

# Evidence-Based Practices for Services to Families of People With Psychiatric Disabilities

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**Family psychoeducation is an evidence-based practice that has been shown to reduce relapse rates and facilitate recovery of persons who have mental illness. A core set of characteristics of effective family psychoeducation programs has been developed, including the provision of emotional support, education, resources during periods of crisis, and problem-solving skills. Unfortunately, the use of family psychoeducation in routine practice has been limited. Barriers at the level of the consumer and his or her family members, the clinician and the administrator, and the mental health authority reflect the existence of attitudinal, knowledge-based, practical, and systemic obstacles to implementation. Family psychoeducation dissemination efforts that have been successful to date have built consensus at all levels, including among consumers and their family members; have provided ample training, technical assistance, and supervision to clinical staff; and have maintained a long-term perspective. (*Psychiatric Services* 52:903-910, 2001)**

Family members and other persons involved in the lives and care of adults who have serious mental illnesses often provide emotional support, case management, financial assistance, advocacy, and housing to their mentally ill loved ones. Although serving in this capacity can be rewarding, it imposes considerable burdens (1-4). Family members often have limited access to the resources and information they need (5-7). Research conducted over the past decade has shown that patients' outcomes improve when the needs of family members for information, clinical guidance, and support are met. This research supports the development of evidence-based practice guidelines for addressing the needs of family members.

Several models have evolved to address the needs of families of persons with mental illness: individual consultation and family psychoeducation conducted by a mental health professional (8,9), various forms of more traditional family therapy (10), and a range of professionally led short-term family education programs (11,12), sometimes referred to as therapeutic education. Also available are family-led information

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and support classes or groups, such as those provided by the National Alliance for the Mentally Ill (NAMI) (13,14). Family psychoeducation has a deep enough research and dissemination base to be considered an evidenced-based practice. However, the term “psychoeducation” can be misleading: family psychoeducation includes many therapeutic elements, often uses a consultative framework, and shares characteristics with other types of family interventions.

In general, evidence-based practices are clinical practices for which scientific evidence of improvement in consumer outcomes has been consistent (15). The scientific evidence of the highest standard is the randomized clinical trial. Often, several clinical trials are pooled by use of a technique such as meta-analysis to identify evidence-based practices. Quasi-experimental studies, and to a lesser extent open clinical trials, can also be used. However, the research evidence for an evidence-based practice must be consistent and sufficiently specific for the quality and outcome of the intervention to be assessed.

The purpose of this article, as part of a larger series on evidenced-based practices for persons with severe mental illnesses (15), is to describe family psychoeducation, the basis for its identification as an evidence-based practice, and barriers to its implementation. We also propose strategies for overcoming these barriers.

### **What is family psychoeducation?**

A variety of family psychoeducation programs have been developed by mental health care professionals over the past two decades (8,9). These programs have been offered as part of an overall clinical treatment plan for individuals who have mental illness. They last nine months to five years, are usually diagnosis specific, and focus primarily on consumer outcomes, although the well-being of the family is an essential intermediate outcome. Family psychoeducation models differ in their format—for example, multiple-family, single-family, or mixed sessions—the duration of treatment, consumer participation, location—for example,

clinic based, home, family practice, or other community settings—and the degree of emphasis on didactic, cognitive-behavioral, and systemic techniques.

Although the existing models of family intervention appear to differ from one another, a strong consensus about the critical elements of family intervention emerged in 1999 under the encouragement of the leaders of the World Schizophrenia Fellowship (16).

### *Goals and principles for working with families*

The main goals in working with the family of a person who has a mental illness are to achieve the best possible outcome for the patient through collaborative treatment and management and to alleviate the suffering of the family members by supporting them in their efforts to aid the recovery of their loved one.

Treatment models that have been supported by evidence of effectiveness have required clinicians to adhere to 15 principles in working with families of persons who have mental illness:

- ◆ Coordinate all elements of treatment and rehabilitation to ensure that everyone is working toward the same goals in a collaborative, supportive relationship.
- ◆ Pay attention to both the social and the clinical needs of the consumer.
- ◆ Provide optimum medication management.
- ◆ Listen to families’ concerns and involve them as equal partners in the planning and delivery of treatment.
- ◆ Explore family members’ expectations of the treatment program and expectations for the consumer.
- ◆ Assess the strengths and limitations of the family’s ability to support the consumer.
- ◆ Help resolve family conflict by responding sensitively to emotional distress.
- ◆ Address feelings of loss.
- ◆ Provide relevant information for the consumer and his or her family at appropriate times.
- ◆ Provide an explicit crisis plan and professional response.
- ◆ Help improve communication among family members.

◆ Provide training for the family in structured problem-solving techniques.

◆ Encourage family members to expand their social support networks—for example, to participate in family support organizations such as NAMI.

◆ Be flexible in meeting the needs of the family.

◆ Provide the family with easy access to another professional in the event that the current work with the family ceases.

### **Overview of the research**

Studies have shown markedly higher reductions in relapse and rehospitalization rates among consumers whose families received psychoeducation than among those who received standard individual services (17–20), with differences ranging from 20 to 50 percent over two years. For programs of more than three months’ duration, the reductions in relapse rates were at the higher end of this range. In addition, the well-being of family members improved (21), patients’ participation in vocational rehabilitation increased (22), and the costs of care decreased (4,20,23,24).

As a result of this compelling evidence, the Schizophrenia Patient Outcomes Research Team (PORT) included family psychoeducation among its treatment recommendations. The PORT recommended that all families who have contact with a relative who has mental illness be offered a family psychosocial intervention that spans at least nine months and that includes education about mental illness, family support, crisis intervention, and problem solving (25). Other best-practice standards (26–28) have recommended that families participate in education and support programs. In addition, an expert panel that included clinicians from various disciplines as well as families, consumers, and researchers emphasized the importance of engaging family members in the treatment and rehabilitation of persons who are mentally ill (29,30).

Delivering the appropriate components of family psychoeducation for patients and their families appears to be an important determinant of outcomes for both consumers and their

families. It has been demonstrated that programs do not reduce relapse rates if the information presented is not accompanied by skills training, ongoing guidance about management of mental illness, and emotional support for family members (31).

In addition, these interventions that present information in isolation tend to be brief: a meta-analysis of 16 studies found that family interventions of fewer than ten sessions had no substantial effects on the burden of family members (32). However, the number of sessions could not completely explain the differences in outcomes. The outcomes may have been influenced by the total duration of treatment rather than the number of sessions, or by the individual therapist's approach to dealing with the emotional reactions of patients and their families. The behaviors and disruptions associated with schizophrenia, in particular, may require more than education to ameliorate the burden on the family and enhance consumer outcomes.

Most studies have evaluated family psychoeducation for schizophrenia or schizoaffective disorder only. However, the results of several controlled studies support the benefits of both single- and multiple-family interventions for other psychiatric disorders, including bipolar disorder (33–38), major depression (39–41), obsessive-compulsive disorder (42), anorexia nervosa (43), and borderline personality disorder (44). Gonzalez and colleagues (45) have extended this research to deal with the secondary effects of chronic physical illness.

Family psychoeducation thus has a solid research base, and leaders in the field have reached consensus on the essential components and techniques of family psychoeducation. This form of treatment should continue to be recommended for use in routine practice. However, several important gaps remain in the knowledge required to make comprehensive evidence-based practice recommendations and to implement them with a wide variety of families.

First, although the members of the World Schizophrenia Fellowship and others have delineated the core components of a successful family inter-

vention, the minimum ingredients are still not clear. This gap was highlighted by a study of treatment strategies for schizophrenia, which found no significant difference in relapse rates between families who received a relatively intensive program—a simplified version of cognitive-behavioral family intervention plus a multiple family group—and those who received a less intensive psychoeducational, or supportive, multiple-family group program (46). However, both programs provided levels of support and education to families that far surpassed those provided by usual services. It will be necessary to conduct studies designed to identify the least intensive and smallest effective “dose” of family psychoeducation.

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Second, increasing the sophistication, variety, and scope of indicators that are used to measure “benefit” is essential. Commonly used benchmarks are subject to complicated intervening variables and need to be correlated with other results. For example, a greater number of hospitalizations for a mentally ill person during the year after family psychoeducation could be a positive sign if it indicates that a previously neglected consumer is getting care and that the family is getting better at identifying prodromal symptoms that indicate an impending relapse (4). The well-being and health of the family should be routinely measured as well.

A third knowledge gap involves the relationship between family psychoeducation and other programs. Since the conception of family psychoeducation, other psychosocial programs have developed a substantial evidentiary base, including supported employment and assertive community treatment (47,48). For example, assertive community treatment combined with family psychoeducation has been associated with better non-competitive employment outcomes than assertive community treatment alone (22). The combination of assertive community treatment, family psychoeducation, and supported employment has been associated with better competitive employment outcomes than conventional vocational rehabilitation, although the contributions of each component could not be assessed in that study (49). The opportunities for family psychoeducation to be combined with or compared with these new psychosocial models have not been fully explored.

Fourth, research is needed to refine the interventions so that they better address different types of families, different situations, and different time points throughout the course of illness. For example, there is some evidence that individualized consultation may be more beneficial than group psychoeducation for families who have existing sources of support or who already belong to a support group (50–52).

Fifth, although family psychoeducation has been tested in a wide range of national and global settings, there is still a need to assess modifications in content and outcome among particular U.S. subcultures and in other countries. In the United States the one study involving Latino families had mixed results (53,54). However, studies in China (55–57) as well as studies that are under way among Vietnamese refugees living in Australia have had results comparable to those of studies conducted in Caucasian populations.

Finally, what happens after a family has completed a psychoeducation program? Families of consumers with long-term problems and disability may need ongoing support and enhanced problem-solving skills to deal

with the vicissitudes of illness. Lefley (58) has described ad hoc psychoeducation in informal settings, such as an ongoing family support group conducted through a medical center. McFarlane (4,59) has used a usually open-ended multiple-family group structure. NAMI's Family-to-Family program is limited to 12 sessions of formal education but offers continuity in the NAMI support and educational group structure (14).

### **Barriers to implementation**

Despite the gaps in the research, the extensive documentation of the basic benefits of family psychoeducation prompts the question of why this service is rarely offered. In general, low levels of contact between clinical staff and family members in public and community-based settings may preclude the more substantial educational or support interventions. Also, the availability of any intervention is limited by the availability of people to provide it and the training necessary to equip those people. The requisite clinicians, resources, time, and reimbursement have not been forthcoming. These deficits imply the existence of larger obstacles related to attitudes, knowledge, practicality, and systems.

### *Consumers and family members*

Implementation of family psychoeducation may be hindered by realities in the lives of potential participants. Practical impediments such as transportation problems and competing demands for time and energy are common (50). If family members perceive that the training provided through family psychoeducation involves expectations of additional caregiving responsibilities, they may stay away (16). Sessions must be scheduled during periods when facilitators are available, but these times may not suit the clients and their families. Family members face significant burdens that may pose barriers to attending family psychoeducation sessions, even though attendance could lighten these burdens (60,61).

In addition, stigma is common—family members may not want to be identified with psychiatric facilities. They may feel uncomfortable reveal-

ing that there is psychiatric illness in their family and airing their problems in a public setting. They may have had negative experiences in the past and be hesitant to expose themselves to the possibility of further negative experiences. Most people have not had access to information about the value of family psychoeducation and so may not appreciate the potential utility of these programs (16). They may believe that nothing will help. Consumers may have similar apprehensions and may worry about losing the confidential relationship with their treatment teams or about losing autonomy.

### *Clinicians and program administrators*

The lack of availability of family psychoeducation may reflect an underappreciation on the part of mental health care providers of the utility and importance of this treatment approach (16,18,31,50). Providers may choose medication over psychosocial interventions, and family involvement may seem superfluous. In addition, some providers may still adhere to theories that blame family dynamics for schizophrenia. Bergmark (62) noted the persistence of psychodynamic theories as a potential barrier, because many families perceive these theories as blaming. The findings on expression of emotion—the original basis for family psychoeducation—are often perceived similarly despite researchers' attempts to avoid implying blame (16,50).

Although the knowledge and underlying assumptions of individuals are important, they are only part of the picture. Wright (63) found that job and organizational factors were much better predictors of the frequency of mental health professionals' involvement with families than were professionals' attitudes. The clinician's work schedule and professional discipline were the strongest predictors, but other organizational factors posed barriers as well. Dissemination of the multiple-family psychoeducation group model developed by McFarlane and colleagues (64,59) has been hindered by a paucity of programmatic leadership, conflicts between the model's philosophy

and typical agency practices, insufficient resources, and inadequate attention to human dynamics at the system level. For example, reasonable concerns about confidentiality may be seen as roadblocks to family involvement rather than as opportunities to create useful innovations (65). Similar barriers to implementation of family treatment approaches have been identified in studies in Italy (66).

Mental health professionals have also expressed concern about the cost and duration of structured family psychoeducation programs (67), even though medication and case management services for clients usually have to be continued for much longer periods than family programs. The lack of reimbursement for sessions with families that do not involve the mentally ill relative—a characteristic of many family psychoeducation programs—is a significant disincentive to providing such services. Caseloads are universally high, and staff's time is stretched thin. Therefore devoting substantial human resources to training, organizing, leading, and sustaining family psychoeducation is seen as a luxury (16). In such an atmosphere, horizons tend to be short. The long-term payoff of fewer crises and hospitalizations and lower total costs of treatment is overshadowed by immediate organizational crises or short-term goals (16).

### *Mental health authorities*

At the health-system level, pressures to focus on outcomes, cost-effectiveness, and customer satisfaction seem in principle to favor the widespread adoption of family information and support interventions. However, other tenets of the current health care environment—such as the emphasis on short-term cost savings, technical rather than human-process-oriented remedies, and individual pathology—discourage clinicians from providing such services, which may be viewed as ancillary. At this level, it seems that the evidence for family psychoeducation has not been accepted. Many of the consumer- and program-level impediments we have mentioned are paralleled in the larger administrative systems: lack of

awareness of evidence, ingrained assumptions about how care should be structured, and inadequate resources.

### **Overcoming barriers to implementation**

Research on technology transfer has identified four fundamental conditions that must be met for change to occur at the individual or system level: dissemination of knowledge, evaluation of programmatic impact, availability of resources, and efforts to address the human dynamics of resisting change (68). Implementation strategies must include clear, widespread communication of the models and of their benefits to all stakeholders. This communication must occur through channels that are accessible and acceptable to the various stakeholders (16), including families, consumers, providers, administrators, and policy makers. It must be accompanied by advocacy, training, and supervision or consultation initiatives to raise awareness and support at all organizational levels (69).

#### *The consumer and family members*

At the level of the individual consumer and members of his or her family, effective treatment models include strategies for overcoming barriers to participation, such as stigma and a sense of hopelessness. Such strategies include offering to hold sessions in the home of the client or family member; helping family members understand that the intervention is designed to improve the lives of everyone in the family, not just the patient; being flexible about scheduling family meetings; and providing education during the engagement process to destigmatize mental illness and engender hope (70,71).

Recent efforts to disseminate family psychoeducation in New York State, Los Angeles, Maine, and Illinois have illustrated clearly the importance of including clients and their families in the planning, adaptation, and eventual implementation of family psychoeducation (72). In New York, dissemination was initiated and sponsored by the state NAMI chapter (73). Dissemination in Maine and

Illinois had dramatically different outcomes, partly because NAMI's Maine chapter provided strong formal support for the effort in that state, whereas the effort in Illinois did not involve NAMI's Illinois chapters (73).

Experience and now some empirical data illustrate the need to include consumers and their families in efforts to disseminate family psychoeducation. The tension often encountered between some consumer advocacy groups and family advocacy organizations can be bridged by emphasizing the complementarity of the outcomes in family work: as consumers' symptoms are alleviated and their functioning improves, their families become more engaged in and satisfied with community life, and both the family burden and medical illness decrease (22,74,75).

#### *Clinicians and program administrators*

Among professionals working in community mental health services, awareness and evidence, although necessary, are often not sufficient for adoption of new programs. Although interventions must adhere to parameters of the family psychoeducation model if good client and family outcomes are to be achieved, they also have to be responsive to local organizational and community cultures. Engagement and implementation strategies, as well as the interventions themselves, must be tailored to local and cultural characteristics, workload and other stresses faced by clinicians and agencies, particular diagnoses, relationships, the duration of illness and disability, and whether the client is currently receiving medical treatment (50,76,77).

Perhaps even more critical to the adoption of family psychoeducation is the need to match both administrative support and expectations for evidence-based practice with a rationale and explication of the advantages of this treatment approach that are meaningful to clinicians. Advantages can include avoidance of crises, more efficient case management, gratitude from families and consumers, and a more interesting, invigorating work environment for clinicians. Recent

studies have shown that on the whole, knowledge about empirical advantages of family psychoeducation, such as reductions in relapse and rehospitalization rates, carry almost no weight in convincing working clinicians to change their attitudes toward families and adopt new clinical practices (73).

Consensus building among agency staff and directors—including a wide range of concerned parties—in a process of planning from the bottom up is critical but must be tailored to address local operational barriers and contrary beliefs. In addition, successful implementation of family psychoeducation has required ongoing supervision, operational consultation, and general support. In a sense, these characteristics help to build consensus on an ongoing basis. For example, the PORT found that it was possible to change current practice by providing a high level of technical assistance and a supportive environment that reflected staff agreement with the principles and philosophy of the new program (67). The recent dissemination of a family psychoeducation program in Los Angeles County succeeded because of the persistent advocacy of the local NAMI group, the support of top management, a nine-month training period, the high aptitude and strong commitment of the trainees, and the skill of the trainer (72).

#### *Mental health authorities and government*

Although it is tempting to assume that implementation of family psychoeducation could be mandated centrally by state mental health authorities, experience suggests that a more complex approach is required. Dissemination of a family psychoeducation program in New York State succeeded partly because of a partnership between the state, the NAMI affiliate, and an academic center. Unfortunately, the state's mental health authority abruptly terminated this large dissemination program before a widespread impact could be made. Maine's recent success was initiated by a state trade association of mental health centers and services, with support from but little involvement by

the state mental health authority, which recently began exploring a formal partnership to continue and deepen this largely successful effort. A simultaneous effort in Illinois, initiated by the state authority but distinctly lacking consensus among center directors or the state NAMI chapter, has been less successful (73). One state that has had some success is New Jersey, which was able to disseminate family psychoeducation by setting expectations and requirements at the state level.

With the exception of the New Jersey effort, experience suggests that the most promising strategy is one in which provider organizations take the initiative with support from consumer and family organizations, the state mental health authority, and the key insurance payers. Appropriate reimbursement for family psychoeducation will follow. Experience also suggests that several years of consistent effort and ongoing monitoring are required for success. Fortunately, this process is not necessarily an expensive one: Maine implemented its family psychoeducation program in more than 90 percent of agencies for about 25 cents per capita over four years, including evaluation costs. The principal costs are in human effort, especially the effort required to overcome resistance to change.

Delivery of services to families must be subject to accountability and tracking. Although many states encourage the delivery of services to families, few monitor such services or make funding contingent on the services being delivered (78). One system-level option is for mental health centers to create a position for an adult family intervention coordinator, who would serve as the contact person for interventions, facilitate communication between staff and families, supervise clinicians, and monitor fidelity (79).

### *Family-to-Family Education Program*

In the absence of family psychoeducation programs, voluntary peer-led family education programs have developed, epitomized by NAMI's Family-to-Family Education Program (FFEP) (14,80–82). FFEP is

currently available in 41 states, many of which have waiting lists. FFEP and other mutual-assistance family programs are organized and led by trained volunteers from families of persons who have mental illness.

These community programs are offered regardless of the mentally ill person's treatment status. They tend to be brief—for example, 12 weeks for FFEP—and mix families of persons with various diagnoses, although they focus on persons with schizophrenia or bipolar disorder. On the basis of a trauma-and-recovery model of a family's experience in coping with mental illness, FFEP merges education with specific support mechanisms to help families through the various stages of comprehending and coping with a family member's mental illness (14). The program focuses first on outcomes of family members and their well-being, although benefits to the patient are also considered to be important (50).

Uncontrolled research on FFEP and its predecessor, Journey of Hope, suggests that the program increases the participants' knowledge about the causes and treatment of mental illness, their understanding of the mental health system, and their well-being (13). In a prospective, naturalistic study, FFEP participants reported that they had significantly less displeasure and concern about members of their family who had mental illness and significantly more empowerment at the family, community, and service-system levels after they had completed the program (83). Benefits observed at the end of the program had been sustained six months after the intervention. Preliminary results from a second ongoing study with a waiting-list control design have revealed similar findings.

Although FFEP currently lacks rigorous scientific evidence of efficacy in improving clinical or functional outcomes of persons who have mental illness, it shows considerable promise for improving the well-being of family members. In recent research and practice, attempts have been made to optimize the clinical opportunities provided by family psychoeducation and peer-based programs such as FFEP by developing

partnerships between the two strategies. For example, family psychoeducation programs have used FFEP teachers as leaders, and participation in FFEP has facilitated eventual participation in family psychoeducation.

### **Conclusions**

The efficacy and effectiveness of family psychoeducation as an evidence-based practice have been established. To date, the use of family psychoeducation in routine clinical practice is alarmingly limited. Research has recently begun to develop dissemination interventions targeted at the programmatic and organizational levels, with some success. Ongoing research must continue to develop practical and low-cost strategies to introduce and sustain family psychoeducation in typical practice settings. Basic research that identifies the barriers to implementing family psychoeducation in various clinical settings is also needed—for example, the impact of clinicians' attitudes, geographic factors, funding, disconnection of patients from family members, and stigma—as well as the extent to which variations in these factors mediate the outcomes of educational interventions.

Dissemination could also be facilitated by further exploring the integration of family psychoeducation with psychosocial interventions—such as assertive community treatment, supported employment, and social skills training—and other evidence-based cognitive-behavioral strategies for improving the treatment outcomes of persons with mental illness. Promising efforts have combined the energy, enthusiasm, and expertise of grassroots family organizations such as NAMI with professional and clinical programs. ♦

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