

# Advances in Interventions for Families with a Relative with a Personality Disorder Diagnosis

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Considerable research has demonstrated the important role that families play in the trajectory of recovery when partners or children have Axis I disorders, and that families need help, given the impact of a family member's mental illness on them. These factors have spurred the development of a variety of programs and interventions for families of people with Axis I disorders, but programs for family members of people with personality disorders (PDs) are few. This is surprising given research that has demonstrated the important role of families in the course of illness in borderline personality disorder (BPD) in particular and the emerging evidence of the salutary effects of family involvement in treatment for BPD. Thus, although some advances have been made in working with families in which a member has a PD, this field is well behind other disorders. Despite the slow start, several programs have been developed for families with BPD; they are described, along with data supporting their utility.

## Introduction

Regardless of diagnosis, families always have been the first line of care for their mentally ill relatives, and this has presented modern challenges since the mandate of deinstitutionalization in the 1960s [1]. Viewed as necessary resources, family members have assumed multiple roles (eg, advocate, caregiver, confidant, coach, guardian) for their relatives. However, these roles do not come without a price. It has long been recognized that family members run the risk of developing psychiatric problems themselves [2]. Data document that stress from having a relative with mental illness is associated with burden, depression, grief, and isolation [3]. Similarly, Winefield

and Harvey [4] found that these family members report higher levels of psychological distress compared with community norms. However, the challenges facing family members of the mentally ill are of such magnitude that they often deplete the family members' capacity to cope effectively, compromising their health and life agenda. Families cannot do it alone. Thus, it is essential to develop and disseminate accessible programs that help family members reduce their stress, distress, and burden (while increasing education and effectiveness), both as a means to help disordered family members recover (and to prevent relapse) and as an end in itself for family members.

This paper will describe family psychoeducation (FPE) and family education (FE) programs that have been shown to be useful for families when they have a member with any one of a variety of Axis I psychiatric disorders, and then provide more detailed descriptions of programs developed specifically for families with a relative with a personality disorder (PD). Because the vast majority of work with families and PD has been developed with borderline personality disorder (BPD), we will focus on BPD family programs.

## Intervention Programs

There are a variety of approaches to family intervention that are relevant when a family member has a serious psychological or psychiatric disorder. Of course, a variety of family therapy approaches may be very useful when they are available. However, our focus will be on more programmatic approaches, especially those that may be offered in groups and/or efficiently disseminated. The reasons for this focus are that families often have enormous difficulties gaining access to services in general, and finding family therapists who are knowledgeable about the specific disorders in their family and that are affordable can be a challenge. There also may be certain advantages to groups with common connections, which we will note. Thus, first we will discuss these types of family interventions in general and then go on to describe interventions developed specifically for families with a relative with a PD.

**FPE**

The intervention modality for families of people with mental illness that has been most researched is FPE [5,6••]. FPE is provided by many different types of professionals as an adjunct to the identified patient's treatment. Early FPE interventions focused primarily on family member change in order to improve patient functioning [7]. Since the initial studies in the 1970s documenting the value of FPE [8], more than 30 randomized clinical trials have demonstrated that FPE is effective in reducing relapse rates. In fact, empirical research supports FPE as the most successful family intervention for schizophrenia [5]. The FPE model also has been adapted to serve other diagnoses such as bipolar disorder [9] and major depression [10,11].

FPE is grounded in the psychosocial construct of expressed emotion (EE) [12]. After administering a semi-structured interview to a family member, an expert rates hostility, emotional overinvolvement (EOI), and criticality based on comments family members make about their ill relative. High EE scores are documented to predict patient relapse in general [13]. Thus, the central goal in FPE since its inception has been to reduce the level of EE in family members in order to improve outcomes for the identified patient.

The centerpiece of FPE is information and education on the targeted psychiatric disorder. However, research has shown that illness knowledge alone is not enough to produce positive results [14,15]. Therefore, the course curriculum also includes teaching skills to families so they may modify their attitudes and behavior toward the patient. Typically conducted in a multifamily group serving six to eight families, it also has a social support component that participants highly value.

Since its inception, the model has increasingly expanded its focus to consider family member well-being, as well as patient outcomes [16,17]. With the model encompassing a competence-based approach that promotes increased capabilities, coping, and support for family members [18], data show improved family member well-being is associated with coping styles that foster mastery and social support. These findings are consistently associated with lower burden, distress, and isolation for families. A review of 43 empirical studies showed that psychoeducation interventions led to a decrease in burden and an increase in functioning and enhanced coping strategies, as well as improvement in family member mental health [19].

Despite the documented value of FPE programs, only approximately 10% of families dealing with mental illness participate in these programs [20]. This small percentage may be due to the number of "requisite clinicians, resources, time and reimbursement requirements," [21] clinicians' lack of expertise in working with families, and/or the required program length, which may last up to 2 years [22]. Further interfering with broad participation are three additional factors: 1) possible implicit blame of families associated with the EE theory, 2) the fact that family member well-being is only of secondary focus [23],

and 3) the clinician perception that family member-clinician contact would not provide significant benefits [24].

**FE**

Some family member concerns, in particular a lack of program dissemination and lack of focus on family member well-being, are now being addressed in a nonclinical (ie, groups led by trained family members, not clinicians), community-based adaptation of FPE called FE [25]. Unlike FPE, which is often seen as a treatment intervention targeting family member pathology, FE is more often promoted and experienced as an education and support intervention for families. Although it shares the same strategies as FPE (education, learning effective coping skills, and social support from the group), the primary targets of FE are the needs of the family members themselves, not the patient per se. Other differences between FPE and FE include the following: 1) family member leadership versus professional (clinical) leadership; 2) no treatment requirement for the patient (thus, FE may also serve family members with ill relatives who are not in treatment; and 3) shorter course duration (eg, 12 weeks is typical for FE, as opposed to the 9- to 36-month duration of FPE programs). Data on FE show encouraging family member outcomes [22,26,27].

*Theory*

Rather than EE underpinnings focusing on family members' problematic attitudes and putative weaknesses or pathology, the FE model builds on theories of stress reduction, coping, and support [20]. In this model, because there is no presumption of family pathology, the focus is on the participating family member's capabilities, the development of coping skills and strategies to enhance the family member's own well-being, and the effective management of mental illness in the family, as well as basic education about the patient's disorder. Of note is that lower levels of family member coping and a lack of social support account for more feelings of burden than the stressors associated with the ill relative's disorder. In addition, coping behavior, when assessed as a mediator, significantly affected the explanatory power of symptoms per se in predicting outcomes [25].

*Description of FE programs*

Most FE programs, conducted by trained family members, last about 12 weeks, typically meeting once per week. Generally provided in group format, the meetings are held most often in the community, independent of the mental health system. Typically, family members have relatives with a variety of Axis I diagnoses, and time is devoted to each disorder.

The most broadly disseminated and well-known FE model is the family-to-family program (FTF) of the National Alliance on Mental Illness [22]. Structured around a highly scripted manual, the series provides

information on schizophrenia, bipolar disorder, major depressive disorder, panic disorder, and obsessive-compulsive disorder, with emphasis on treatment, medication, and rehabilitation. The receptivity to FTF has been high, with more than 100,000 participants in 45 states across the country. Although FTF is in its infancy in comparison to FPE, its availability and popularity are increasing, and at its current rate of availability, participation may surpass that of the FPE.

### FPE and Intervention for Families of People with BPD

Although people with BPD typically have co-occurring Axis I disorders, the essence of their difficulties and the associated problems that their families encounter are not really addressed in traditional FPE or FE. Thus, clinicians who work predominantly with people with BPD (the most common PD) and their families have developed specialized family intervention programs. Few family programs of any kind for other PDs have been reported and evaluated.

In contrast, there have been three manualized FPE programs for BPD described in the literature. One program, designed and conducted by Gunderson et al. [28] at McLean Hospital in Belmont, Massachusetts, is based on the work of McFarlane et al. [16] but has been adapted and extended to BPD families. The second program, dialectical behavior therapy (DBT)-family skills training, designed by Dr. Perry D. Hoffman and colleagues at New York Presbyterian Hospital in White Plains, New York (in consultation with Dr. Alan E. Fruzzetti), is based on Linehan's [29,30] DBT. The third program is the work of Fruzzetti [31••] and colleagues at the University of Nevada. Interestingly, despite encouraging pilot data, dissemination of these programs also has been modest, perhaps for reasons similar to those that have limited dissemination of FPE programs for Axis I disorders as noted previously. In the following sections, each of these programs will be described.

#### Gunderson/McLean program

Family interventions for BPD, in many ways, have been borrowed and adapted from the psychoeducational approaches that were developed for schizophrenia [28]. For example, high negative emotional expression (ie, criticality, hostility, and EOI) in the relatives of patients with schizophrenia has been found to be related to poorer patient outcomes [13]. The need for psychoeducational programs for families of patients with PDs was also related to the fact that generally, families were ill informed about PD diagnoses, although they may have been informed about the current clinical disorder [32]. Gunderson and Hoffman [32] found that families identified three major problem areas: problems with communication, anger, and suicidality.

With these in mind, Gunderson et al. [28] developed an intervention for families of patients with BPD based on

family psychoeducational approaches for schizophrenia. The intervention program has a joining phase and a multifamily group phase. In the joining phase, the diagnosis of BPD is explained to the family members without the patient in attendance. The joining phase also allows for the therapists to build an alliance with the family members and to invite them to participate in the multifamily group. The multifamily group involves four to seven families, and the sessions focus on developing effective problem-solving approaches to common family concerns regarding their relatives with BPD.

#### Hoffman/New York Hospital program (DBT-family skills training [DBT-FST])

Hoffman et al. [33] developed a family treatment approach based on DBT called DBT-FST. This approach stresses the importance of education, skill development, and environmental change. Specifically, the program attempts to have family members interrupt the cycle of invalidation that may play a role in maintaining the borderline disorder in their affected relative [34]. DBT-FST is based on the concept of EE in family members of borderline patients, in which research has documented that in these families with BPD, EOI with the BPD relative had positive effects longitudinally [35]. This finding is in contrast with findings in families of patients with schizophrenia and other Axis I disorders (in which higher EOI predicted poorer long-term functioning [13]) and suggests that borderline patients need the involvement of family as long as emotional validation accompanies any criticism or hostility.

DBT-FST is an intervention that includes the patient and his or her family members in a group that meets weekly for approximately 6 months. The sessions are organized into two parts: The first part is a didactic session focusing on skill development, and in the second part, the group applies the skills using Linehan's dialectic concept of balancing acceptance with change.

Several other DBT programs have taught the individual DBT skills to family members [36], providing a variant of DBT-FST, or added traditional family therapy components to ongoing DBT for adolescents [37], highlighting the need for more family involvement in treatment of severe PDs.

#### Fruzzetti/University of Nevada, Reno program (DBT with couples and families)

This family program was developed as an integral part of a standard outpatient DBT treatment program [29,30,38]. Recognizing the utility of having patients and family members learning complementary skills and using similar language, this family intervention program includes a core FPE component that may be delivered to individual families or in groups and may include the patient with family members or include only family members of the patient. Certain core skills from individual DBT [30] are included, such as mindfulness and components of emotion

regulation. In addition, family skills such as relationship mindfulness, accurate expression, validation, problem management, and closeness skills (for couples) and parenting skills (for parents) are included [31••,39,40].

These skills are based on a transactional, or biosocial, model of the development and maintenance of BPD [34]. This model suggests that individuals bring certain vulnerabilities to reacting with negative emotion to various situations and that these vulnerabilities may be temperamental (biological) or learned over time. A person with these vulnerabilities is then at greater risk when living in an “invalidating” family environment in which his or her private experiences, such as emotions, wants, and beliefs, are not understood by others and are criticized, ridiculed, or simply misunderstood and ignored (all forms of invalidation). Therefore, invalidation can take many forms, ranging from harsh, critical, and judgmental to well-intentioned but terribly mismatched or not understanding. The theory thus suggests that helping people find ways to express their experiences accurately and skillfully will make it easier for others to validate, and that being validated in turn makes it easier to identify important emotions and wants and to express them accurately. The skills in DBT with couples and families are built around this particular transaction [31••].

The format of the program may vary. For example: 1) If sufficient numbers of couples are available, a couples group may be offered (Fruzzetti and Mosco, Unpublished data); 2) if many parents of adolescents or young adults are in need of services, a parent group may be appropriate; 3) a mixed-constellation family group can be provided (similar to FST, previously described); or 4) skills can be taught in ongoing family therapy. In addition to skill training, ongoing individual family sessions (couples therapy or family therapy) typically are provided. This provides valuable opportunities for assessment and intervention, especially around key targets such as suicidal behavior, self-injury, aggression, and drug use [40,41•].

Recent studies suggest that this approach may be effective with couples (Fruzzetti and Mosco, Unpublished data), with parents of adolescents with significant BPD features [42], and as an adjunct to augment outcomes for individuals with BPD in standard DBT [31••].

### Family Connections (FC) Program

As noted, the dissemination of family interventions such as FPE for BPD has been slow. In order to provide access to many more families, a family education version of DBT with families called FC was developed by the authors within the National Education Alliance for Borderline Personality Disorder [6••]. The FC program was designed for family members of individuals with BPD, and only family members attend.

The FC program was designed to meet three different needs of family members: 1) education (about BPD and

about family functioning); 2) individual and family skills, to manage their own negative reactions and those of their family members and to build better and more satisfying relationships; and 3) social support, from other group members who have lived through similar experiences.

To date, most FC programs have been led by family members, although some clinicians also offer the same curriculum. Thus, community FC is more similar to FE programs, whereas clinic FC has more in common with FPE programs. Either way, the curriculum includes the following modules: 1) introduction and orientation (goals and guidelines for the group, overview of the program, and introduction); 2) FE (eg, understanding BPD, research on treatments); 3) relationship mindfulness skills (describing a “validating family environment” and the role of mindfulness of others in increasing understanding, managing negative emotions, and reducing invalidating responses); 4) family environment skills (understanding reciprocity in relationships and how individual and family well-being are interdependent); 5) validation skills (what to validate and how to do it); and 6) problem management skills (how to use all the previous skills to choose whether to accept a situation or problem or to try to change it, and how to engage effectively in collaborative change in a family).

Each group has a teaching component, a practice and discussion component, and a support component, all built around handouts developed for each module. Group leaders, whether they are family members or professionals, go through extensive training in delivering the FC education and skills components and in managing the group, and all participants complete assessments before they begin the program, after its completion, and at a follow-up several months later.

Two studies about the effectiveness of FC have been conducted [6••,43•]. In both studies, participants reported significant improvements (reductions) in subjective burden, objective burden, and grief, with significant improvements (increases) in empowerment and mastery. In all cases, improvements were enhanced or maintained at the time of the follow-up evaluation. In addition, in the second study, participants also reported significant improvements in depression. Further research is needed to determine whether all components are contributing to these improvements (ie, education, skills, and group support) or if there is differential contribution to outcome. Regardless, FC is a promising program that is now available in more than a dozen states, in Canada, and in several European countries.

### What More Is Needed

The prevalence of BPD alone hovers around 1% of the population, and considerably more than one half of these individuals engage in suicidal and self-injurious behavior [44]. These are severely disordered individuals

whose problems can be very stressful for family members. In addition, family members can act in ways that help or exacerbate the emotional difficulties that people with BPD have. However, despite the advances noted previously, the vast majority of these families still do not have access to any specialized services, much less evidence-based services, if they have a family member with a severe PD.

The reality is that PD funding is well behind funding for many Axis I disorders (clinical services and research), even compared with those Axis I disorders of similar severity and prevalence. Most funding for services relevant to PDs goes to individual treatment, despite the evidence that quite brief (and very efficient) family interventions are effective. Also, the vast majority of research funding goes toward understanding biological underpinnings of PDs, toward individual treatment development or treatment comparison research, etc. (all worthy enterprises also, of course). It is likely that the reason that BPD is the only PD with much research or clinical activity for families is due to the severity and high utilization of services of those with BPD (not its prevalence per se).

One way to improve available services and indirectly improve the research and development that creates those services is through broad education [45]. If clinicians are more aware of the impact that family involvement can have on their patients and their loved ones, they may support (even demand) their availability more often. Similarly, patients and family members can advocate through any mental health provider or system for relevant and evidence-based services.

## Conclusions

There is consistent evidence that family involvement in treatment is good for patients with Axis I disorders and that family members suffer considerable burden, grief, and depression when a spouse/partner, child, or other family member has an Axis I disorder. Also, FPE and FE programs have been shown to be effective with Axis I disorders. Despite this considerable body of work, the development and evaluation of accessible family programs for people with PDs has been slow. However, programs have been developed more recently for families with a relative with BPD. Most often connected to DBT (the treatment for BPD with the most empirical support), a variety of FPE (such as DBT-FST, or DBT programs for couples and families in professional settings), FE (such as FC), and other intervention programs are increasingly available. Early studies suggest that these programs may be beneficial to patients with PDs (in particular BPD), as well as to family members. However, considerably more research (and research funding) is needed in order to develop and evaluate more, and more effective, programs.

## Acknowledgment

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