

Family Education or Behavioral Family Psychoeducation: Making a Choice

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When people discover that a member of their family has developed a serious mental illness they typically are in shock. They are not prepared for this life-shattering event.. They are puzzled and frightened by strange behaviors, worried about what will happen, appalled by this disruption in the course of what has seemed like normal development, and at a loss for what to do. The experience is virtually the same for families everywhere in the world. They now must cope with the burden of mental illness and it is great.

Almost always, the ill person is taken to medical experts for help and usually is placed in a hospital. Examinations are carried out, sometimes members of the family are interviewed, medication is prescribed, and other treatments may be recommended. After a few days, or sometimes after a much longer time, the ill person is released to return home. Most often the family has been told nothing. There has been no instruction about medications, about coping with strange behavior, about dealing with a person who insists that she or he is not ill and then they may be told that it is the family's fault. In short, the professional staff has ignored the family, until time to return home and then apparently it is assumed that the family will know what to do.

What do families want? Many surveys have shown the same thing. They want information about the mental illness so they can cope better. They want to know specifics about medication, psychosocial treatments, housing options, and social supports. They want to know how to obtain the best treatment possible and they want to know what they can do to help and not interfere with treatment. Until the 1980s this information was rarely available. However, now the situation is different, and several ways of helping families have been developed. Some of these have demonstrated effectiveness with carefully conducted clinical trials. Others have not passed the tests of scientific examination, but offer benefits that are obvious to families. I will review some of these today and try to sort out what the advantages and disadvantages are for the various forms of family intervention..

In reviewing evidence for the effectiveness of ways of helping families several kinds of information have been used. These include reports by family members of what they found useful, or not useful. Reports by mental health professionals who have described their programs and offered their opinion about effectiveness have been scanned and most important are the controlled trials when research participants are randomly assigned to the program in question or to a control group. These randomized, controlled trials provide the most convincing evidence of whether an intervention is effective and in what way.

Worldwide, families are the principal caretakers of people with serious mental illnesses. They may be with the ill person twenty-four hours per day, not just for eight hours as for professionals in a hospital. Quite clearly, in order to cope with schizophrenia and other severe and persistent mental illnesses the families need information, but to relieve burden there also must be a reduction in the patient's symptoms. Research has shown that burden is greatest when the ill person's symptoms are most severe and burden decreases when the symptoms decrease (Johnson, 1994).

Family Therapy

Family therapy is the oldest professional intervention for families, having been developed in the 1960s by Ackerman (1966) and others. Several versions of family therapy have been created, some of which are designed for use with families of people with schizophrenia. This type of therapy is conducted by trained professionals. There were several uncontrolled studies of effectiveness, and the usual anecdotal accounts, but there were few controlled studies and these were so flawed that Terkelsen (1983), after reviewing the literature, stated there was no evidence for effectiveness. Perhaps even more important is that families of people with schizophrenia tended not to like family therapy. A key element of family therapy was that it was reasoned that the family must have been a pathological system because it caused a serious mental illness in a child. Therefore, the family as a system was the patient. Relatives did not like this because they knew it was not they but the ill relative who was the patient and who needed treatment. The other principal objection is that family therapy does not provide educational information. As adaptations to include more education are made to family therapy, results for patients with schizophrenia appear to have improved (DiGiacomo, et al., 1997)

Family Organizations

Family organizations such as Zenkaren in Japan, the oldest, or NAMI in the United States, one of the largest, or any of the many other family organizations found in most parts of the world provide many benefits to families, but they are not interventions provided by mental health professionals. Professionals should refer families to these organizations for the benefits that might accrue. Participation in these groups provides members with much valuable information; especially about how to obtain services in local areas. Other family members have this information because they have been there and have had the experience of seeking information. In addition, monthly meetings usually have speakers who provide useful information. Many groups have newsletters that also help to convey helpful information.

A major limitation is that many families are reluctant to participate. They are afraid of the stigma they would suffer if it should become known that they have a person with mental illness in the family. In addition, many people find it is simply too painful to think about mental illness or to talk about it with others. They stay in isolation, and ignorance. Because of this head-in-the-sand posture, many people do not even read about mental illness or look for information on the internet.

Family Education-Brief

Undoubtedly the most popular way of helping families in the United States and the United Kingdom has been to provide family education. This is the term used by Lam (1991), although he did not give a clear rationale for the distinction he drew between family education and family psycho-education. The latter requires a longer period of time, includes the patient with others in the family, and involves more actual practice in addition to the presentation of information. Both family education and family psychoeducation provide information about the illnesses and how families can cope better.

The various family education programs seem to have similar objectives and to present similar material whether they are presented on a single day or in a series of evening meetings. Most family education programs are presented by mental health professionals often following the Survival Skills Workshop method described by Anderson, Reiss and Hogarty (1986) or close variations on this program. I used their information in conducting family education sessions at St Joseph Hospital in Houston for many years. I used a full-day format for ten to fifteen families.

There have been many evaluations of family education programs (e.g., Abramowicz & Coursey, 1989; MacCarthy et al., 1989; Posner et al., 1992; Smith & Birchwood, 1987) and the results are consistent. Families in the shorter family education programs learn about serious mental illness, they show a change in attitudes toward the ill family member and they sometimes show improved views about themselves, such as having a greater sense of self-efficacy.

An especially interesting version of family education is the NAMI Family-to-Family program. The unique feature of this program is that it is presented by family members who have been especially trained to conduct the sessions. Family-to-Family includes the following topics in twelve sessions: There is an introduction which explains the basic rationale of the course, this is followed by sessions of schizophrenia and affective disorders to explain the diagnostic features, causes and symptoms, then there is a session on problem-solving, and on to a session on medications, and finally sessions

on understanding the perspective of the person with mental illness, communication in families, self-care, rehabilitation and advocacy.

The Family-to-Family program is popular, a thousand people took part in Houston alone one year, but evidence of effectiveness is limited. There has only been one study (Dixon, 2001) and it did not have a control group. The results showed that families learned about serious mental illness, they felt empowered to deal with the mental health system, and they felt better able to cope with problems presented by the ill family member. There is another outcome: the membership of NAMI has increased substantially since the Family-to-Family program was begun. Another reason for promoting Family-to-Family is that some many families have given up on ever receiving family education from mental health professionals. In a similar way, they have created Psychosocial Clubhouses and Drop-In Centers.

Trainers are prepared to conduct the Family-to-Family sessions held on a weekend in Washington, DC, in the spring of the year. The cost for this training is about \$400. In addition, there is a charge for the manuals that the trainer uses and for those used by family members in the sessions. Usually two people act as session presenters and leaders. Training sessions are in English. People from countries other than the USA may participate in sessions. It is expected that they would see that good translations are made of materials used in the sessions.

There are some limitations for Family-to-Family. One is that people from some cultures would prefer that family education be provided by experts, that is, mental health professionals. The section of the course on medications would be especially open to this bias. This may be the case for people from Asia or Latin America where people expect to obtain assistance from experts, not from people like themselves. Training by other family members would not be viewed as substantial.

Family Psychoeducation

It may be that the main difference between family psychoeducation, also called Behavioral Family Therapy, and the family education programs is length of time families spend with the program, but there are other important differences. The patient is included as a full participant with other members of the family in these sessions. This is not the case for family education programs. In addition, family psychoeducation programs tend to involve problem-solving and coping skills training, not just as an exercise in a single workshop, but as an on-going part of family life.

There are many versions of family psychoeducation. The program developed by Goldstein (1978) was first, and it was followed soon by Leff (1985), Falloon (1987), Hogarty (1991) and Tarrier

(1989). McFarlane developed a form that makes use of multiple families (1990). There have been 39 controlled studies of family psychoeducation making it one of the most researched forms of psychosocial intervention for schizophrenia.

For purposes of brevity, this review will focus on only one form of family psychoeducation; that developed by Falloon and associates and called Behavioral Family Therapy.

According to Falloon, families have the following problems in dealing with schizophrenia: 1) lack of understanding of the complex nature of schizophrenia and its social impairments, 2) lack of skills to cope effectively with acute and chronic symptoms of schizophrenia, 3) difficulties in expressing feelings, negative and positive, toward the patient, 4) difficulties in reducing tension in the family through effective problem-solving, and 5) a tendency to feel stigmatized and to limit social contacts outside the family circle.

Method

The major elements of Falloon's family psychoeducation program have the following elements:

1. Family work is integrated into an interdisciplinary team.
2. Engagement--listen to the family; do home visits when needed.
3. The patient is involved in training sessions
4. There is on-going assessment to help retain focus.
5. Assessment of family strengths, problems; individualize goals.
6. Attention to social and clinical needs of patient and the family.
7. Optimum management of patient's medication.
8. Initial intensive education program for patient and family followed by continuing education targeted at family needs.
9. Promote clear communication and active listening.
10. Train family in problem-solving techniques.
12. Assist in the regulation affective interactions.
13. Deal with feelings of loss that are associated with the patient's disability.
14. Recognize that people with serious mental illness may be highly vulnerable to stress.
15. Learn to manage stress, not eliminate it.

A program of this type may continue from a few months to several years with the length of time based on family interests.

Family Psychoeducation Results

There have been many clinical evaluations of family psychoeducation. In all of these patients in program and control groups received medication presented at optimal levels and most patients were adherent. Results of these studies show that family psychoeducation programs have a powerful effect in delaying relapse rates. Looking only at the first of these studies, we find that at the nine to twelve month follow-up time 38% of the control group patients had relapsed compared with 7% of the family psychoeducation patients. At 24 months, 61% of the controls had relapsed and only 21% of the family psychoeducation group had had a relapse. There is evidence from two studies that relapse prevention lasts even longer than two years. Falloon has reported that for forty studies that had treatment as usual or individual psychotherapy as the control condition, the mean effect size, a statistic used to indicate strength of a treatment was .83 for the program groups, this is very strong, and .20 for control groups. This is quite weak. In addition, results reported by Falloon and associates (1984, 1985) showed positive effects that went beyond those for relapse rates. Patients were better adjusted socially and relatives reported being less burdened. Forty studies have now been conducted and most have had these same positive results on relapse and symptom reduction.

For Which Families?

For which families and patients is family psychoeducation most useful? This is a difficult question to answer given the absence of relevant data. It is clear that the psychoeducation programs have proven useful for families in many countries, but to say that they would be useful for people of all ethnic groups is not possible because the range of cultural groups has not been tested. The programs have been effective with patients who were first admissions to treatment, and with others who have been in the mental health system for years. They have worked for women and men, for families high in expressed emotion, that is the tendency to be critical, hostile or over-involved, and families that are low in these behaviors. They have been useful for schizophrenia and bipolar disorder, and there is some evidence of their effective use with depression, eating disorders, and substance abuse. Positive results have been obtained in the United Kingdom, United States, Japan, Germany, Italy, Greece, Spain, Norway, Sweden, China, and other countries.

Can family psychoeducation be effective if highly trained professionals are not available for their operation? The answer is no and yes. To provide family psychoeducation a trained staff is needed. Training of staff must include emphasis on the special attitudes or ideologies of this approach in the special techniques that are used and it is essential that the practitioners have clinical skills. Falloon in

England, McFarlane in New York and Michigan, and the several Chinese studies have demonstrated that staff can be trained to operate in usual work settings and provide quality services. NAMI member, Mona Wasow, read about family psychoeducation and became convinced that her community, Madison, Wisconsin, should offer it in the local mental health center. She invited the center director and most of his staff to lunch and presented them with the idea. They agreed with her and within days were receiving needed training. It can be done.

Is family psychoeducation enough? Hogarty's addition of his Personal Therapy (1997) to family psychoeducation was superior to the family intervention alone. The same was true for Buchremer's (1997) study in which adding cognitive therapy to the family intervention resulted in a better outcome. Furthermore, the best short-term outcome obtained in earlier research studies was Hogarty's family psychoeducation plus social skills training group. There is a growing consensus that people with severe and persistent mental illnesses should be treated in community-based optimal treatment programs. These are also called integrated treatment programs (Malm, Ivarsson, Allebeck, & Falloon, 2003). Treatment and rehabilitation are individualized, the patient and family work closely with the clinical staff, and interventions are guided by on-going assessment. An array of services are provided, depending on patient and family needs. Intensive case management would help non-adherent patients. Cognitive behavioral therapy is available for medication-resistant symptoms, social skills training is used.

Not all families want to participate in any of the programs I have mentioned. Some say they are not interested and continue to believe that mental illness will just go away eventually. Some do not have time. People have jobs that are demanding, and often they have more than one job and are rarely home. There may be other children who require care. Some families do very little together and do not fit into the family psychoeducation model. They do not even have meals together, let alone have time or energy to take part in challenging problem-solving sessions with a seriously mentally-disordered person. For many the only time together is when they are in front of the television. Father's often cannot take part because they are absent from the family.

Some families agree to participate, but drop out before the training is complete. Montero and associates in Spain (1999), found that families with older patients, those having had many hospitalizations, those in small households, and those with relatives having little knowledge of mental illness at the beginning of the program were more likely to drop out.

Comparative Costs

What does each method cost? Obviously, membership in a family organization is the least expensive with minimal expenses for membership fees and convention participation. Family education sessions conducted over a period of 6 to 12 hours by mental health professionals cost little. Nevertheless, in some settings family education sessions have been stopped when managed care administrators decided that the sessions do not generate revenue for sponsoring hospitals. This happened to my sessions at St. Joseph Hospital. The new administrator did not understand the value of the sessions for families and he ended them. The Family-to-Family program is relatively inexpensive, but there are start-up costs, including payments to trainers-of-trainers. Most of these costs have been covered by state mental health programs or private foundations.

Extensive family psychoeducation, with its professional staff, is fairly expensive, but it has been demonstrated to be cost effective, primarily because it leads to a decrease in relapse and associated use of expensive hospital facilities. It should, therefore, be attractive to administrators. Nevertheless, in the United States it is available only in a few states in part because some insurance companies are unwilling or reluctant to pay for participation in family programs, and they will certainly not pay for long-lasting programs. There is an emphasis on doing things fast, even if not very effective.

There are other barriers to implementation of the programs such as failure to adopt a vulnerability/stress model, belief that medication is the only appropriate treatment and ignorance of family programs by mental health professionals and administrators. These barriers are formidable and they mean that dissemination of family programs requires extensive preparation and training, and unrelenting advocacy from family organizations.

Family psychoeducation requires well-trained professionals to deliver the family program. These professionals now are in place throughout Europe. The program called Meriden in Birmingham, England, is typical. This group has now trained several hundred workers and trainers. The instigation of this activity is new legislation that requires mental health services to include families in treatment.

However, the British situation seems to be unique. In most countries mental health professionals have no awareness of the need for family training and do not know about family psychoeducation. There are other problems. Some professionals resist anything behavioral. They are still trapped by psychodynamic theories and methods, usually in watered-down form. I recently learned that the Social Work graduate training program has required courses on psychodynamic theory and practice, but nothing on cognitive or behavioral methods.

Best Practices

The Schizophrenia Patient Outcomes Research Team or PORT reviewed family interventions and recommended that they be utilized when possible and that they be continued for at least 9 months for best effects (Dixon & Lehman, 1995). Thus, emphasizing the value of longer programs they have endorsed family psychoeducation. They did not recommend any particular form of family psychoeducation although there is some evidence that the behavioral family management programs produce best results. However, there are many exceptions and reviews of evidence-based treatment (Mari & Schreiner, 1994; Baucome et al., 1998) have not resolved the question of whether one form of family psychoeducation is better than other forms.

Are family programs better than direct interventions with patients? When family programs are compared with standard services consisting of medication and case management, family interventions are usually superior. However, if the patient-intervention is one that provides carefully designed behavioral training on medication usage, the meaning of the illness, problem-solving and coping training, as was the case in a Dutch study (26) results are about the same as for family psychoeducation. It may be, however, the Linszen individual program was extraordinarily good. In contrast, individual treatment was not better in Falloon's study where the control group received supportive psychotherapy.

Some Generalizations About Family Programs

Participation in family organizations, being in family therapy, taking family education classes or being part of family psychoeducation are not the same and do not have the same outcomes, costs are not the same, and the amount of family time required is not the same. It is possible to make a few generalizations about what each does.

1. If information is provided there tend to be positive educational outcomes for relatives.
2. More sessions are better than few sessions.
3. Include the patient in sessions if the goal is to reduce relapse.
4. For serious mental illness medication must be maintained at an optimal level.
5. Programs that individualize are better than those that do not
6. An environment that is clear, simple and free of excess negative emotions, as tends to appear in family psychoeducational programs, is less likely to cause relapse
7. Family psychoeducation is not always better than appropriate individual therapy.

Choices To Be Made

Family members, family organization administrators, and mental health professionals have choices to make in selecting ways of helping families. These choices can be made on the basis of what their goals for families are and what resources are available. If they want to help relatives of people with serious mental illness, to relieve their burden and help them cope better, but have only limited resources, then family education may be the reasonable choice. If, however, the goal is symptom alleviation and relapse reduction, in addition to support for relatives, and if necessary resources can be found, then family psychoeducation should be the choice. If the goal is recovery and resources are available, the question remains open but it appears that family psychoeducation carried out for a long time will suffice, or it may be that even more powerful interventions, yet to be developed, are necessary.

Despite this apparent success for the Family-to-Family program, it may be that its sponsor, NAMI, is doing families a serious disservice if they do not go on to recognize and urge adoption of the longer, more intensive programs that would have positive results for patients and their families. In contrast, the World Fellowship for Schizophrenia and Allied Disorders has reviewed the strengths of the different programs and has chosen to promote adoption of family education and family psychoeducation to meet the needs of different families.

Conclusion

Families who have struggled with schizophrenia or other serious mental illnesses for many years, and who recall the terrible first years of the illness, routinely say they wish any of the family programs described here had been available to their families. I know that in my family we would have reached out for information, training, advice, consultation, and education. A one-day session would have been welcome, and many family members would have benefited, but a two or three-year program would have been better. The state of science for family interventions is such that there is considerable evidence that they are effective. Now it is time to see that every family has the opportunity to take part in these programs. Not all families will be able to take part, some will not want to, and for them alternatives should be available, but all should have the opportunity to participate.

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Internet Resources

A remarkably useful and accurate source of basic information for individuals who want to develop family education programs can be found on-line at

www.schizophrenia.ca/handbooktoc.html

Other useful information can be found at

www.world-schizophrenia.org

www.nami.org

Table 2

Family Psychoeducation Relapse Rate Results

		Follow-Up Period (Months)					
		9-12		24		Longer	
		Group (% Relapse)					
P = Program; C = Control							
<u>Investigator</u>	<u>Year</u>	<u>P</u>	<u>C</u>	<u>P</u>	<u>C</u>	<u>P</u>	<u>C</u>
Goldstein	1981	0	16				
Leff	1982	8	50	20	78		
Falloon	1985	6	44	17	83		
Hogarty	1986	0	41	25	66		
Tarrier	1988	12	53	33	60	67	88
Xiong	1994	12	33	13	44		
McFarlane	1995	8	21	18	32	50	78
Combined Mean		7	38	21	61	58	83

Addendum

Here is what I have learned about the NAMI Family-to-Family family education program.

The board of the World Fellowship for Schizophrenia and Allied Disorders has reviewed family education programs and have recommended that if at all possible longer, more intensive programs such as Falloon's Optimal Treatment Program, Leff's family psychoeducation program, or McFarlane's multiple family program be used with families. These programs are much more likely to reduce the patient's symptom level and need for rehospitalization. These programs, as they are currently operated, require the work of specially trained mental health professionals. As the Family-to-Family program has not been evaluated with scientific methods there is no way to know how effective it is. Early results suggest that it is effective in providing families with information that they need to cope with serious mental illness. In my own view, the Family-to-Family program could be an excellent first step to a more intensive and extensive program. It is not incompatible with programs such as that developed by Falloon. It can also be used as a single, stand-alone, program, but a reduction in relapse and symptom severity, should not be expected.