with mental illness

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SUMMARY

Stereotypes, assumptions, and stigmas associated with mental illness deeply affect the lives of family members of individuals with mental illnesses. Whether taking the form of Direct Public Family Stigma, Indirect Public Family Stigma, or Family Member Self Stigma, these experiences harm family member well-being, family relationships, and families' accessing of professional and natural supports to assist them and their loved ones. The NAMI Family to Family (FTF) program was created out of the stigma and discrimination that family members often face. Our team's recent randomized trial of FTF outcomes, and previous qualitative study of FTF change processes, are both presented to provide data and insights about FTF as one example of family education and support programs addressing family stigma. We conclude with brief comments on the current status of family stigma interventions in professional mental health services and self help programs, and suggestions for future advancements.

INTRODUCTION

In this paper we address stigma faced by family members of individuals with mental illnesses in four ways. First we describe several types of family stigma, their origins and impacts. In Section II we ground these concepts in the experiences of family members and the resulting development of the NAMI Family to Family (FTF) education program. Next (Section III), we analyze how FTF influences family member stigma experiences via results from two studies: a randomized controlled community trial, and a qualitative change-processes inquiry. Finally, in Section IV, we discuss implications of the status quo regarding family stigma and present suggestions for future advances.

Family members of people with mental illness are stigmatized through stereotypes and prejudices that negatively impact them and their family system. This can take the form of Direct Public Family Stigma, Indirect Family Stigma, and be internalized by family members as Family Member Self-Stigma.

Direct Public Family Stigma (DPFS) includes negative stereotypes, prejudice and discrimination directed at family members from others. Corrigan and Larson[1] and others identify blame as a main expression of DPFS. Others often blame parents, spouses, adult children and other relatives for causing their relative's mental illness through incompetence (e.g., myths that poor parenting causes mental illness) or exacerbation. For example, the spouse or adult children of a person with mental illness may be blamed for not helping him/her prevent relapse. More recently, families are sometimes blamed for genetics – parents for passing on or spouses for procreating with "tainted genes." Siblings may feel tainted themselves, especially if they wish to have children.

Indirect Public Family Stigma (IPFS), in the past referred to as "courtesy" or "associative" stigma[2], stigmatizes family members for being associated with the person who has mental illness. Whereas DPFS blames family members for causing or contributing to mental illness, IPFS transfers the stigma associated with mental illness directly to the relative (i.e., family members assumed to be 'crazy' because they live with or love someone who is 'crazy'). Corrigan and Larson[1] describe this as "contamination". DPFS and IPFS may come from diverse sources (strangers, social institutions, workplace) and are especially hurtful coming from family members or other respected people.

In response to both forms of public stigma, family members often experience Family Member Self Stigma (FMSS); family members internalize the stigma they experience and come to believe it as true of themselves. Corrigan and Larson equate FMSS with shame[1]. Family members may feel ashamed of their ill relative, or of having mental illness in their family, as if they are at fault. They may also experience FMSS as embarrassment – for their relative's deviation from social norms or their

family's distress. Like internalized stigma among people who have mental illness[3] FMSS can lead to isolation, withdrawal, avoidance, and secrecy. Additionally, family members free from FMSS may nonetheless withdraw to avoid the prejudicial attitudes and discriminatory behaviors of others.

All types of family stigma have substantial negative impacts. They can isolate family members from relatives, friends and neighbors, lead them to avoid professional help, reduce self-esteem, and increase anxiety and depression. Family stigma also stresses the family system – causing ambivalence, tense relationships, blaming, and hampering members' ability to help each other or seek necessary treatment. Bryne points out that family members may attempt to hide the mental illness, or the person with mental illness, creating an additional obstacle to seeking help[4]. Moreover, seeing self stigma among one's relatives can reinforce self stigma in the person with mental illness (i.e., "I can tell my family is embarrassed by me, so I must be embarrassing").

While public interventions work to reduce sources of stigmatization[5], families need assistance coping with the stigmas they currently encounter. Such supports should help families develop awareness of stigma, provide supportive environments to discuss its effects, and help attendees learn and practice coping skills. As one such resource, NAMI's widely disseminated Family to Family education program (FTF) is designed to address a wide range of unmet family needs including anti-stigma assistance.

Family Stigma, NAMI & the FTF Program

"My sister became ill with paranoid schizophrenia in 1960. Determined to help her, my parents were reproached and dismissed as pathogenic. They never fully recovered from this. Twenty years later my daughter was stricken with the same illness. Surely, I thought, by now things have changed. But, it was as if the world had stood still. ... No one came forward to inform, to counsel or comfort me as I reeled from the trauma of her psychotic illness. A psychiatrist informed me that my daughter's "infant psychosis", due to early maternal indifference, was breaking through, and recommended that I attend a family therapy session with my ex-husband of 15 years... Here we were assured that once we stopped "using her symptoms" as a cover-up for our own marital failure, she would be fine".

These family experiences placed Dr. Joyce Burland squarely in the 20th century era of family blame, where loving caregivers were shamed as unfit parents and perpetrators of dysfunction, denied information by the misapplication of rules of confidentiality and left to cope in isolation with the stress and dangers serious mental illness can bring. NAMI was founded in 1979 primarily in response to the discrimination caused by family blame, resulting public attitudes, and the too frequent disregard of families in desperate need. Although NAMI founders advocated for mental health authorities to create family education programs across the nation, this goal was not achieved. Instead, by 1989, NAMI resolved to create family programs of its own. First into the field was the NAMI-Vermont Family Education program, developed by Dr. Burland and available to families in 1991. It then evolved into the current national NAMI Family to Family education program (FTF).

FTF is a free 12-week class with a highly structured curriculum, taught by trained family member volunteers in the community, and open to any family member of a living adult with mental illness. In weekly 2–3 hour sessions, attendees receive information about mental illnesses, medication, and rehabilitation. They learn self-care, mutual assistance and communication skills, problem-solving strategies, advocacy, and develop emotional insight into their responses to mental illness[6-8].

Given her own formative experiences as a family-member and a mental health professional, in creating FTF Dr. Burland was determined to write a course that would reclaim family members' dignity as loving caregivers, celebrate their strengths, sympathize with their upheaval, and give them tools for insight, empathy, effective support of their loved one, and advocacy[7,8]. In addition to crucial medical information, the program focuses on families' pressing realities, particularly the trauma of coming through loss, grief, fear and uncertainty, and coping with the life challenges of mental illness. Dr. Burland's background in feminist liberation theory and her years of clinical practice with families greatly influenced her perspective; here was a marginalized group largely unaware of how learned stereotypes clouded their understanding. Many had not only deeply internalized messages of personal guilt, but had also also accepted stereotypes that charged patients with immaturity and irresponsibility when they failed to improve. Therefore, much of FTF is devoted to consciousness-raising to help caregivers challenge stigmas and to recognize how much false myths influence their interpretation of their relative's illness and behaviors and act in response. FTF encourages insights and empathy, leading family members to see the daily heroism in their relatives' efforts to reconstruct their lives.

Because the knowledge base for this process resides in families' lived experience, in creating FTF Dr. Burland determined that family education could rest responsibly in the hands of family members as teachers. Modeling truth-telling and breaking the silence about their own challenges as parents, siblings, adult children or spouses empowers class attendees to confront and overcome the shame and stigma burdening their lives.

What started in 1991 as a group of 18 volunteer teachers and 150 class participants in Vermont today comprises over 10,000 family member trainers and teachers who have served over 350,000 graduates nationally and internationally. FTF is now offered in 49 U.S. states, Puerto Rico, Canada, Mexico, and Italy. This growth is an indication of families' need and desire to overcome historical and contemporary stigmas. By entrusting this stigmatized group with the personal responsibility for radical change, FTF works to create a system of transformation toward appreciation, respect and inclusion.

What are the data regarding FTF and stigma?

1. FTF randomized trial and family stigma

Our team has conducted several studies that permit consideration of whether FTF reduces stigma among its family member participants[9-14]. This section describes the randomized controlled trial (RCT) of FTF in which we used a stress-coping conceptualization of FTF's impact, and evaluated constructs related to the experience of family stigma. We conducted the RCT in diverse regions of Maryland served by five NAMI affiliates from 3/15/2006 and 9/23/2009[13,14]. Existing family-member teachers delivered FTF, using usual locations and schedules. All RCT participants provided consent and were assessed at baseline (before FTF started). They were then randomized to either take the class right away (intervention) or to wait at least three months until the next course (control). Both groups could use any other supports they wished, and all were interviewed again three months later (after FTF). We then interviewed intervention condition (FTF) participants a third time, six months after the conclusion of the program.

Assessments included the Family Empowerment Scale[15], an FTF knowledge test (available from authors), the COPE emotion-focused coping subscales (seeking social support, positive reinterpretation and growth, acceptance, and denial)[16]; the Brief Symptom Inventory[17, BSI-18;]; and the Center for Epidemiological Studies Depression Scale[CES-D;18,19]. The Family Assessment Device (FAD) was used to assess family functioning[20,21], and the Experience of Caregiving Inventory[ECI; 22] measured caregivers' appraisal of illness-related demands.

RCT Results: FTF participants showed significantly greater improvements in empowerment (family, services system, and community) and knowledge about mental illness than control condition participants. FTF participants compared to controls also showed significantly greater improvements on the COPE Acceptance subscale which emphasizes the importance of accepting one's family member's illness, significantly greater reductions in anxiety on the BSI, and significantly improved FAD problem solving scale scores[13]. Additionally, FTF brought significant improvements in the ECI Positive Personal Experiences scale compared to controls. For example, FTF participants reported a greater sense that they "have contributed to the others' understanding of the illness," that they have "met helpful people," and that family members for whom they are took FTF have "shown strengths in coping with illness" than controls. All of these significant benefits from FTF were sustained at six months after the completion of FTF[14].

Thus the RCT provided empirical support that NAMI's FTF program could mitigate the impact of stigma on family members of individuals with mental illness. Although the mechanisms are uncertain regarding how the changes associated with FTF are linked, each of the outcomes associated with FTF can be viewed as addressing a direct or indirect effect of stigma. For example, FTF may begin to reverse the anxiety and depression associated with family member stigma. The improvements in family functioning and problem solving brought by FTF may help families better address negative consequences of family stigma they experience, and FTF-related improvements in coping, acceptance, and empowerment underscore that FTF may reduce the isolation and erosion of self esteem that FMSS can involve. Through FTF, family members may be better equipped to contend with the prejudices and discriminations associated with mental illness, reducing the impact of direct and indirect family stigma on them and reducing their experience of self stigma. Further, FTF related improvements in empowerment and knowledge about mental illness may allow participants to better challenge the damaging assumptions of public stigma. Additionally, FTF's demonstrated ability to help family members understand the experiences of individuals struggling with mental illness may not only reduce FMSS, but may also reduce stigma coming from family members.

2. Qualitative study data on family stigma

To investigate change processes within FTF, our qualitative study of FTF used semi-structured interviews with 31 Maryland FTF graduates[12]. Across diverse families, participants described how FTF's combination of information, insights, and strategies improved their understanding of their relative's illness and themselves, and improved their coping, communication, and relationships.

Although a few interviewees reported no encounters on stigma, most articulated painful examples of family stigma (all types), especially shame, blame, and feelings of guilt were reported. One parent remembered: "There is a tremendous amount of guilt and a huge amount of shame when all of sudden you're in the neighborhood and your [ill relative] is acting out and you just feel horrible and you just kind of wanted to dress them like a little puppet or something [in order] to look somehow like your house is sane."

Others, especially parents, addressed FMSS and self-blame directly: "As a parent you raise children to the best of your ability but when you look back on it and you remember the incidents, the negative incidents, and the thing that brought conflict and enduring poor relations with the individuals in your family. You come to look at the things you did and say, "Gee, that was wrong or I could have done better or I could have taken a different direction and maybe avoided this situation [mental illness] that has come and colored attitudes towards our daughter or other members of the family and toward us because we didn't handle it the best way".

Taking the FTF course cannot eliminate societal stigma. However, this study suggested that FTF helps to reduce the impact of such stigma on family members in several important ways. First, interview participants described attending the FTF groups – getting to know and talk with other family members in similar situations – as having de-stigmatizing effects. Often this began with a simple but profound breaking of silence through experiencing commonality. For example, one sister of a woman with mental illness said, "And my parents met all these other people [at FTF] who have kids who are, you know, in the same and worse situations. – so now it's not a taboo topic. It's not like a topic where everybody goes, 'ooh', and leaves the room, because that's like what used to happen".

Another reflected "I think the reality of it all, that all of us had the same type of problem…that was an eye-opener". A third person described starting alone but becoming part of a circle of acknowledging connection and then reaching out: "I took the class alone but then have been disseminating all the information to my parents and friends too. I give out FTF pamphlets. Stigma leads too many people to suffer alone and so we are like a network to break this down". Participants' growing awareness also added to their appreciation of stigma their ill relative faces: "I think one of the biggest things is realizing that my husband is dealing with a stigma … and that is part of his ups and downs …His uncle straight up told him I don't understand why you have to take medication. Why can't you just pull it together? … I didn't realize how much stigma there was. We talked a lot about that in the class. When I started thinking through it and I started looking around I realized, "Yea, there is a lot" and he is dealing with it".

Second, interviewees cited FTF's provision of information – about what causes certain behaviors, awareness of myths and discrimination, building self-care knowledge and skills, and not wasting energy on things outside of one's control – as highly valuable. By far, the most frequent and heartfelt comments emphasized the effect that FTF information has in reducing family members' feelings of or fears of guilt: "The beauty of the course to me was that it did remove our sense of guilt. Because we [had] felt… "What did we do wrong? We did the best we could. And yet, here's this problem." But I think this class, going through it, seeing the other people, made us recognize… and NAMI emphasized it over and over again: Don't feel guilty about this".

Third, some participants found that FTF not only raised their consciousness, but also moved them to take action to help reduce stigma's impact in the lives of other consumers and families. Echoing numerous participants, one interviewee said "… information about stigma and how bad it is was really very important. How society looks at people stayed in my mind. And it makes me want to do more, to lobby and help reduce stigma. I plan to look into becoming a teacher to contribute more."

Additionally, some reported that FTF had direct effects on family interactions. Some noticed changes in their own behavior: "The class helped me to deal with her, with the signs…What to do immediately if she stopped taking the medication, to confront her in a good manner. I didn't know how to do that [before]. She stopped taking the medication; I would probably have said "Get the hell out of my house. I'm sick of you!"

Others reported that their loved ones had noticed changes: "Instead of isolating her and her always feeling like we were blaming her [for her illness] 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 as opposed to you know sitting on opposite sides of the table".

Overall, the qualitative study provided evidence of the mechanisms by which FTF reduces stigma experienced by family members and leaves them better equipped to cope with it.

DISCUSSION

Families of individuals living with mental illness can encounter family stigma at home, within their family, in the community, and in the very mental health and human service systems designed to help them and their loved one. An unfortunate paradox persists in which relatives of people with mental illnesses feel that mental health providers don't engage with them enough or effectively, while at the same time providers working to make their programs more client and family centered feel they offer many ways for families to connect, but that family members don't engage with them enough or effectively.

Stigma is a substantial contributor to this problem. Any family member has only their limited experience with providers from which to draw conclusions. And, any provider has only their limited experience with family members to shape their impressions. Conclusions drawn with such incomplete information tend to be influenced by biases that fill in gaps with negative assumptions – such as that providers are too busy, or family members are counterproductive. Thus, contrary to antagonism that can arise between such providers and families, both actually face a common foe in stigma.

Family members and consumers aware of how stigma works and equipped to fend off some of its effects may be more compassionate with themselves and less ambivalent and stereotype-prone regarding mental health providers and programs. They may feel more comfortable taking providers up on invitations to interact, may ask better questions, and may come to provider interactions with a more open mind. In parallel, providers aware of how families are stereotyped and stigmatized and who are better equipped to counteract stigma's effects on their own perceptions may reciprocate.

Unfortunately, both groups often have to navigate these stressful situations without the helpful insights and strategies. Most mental health providers receive minimal to no training in avoiding or resisting mental health related stigmas, nor in the realities of the family members of their clients. Many do develop excellent skills in both, but usually because they have taken personal interest in doing so. This situation treats "families" and 'stigma' as special electives, when in reality both daily parts of mental health practice, and of families' lives. Therefore, educational and practical experiences that help mental health providers and trainees not only understand stigma, but also appreciate its impact, the trauma of mental illness in one's life and family, and the resilience of family members and consumers[23], need to be commonplace, as foundations for quality mental health. In addition to some advances in formal training programs one community resource is NAMI's Provider Education Program, in which family-member and consumer facilitators use a structured curriculum to guide providers to a more nuanced and empathetic understanding of their lived experiences.

Similarly, family members often lack access to the stigma help they need. Lefley commented[24] that any resource allowing family members to become active in their own behalf, to take the lead in their own coping and thriving, to achieve mastery of the difficulties they face, should be made widely available. FTF is one such resource, and addresses stigma (among many other topics), via destigmatizing information and contact[1], trauma-recovery sensitivities[8], and self help principles[25]. However, despite its considerable development, many families still don't know about it. Additionally, FTF covers many topics. Families, consumers, and providers alike may also benefit from specific stigma-focused learning opportunities. For consumers and families, In Our Own Voice[26] and the Connecticut family companion version of it are one example[6], as are recent consumer-specific psycho-educational interventions[27,28]. Working to both reduce the stigmas associated with mental illness and to help family members and providers respond to stigma in healthy and constructive ways will help both be the best possible allies in the recovery of their loved ones and clients living with mental illness.

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