Family Connections: A Program for Relatives of Persons With Borderline Personality Disorder

PERRY D. HOFFMAN, PH.D. † ALAN E. FRUZZETTI, PH.D. ‡ **ELLIE BUTEAU, PH.D.**§ EMILY R. NEIDITCH# **DIXIANNE PENNEY, DR. P.H.** † † MARTHA L. BRUCE, PH.D., MPH±± **FREDERIC HELLMAN**§§ ELMER STRUENING, PH.D.##

This study assessed changes in family members who participated in Family Connections, a 12-week manualized education program for relatives of persons with borderline personality disorder (BPD). Family Connections, led by trained family members, is based on the strategies of standard Dialectical Behavior Therapy (DBT) and DBT for families. The program provides (a) current information and research on BPD, (b) coping skills, (c) family skills, and (d) opportunities to build a support network for family members. Forty-four participants representing 34 families completed the pre-, post-, and 6-month postbaseline self-report questionnaires. Analyses employing hierarchical linear modeling strategies showed significant reductions in grief and burden, and a significant increase in mastery from pre- to post-group assessment. Changes were maintained at 6 months post baseline.

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[†]Assistant Clinical Professor, The Mount Sinai School of Medicine, New York, NY; President, National Education Alliance for Borderline Personality Disorder, Rye, NY.

[‡]Associate Professor of Psychology, University of Nevada, Reno.

[§]Instructor, Tufts University.

[#]Research Assistant, Weill Medical College of Cornell University, White Plains, NY.

^{††}Executive Vice President, National Education Alliance for Borderline Personality Disorder (NEA-BPD). ‡‡Professor, Weill Medical College of Cornell University, White Plains, NY.

^{§§}Program Evaluation Specialist II, Epidemiology for Mental Disorders Research Department, New York State Psychiatric Institute.

^{##}Director, Epidemiology of Mental Disorders Research Department, New York State Psychiatric

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INTRODUCTION

The diagnosis of borderline personality disorder (BPD) reveals a complex, confusing, and challenging disorder not only for patients and mental health professionals, but also for family members of those with BPD. Not surprisingly, the behaviors that commonly accompany BPD, such as suicide attempts, intense anger, and self-injury, create stressful situations for persons with BPD and their family members, who frequently report being overwhelmed by the chaos that results. Unlike other psychiatric disorders, for which services exist to support patient and family member well-being, the families of BPD persons are frequently neglected (Glick & Loraas, 2001; Harman & Walso, 2001; Hoffman, Struening, Buteau, Hellman, & Neiditch, 2005). Although family members of those with BPD often experience burden, depression, loss, grief, and other kinds of distress (Berkowitz & Gunderson, 2002; Hoffman & Hooley, 1998; Hoffman et al., 2005), no standardized programs to alleviate the impact of this disorder on relatives have been evaluated.

In striking contrast, family programs for relatives of persons with psychiatric disorders other than BPD, when available, have taken a valued role in treatment settings (Dixon et al., 2001). Although not yet widely disseminated enough, several modalities of services are available for relatives of persons with schizophrenia, bipolar disorder, and major depression, for example. Specifically, two categories of family programs exist: family psychoeducation and family education (Hoffman & Fruzzetti, 2005; McFarlane et al., 1995). In the former, the professional family psychoeducation model, mental health professionals lead educational support groups that include both the family members and patients. Complementing these professional services is the family education model, in which trained family members lead educational support groups consisting only of family members. Each modality is supported by data that demonstrate improvements in the patient, the participating relative, or both. In family psychoeducation, programs have been shown, often in combination with medication, to effect a reduction in patient relapse and rehospitalization, and an increase in patient well-being (McFarlane et al.). Family education groups conducted solely for the relatives and not directly targeting patient change have demonstrated significant improvements in family member well-being (Dixon et al., 2001; Falloon & Pederson, 1985).

The study reported here evaluates Family Connections (FC), a 12-week multiple-family education program modeled structurally after the National Alliance for the Mentally Ill's (NAMI) highly valued Family-to-Family Program (FFP). Dixon and colleagues' (2001) FFP assessment timeline model with three time periods—pre-, post-, and 6 months post baseline—was followed. Designed to meet the needs of relatives of persons with borderline personality disorder and its related problems such as emotion dysregulation, self-injury, mood lability, and relationship difficulties, Family Connections is led by trained family members who, after completing the required training course, then conduct groups in their own areas. Training has been standardized to follow the FC program manual closely (Fruzzetti & Hoffman, 2004), and includes (a) initial participation in an FC program as group members; (b) approximately 20 hours of formal training to lead an FC group (e.g., lecture, discussion, role playing); and (c) weekly consultation after the leaders start a new group on their own. Leaders serve in a teaching and mentoring capacity for their group members, providing the course curriculum in a nonjudgmental, supportive environment. They also

model a no-blame approach, providing examples of skill application from their own real-life experiences.

To help determine the suitability of individuals as leaders, potential leaders participate in an in-person interview (or a phone interview if necessary), followed by attendance at a training weekend. Several factors contribute to selection as FC leaders: (a) active participation in the formal leaders' training; (b) ability to role play being a group leader and to provide competent psychoeducational instruction; (c) ability to role play competent group leadership and group management, using a nonblaming and nonpunitive style; (d) ability to role play with a coleader and work together to manage a group effectively; (e) willingness to receive consultation and supervision (including either being observed or having an audiotape available for review for all groups); and (f) interest and enthusiasm about leading an FC group. A final decision concerning appropriateness to colead a series is ideally a mutual decision made by the trainers, in discussion with the potential leaders, at the completion of the training course.

The content of the FC program, developed in consultation with several family members and individuals with BPD, was adapted largely from existing curricula created by the first two authors. The content includes psychoeducational materials reflecting current literature on BPD and on family functioning, and some skills adapted from individual Dialectical Behavior Therapy (DBT; Linehan, 1993). It also includes relationship and family skills developed by the authors, based on DBT theory (e.g., Hoffman, Fruzzetti, & Swenson, 1999; Fruzzetti & Fruzzetti, 2003).

The FC program (Fruzzetti & Hoffman, 2004) is divided into six modules: Module 1: the most current information and research on BPD (e.g., symptoms, course of illness); Module 2: psychoeducation regarding the development of BPD, available treatments, comorbidity, and a primer on emotion reactivity and dysregulation; Module 3: individual skills and relationship skills to promote participant emotional well-being (including emotion self-management, mindfulness, letting go of judgments, decreasing vulnerability to negative emotions, and skills to decrease emotional reactivity); Module 4: family skills to improve the quality of family relationships and interactions (letting go of blame and anger, acceptance skills in relationships); Module 5: accurate and effective self-expression (how to validate); and Module 6: problem management skills (e.g., defining problems effectively, collaborative problem solving, knowing when to focus on acceptance and when to focus on change). All modules include specific practice exercises and homework. In addition, throughout the program, FC provides a forum in which participants can build a support network.

Program fidelity was ensured by periodic visits to sites by the first author, and weekly hour phone supervision with each pair of group leaders to review the curriculum presented the previous week and the class homework practice exercises completed. The FC program manual allowed the authors to evaluate the ability of group leaders to deliver the program effectively and in a manner consistent with content in the manual.

The FC program targeted change in consistently problematic constructs for family members: burden, depression, grief, and mastery (Family Perspectives on Borderline Personality Disorder Conference, 2002; Hoffman, Buteau, Hooley, Fruzzetti, & Bruce, 2003). It was hypothesized that (a) there would be a decrease in burden, grief, and depression from pre- to postparticipation in FC; (b) there would be an increase in

mastery from pre- to postparticipation in FC; and (c) the changes would be maintained at 6 months post baseline.

The constructs for the study, as defined by their respective measurements, were (a) burden: family member reported stressors due to the ill relative's symptomatology and behavior, both on other relationships and interfering in daily activities; (b) depression: levels of depressive symptomatology that the family member experienced during the past week, such as sleep restlessness, being bothered by things, and feeling hopeful about the future; (c) grief: the cognitive, emotional, and psychological experiences such as sadness, pain, and loss associated with having a relative with a mental illness; and (d) mastery: the identification of self-management skills to cope with having a relative with a mental illness.

METHODS

Participants learned about the 12-week program from various sources: their relative's therapist, regional NAMI offices, facilities treating patients with borderline personality disorder, and the Web site of the National Education Alliance for Borderline Personality Disorder (http://www.borderlinepersonalitydiso.com) (Family Perspectives on Borderline Personality Disorder, 2003). Fifty participants enrolled, and 44 participants representing 34 families completed the Family Connections program at three sites. Recruitment was conducted with comparative ease. In fact, after the completion of the first series in any given location, each site accrued a waiting list. All potential participants were willing to participate in research and actually stated appreciation both for the development and research of a program to assist families. Each person provided written informed consent prior to the initial assessment.

Participants

Thirty-nine of the 44 participants were parents (27 mothers [61.4%] and 12 fathers [27.3%]), 4 were spouses/partners (2 husbands, 1 wife, 1 partner [9.1%]), and 1 was a sibling [2.3%]). Mean age of group members was 55.5 (SD=10.0); mean age of the BPD family member patients was 25.1(SD=9.8); and the mean number of years that the relative had suffered from BPD was 7.7 (SD=7.3). Ninety-one percent of participants reported a yearly income level at \$50,000 or above. Group attendance was high, and on average, participants missed only two of the 12 meetings (present for 83%). The dropout rate from the program was 12%. A variety of reasons, such as the unexpected death of a parent or discomfort with the presence of an ex-spouse, were reported as causes. No participants reported dropping out because of dissatisfaction with the FC program. Overall, 80% of participants completed the follow-up assessment. A few participants were unreachable at 6-month postbaseline follow-up (n=3), and the remaining (n=3) nonresponders reported that they did not have time to complete the assessment packet.

Procedure

Before beginning the FC program, 2 weeks after program completion, and 6 months post baseline, family members completed a research packet consisting of several scales and demographic questions. To provide an opportunity to compare our research with research on families with relatives with other mental illnesses, the assessment included measures of depression, burden, grief, and mastery scales, all used in two

previous major family studies: the Family Impact Study (Struening et al., 1995) and the NAMI Family-to-Family Study (Dixon et al., 2001).

Specifically included were the Burden Assessment Scale (Reinhard, Gubman, Horwitz, & Minksy, 1994), which assesses levels of objective and subjective burden, and the Perceived Burden Scale (Struening et al., 1995), which assesses interpersonal burden and role strain. Participants also completed the Revised Center for Epidemiologic Studies Depression Scale (CES-D; Struening et al.), the Grief Scale (Struening et al.), which focuses on the respondent's current feelings of grief, and the Mastery Scale (Dixon et al., 2001), which rates perceptions of coping. The Cronbach's alphas of the four scales described ranged from .75 to .92. All measures were repeated at posttest and at 6 months post baseline.

RESULTS

Hierarchical linear modeling (HLM)¹ was used to assess change from preto posttest, and from posttest to 6 months post baseline. In the context of this study, HLM was a more appropriate analysis than traditional repeated measures because the data structure includes two levels of nesting: time points within family members and family members within families. In addition, the current analysis includes 20% missing data at the 6-month postbaseline assessment, and additional data missing at random at the first two time points. Repeated measures analysis of variance (ANOVA) procedures delete participants who do not have data at all time points involved in the analysis, while HLM includes these participants in the analysis, thereby increasing the power of the analysis. Therefore, we have three time points nested within each of 44 family members, who are in turn nested within 34 families; this constitutes a three-level model with time (level 1) nested within family members (level 2) nested within families (level 3). Twenty-four of the family members were the only person from their family participating in this study, while the remaining 20 family members were coupled with someone else from their family.

Using HLM, burden, depression, grief, and mastery were modeled separately as a function of change between pre and post, and between post and the 6 months post baseline. The passage of time during each period is represented in the model by a dummy variable at level 1. Therefore, the model includes two dummy variables at level 1, the first representing the difference between pre- and posttest, and the second representing the difference between posttest and the 6-month postbaseline follow-up. Posttest is the category chosen as the reference group (represented by the intercept in the model), so that the level 1 slope coefficients would represent the relevant mean levels of change over time.

The HLM models indicate that levels of burden and grief decreased, and mastery increased from pre-Family Connections to post-Family Connections. Results indicate that from pre- to post-Family Connections, the mean score of all family units on the Burden Assessment Scale² decreased by an average of 4.14 points³ $(d=.28)^4$. Overall,

¹The software HLM 5.04 (Raudenbush, Bryk, & Congdon, 2000) was used; the method of estimation used was full maximum likelihood.

²Because of a near singularity occurring in the BAS data, the intercept variance at level 2 was set to zero.

³This average is the regression coefficient at level 2 of the HLM model.

⁴Effect sizes were calculated from raw means.

Table 1			
Descriptive	Statistics		

Variable	Range	Pre Mean (SD)	Post Mean (SD)	Follow-Up Mean (SD)
BAS	20-80	51.41 (10.98)	48.35 (11.27)	40.76 (12.06)
PBS	7-28	20.47 (4.13)	18.06 (4.38)	17.04 (4.07)
CESD	14-56	26.58 (9.03)	25.53 (7.32)	24.71 (8.78)
Grief	15 - 75	52.41 (10.49)	47.62 (10.60)	44.46 (10.64)
Mastery	15-60	39.36 (6.95)	43.28 (6.48)	44.40 (5.51)

Note. Means were run separately for samples at each time point. BAS is Burden Assessment Scale; PBS is Perceived Burden Scale.

the mean grief score of all family units decreased by an average of 4.99 points (d=.45), and the mean mastery score increased by an average of 4.43 points (d=.58), Burden Assessment Scale, t(32)=2.15, p<.05; Grief Scale, t(32)=2.78 p<.01; Mastery Scale, t(33)=-3.31, p<.01. Results showed no change in the mean family unit depression from pre- to post-FC, t(28)=.1.42, p>.05, or in the mean family unit Perceived Burden Scale score, though a trend did appear for this change, Perceived Burden Scale, t(27)=2.00, p=.06. See Table 1 for level 1 means at the three time points.

During the 3 months after FC ended, results show that the average family's score on the Burden Assessment Scale continued to decrease by an average of 5.78 points (d=.65), t(32)=-2.53, p<.05. Changes in mastery and grief were maintained during those following 3 months, with no significant increase or decrease: mastery, t(33)=-.17, p>.05; grief, t(32)=-1.34, p>.05. No change in depression or perceived burden occurred during the 3 months post-FC, t(28)=1.66, p>.05; t(27)=-.37, p>.05.

The level 3 variance components were tested for significance; this significance level indicates whether individual families significantly vary from the mean intercept and slopes for all families. If significant variation exists, future research should consider family-level variables to be entered that may explain some of the variation in burden, grief, and mastery across families.

For perceived burden and mastery, a significant amount of variation does exist around the mean intercept for all families (i.e., posttest scores on the scales). For grief, no variation existed around the intercept, and for the Burden Assessment Scale, the variance for the intercept had been fixed to zero (see Note 2). For both burden measures, grief and mastery, significant variation exists around the mean rate of change for all families from pre to post, and the mean rate of change between post and 6 months post.

DISCUSSION

Families of persons with borderline personality disorder are an underserved population. No standardized information has been available to educate them, support them, and help them understand the disorder, the chaos that often exists, or the impact of the illness on their ill relative or themselves (Hoffman et al., 2003). The Family Connections program is one opportunity for these families to receive much-needed information, skills, and support. Analyses from this pilot study indicate that

family members experienced decreases in their levels of burden and grief, and increases in their level of mastery over the duration of the FC program. Analyses also indicate that these changes were maintained 3 months after the program had ended.

Although often feeling deskilled by BPD, with its associated problematic behaviors that are difficult to comprehend, family members report that they are frequently isolated and alone in dealing with their loved one's struggles. Equally difficult is experiencing friends and family members as judgmental about the often traumatizing crises that occur and what they endure (Hoffman et al., 1999). Family members often report a sense of "surplus stigma," even from those more enlightened about mental illness. Surplus stigma is stigma that is over and above what is typically experienced by family members of persons with other serious mental illnesses. The phenomenon is perhaps best illustrated by the example of a family member being told by some mental health professionals and occasional hospital administrators, "I don't accept BPDs in my practice," or "We don't want those patients in our hospital."

Family Connections is a program specifically designed to addresses these issues. Data indicate that family members who participated in FC reported significant changes in several key dimensions that are consistently reported to play a central role in their lives: burden, grief, and mastery. These constructs—burden, grief, and mastery—encompass phenomena that often plague family members with issues such as financial concerns, worries that one's own behavior may exacerbate BPD symptomatology, mourning lost expectations, and guilt around etiology of the disorder. By acquiring the most current information on the disorder, learning new emotion and coping skills, and having a support network, several important aspects of family member well-being improved significantly from pre- to post-FC group participation. Importantly, the FC program itself was conducted by several pairs of leaders in different localities, suggesting the transportability of the program.

It is important to note the lack of change in depression on the CES-D vis-à-vis improvements on other dimensions, but this lack of statistical significance for change in depression should not necessarily be interpreted as an inability of FC to decrease depression. This finding could simply reflect low statistical power due to the small sample size used. That change over time was detected in other variables shows the strength of the relationship between FC and these other well-being variables.

As hypothesized, well-being gains were maintained beyond program completion, and levels of burden were further reduced during the post-3-month period. Although it is difficult to explain definitively the additional decrease in burden at follow-up, one hypothesis consistent with the data is that skills learned in the FC program had a salutary effect either on relationships in the family (decreasing actual burden), or on acceptance of the situation such that the actual "burden" of caregiving was experienced as less problematic.

These results provide initial support for the FC program. However, much further research is needed. Given that there was no control group in this study, it is with caution that we attribute changes in participants' well-being solely to participation in the FC program. However, that pre- to post-FC changes were maintained from post-FC to the 6-month postbaseline assessment does offer support for FC being responsible for these improvements. But the effectiveness of the FC program must be evaluated in comparison with one or more control conditions in the future. Although the link between the program and improvement in burden, grief, and mastery from pre- to post-Family Connections was supported by the results obtained at the 6-month

postbaseline follow-up, further research is needed to understand these ongoing improvements, and longer follow-ups must be collected and reported to understand whether the impact of FC is long lasting.

Although family members reported experiencing the value of the three components of FC (information, skills, and support network) in their efforts to remain centered amid confusion, we need to identify and understand the mechanisms of change demonstrated in this initial evaluation. Given that results of the HLM analyses indicated that there is a significant amount of variation in change over time to explain at the family level, one way to examine important explanatory variables is to enter relevant variables that vary by family member into level 2 of the HLM models, and variables that vary by family into level 3. Using these predictors, we may be able to explain some of the variation that currently exists between and within families over time.

This study is the first critical step in these lines of research, and equally important, serves as a major step toward filling the void that exists for family members of persons with BPD.

REFERENCES

- Berkowitz, C.B., & Gunderson, J.G. (2002). Multifamily psychoeducational treatment of borderline personality disorder. In W.R. McFarlane (Ed.), *Multifamily groups in the treatment of severe psychiatric disorders* (pp. 268–290). New York: Guilford Press.
- Dixon, L., Stewart, B., Burland, J., Delahanty, J., Lucksted, A., & Hoffman, M. (2001). Pilot study of the effectiveness of the Family-to-Family Education Program. *Psychiatric Services*, 52, 965–967.
- Falloon, I., & Pederson, J. (1985). Family management in the prevention of morbidity of schizophrenia: The adjustment of the family unit. *British Journal of Psychiatry*, 147, 156–163.
- Family Perspectives on Borderline Personality Disorder. (2002). From Research to Community. Breakout Proceedings Conference of the National Education Alliance for Borderline Personality Disorder and Columbia University College of Physicians and Surgeons, New York, NY.
- Family Perspectives on Borderline Personality Disorder. (2003). BPD and Co-occurring Disorders. Conference of the National Education Alliance for Borderline Personality Disorder and Weill Medical College of Cornell University, White Plains, NY.
- Fruzzetti, A.E., & Fruzzetti, A.R. (2003). Borderline personality disorder. In D.K. Snyder & M.A. Whisman (Eds.), *Treating difficult couples: Helping clients with coexisting mental and relationship disorders* (pp. 235–260). New York: Guilford Press.
- Fruzzetti, A.E., & Hoffman, P.D. (2004). Family Connections workbook and training manual. Rye, NY: National Education Alliance for Borderline Personality Disorder.
- Glick, I.D., & Loraas, E.L. (2001). Family treatment of borderline personality disorder. In M.M. MacFarlane (Ed.), *Family therapy and mental health: Innovations in theory and practice* (pp. 135–154). New York: Haworth Clinical Practice Press.
- Harman, M.J., & Walso, M. (2001). Family treatment of borderline personality disorder through relationship enhancement therapy. In M.M. MacFarlane (Ed.), Family therapy and mental health: Innovations in theory and practice (pp. 215–235). New York: Haworth Clinical Practice Press.
- Hoffman, P.D., Buteau, E., Hooley, J.M., Fruzzetti, A.E., & Bruce, M.L. (2003). Family members' knowledge about borderline personality disorder: Correspondence with levels of depression, burden, distress, and expressed emotion. *Family Process*, 42, 469–478.

Hoffman, P.D., & Fruzzetti, A.E. (2005). Psychoeducation. In J.M. Oldham, A. Skodol, & D. Bender (Eds.), *Textbook of personality disorders* (pp. 375–385). Washington, DC: American Psychiatric Publishing.

- Hoffman, P.D., Fruzzetti, A.E., & Swenson, C.R. (1999). Dialectical behavior therapy: Family skills training. *Family Process*, 38, 399–414.
- Hoffman, P.D., & Hooley, J.M. (1998). Expressed emotion and treatment of borderline personality disorder. *In Session: Psychotherapy in Practice*, 4(3), 39–54.
- Hoffman, P.D., Struening, E., Buteau, E., Hellman, F., & Neiditch, E. (2005). Family Perspectives Survey. Manuscript in preparation.
- Linehan, M.M. (1993). Skills training manual for treating borderline personality disorder. New York: Guilford Press.
- McFarlane, W.R., Lukens, E., Link, B., Dushay, R., Deakins, S.A., & Newmark, M. et al. (1995). Multiple-family groups and psychoeducation in the treatment of schizophrenia. *Archives of General Psychiatry*, 52, 679–687.
- Raudenbush, S., Bryk, A., & Congdon, R. (2001). *HLM for Windows* (Version 5.04). Lincolnwood, IL: Scientific Software International, Inc.
- Reinhard, S., Gubman, G., Horwitz, A., & Minksy, S. (1994). Burden Assessment Scale for families of the seriously mentally ill. *Evaluation and Program Planning*, 17, 261–269.
- Struening, E., Stueve, A., Vine, P., Kreisman, D., Link, B., & Herman, D. (1995). Factors associated with grief and depressive symptoms in caregivers of people with mental illness. *Research in Community and Mental Health*, 8, 91–124.