

# Providing Services to Families of Persons with Schizophrenia: Present and Future

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## Abstract

**Background:** The important role of families and other caregivers in the lives of adults with schizophrenia is well documented. Persons with schizophrenia frequently live with their families of origin, and the vast majority have regular family contact. Families of persons with schizophrenia have also been demonstrated to have significant needs. Families most frequently cite the need for education and support in helping them to cope with their family member's illness. Further, numerous studies have documented the benefits of interventions designed to meet the needs of family members.

**Aims of the Study:** This paper identifies critical issues and challenges in the provision of services to families of persons with schizophrenia and other serious and persistent mental illnesses.

**Methods:** This study draws from both a literature review and a summary of pertinent data from the Schizophrenia Patient Outcomes Research Team (PORT).

**Results:** Recent best practices standards and treatment recommendations specify that families should be given education and support. One of the PORT treatment recommendations states that 'Patients who have on-going contact with their families should be offered a family psychosocial intervention which spans at least nine months and which provides combinations of: Education about the illness; Family support; Crisis intervention; and, Problem solving skills training'. The PORT treatment recommendations are based on well designed and rigorous research on family psychoeducation programs that demonstrate reduced relapse rates and improved patient and family well-being for persons whose families receive psychoeducation. While family psychoeducation programs have been the subject of extensive treatment trials, family members and family organizations have endorsed a variety of other models of services such as family education and consultation models. These models have not been as rigorously researched as family psychoeducation. Control groups are generally lacking. No consistent findings have been reported, although isolated studies have found increased knowledge, self-efficacy and greater satisfaction with treatment among families who have participated in family education programs. Remarkably little is known about the extent to which families actually receive appropriate services. However, PORT data from administrative claims and client interviews suggest that family services are minimal. Further, previous research has consistently revealed that families have high levels of dissatisfaction with mental health services.

**Discussion:** If family psychoeducation is effective, why do all the data suggest that it is scarcely offered? Even use of family

education programs, which are perhaps easier to deliver and cheaper, is limited. Some answers to these questions may be found in evaluations of efforts to disseminate family education and psychoeducation models. The Schizophrenia PORT sponsored a dissemination of William McFarlane's multiple family psychoeducational group. One obstacle to implementation was lack of programmatic leadership at agencies. Another was conflict between the philosophy and principles of the family model and typical agency practices. Dissemination efforts of the MFPG model are under way in the states of Illinois and Maine.

**Implications for Further Research:** Four main areas of research are necessary to achieve progress in providing services to families and persons with serious and persistent brain diseases such as schizophrenia.

- (i) We need a better understanding of the current state of affairs, including systematic exploration of what kinds of service different kinds of family are receiving or not receiving and from whom. Research on treated populations is not sufficient. Billing records alone will not account for the informal clinician/family contacts, which are valued. This research must include the patient, family and clinician perspectives as well as incorporating systemic factors such as financing and organization of services.
- (ii) A second area of research should focus on family interventions. What works for whom and at what cost? What are the critical ingredients of successful family models? Peer-led community family education programs are severely under-researched. While psychoeducation has established efficacy, it may have maximal value in first-break patients. How can the acceptability of psychoeducation to families and clinicians be maximized? Are there ways to capitalize on the best of clinician-run and family-run models to create hybrid models? Does family psychoeducation shift costs toward or away from families?
- (iii) How can successful family services models be disseminated effectively? Although it is still necessary to know more about the current status of services to families, it is quite clear that the best researched psychoeducation programs have limited, if any, penetration in typical communities. Approaches that combine grassroots participation of clinicians and family members as well as efforts with senior administrators and payers are likely to yield the greatest success.
- (iv) More research is necessary on the role of families and other caregivers in recovery and course of illness. This research must be driven by an appreciation of the biopsychosocial model and be empirical rather than ideological. Such an approach will optimally protect families from their own tendency to self-blame and from the tendency of the medical models prevalent in industrialized countries to find blame, fault and pathology.

Received 15 July 1998; accepted 20 November 1998.

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Source of funding: none declared.

## Introduction

The important role of families and other caregivers in the lives of adults with schizophrenia is well documented. Persons with schizophrenia frequently live with their families of origin, and the vast majority have regular family contact. Families of persons with schizophrenia have also been demonstrated to have significant needs. Families most frequently cite the need for education and support in helping them to cope with their family member's illness. Further, numerous studies have documented the benefits of interventions designed to meet the needs of family members. However, knowledge of families' needs and the benefits of services has not led to widespread implementation of services for families in traditional treatment systems. This paper identifies critical issues and challenges in the provision of services to families of persons with schizophrenia and other serious and persistent mental illnesses.

## The Schizophrenia Patient Outcomes Research Team Treatment Recommendations: What is best practice?

The Schizophrenia Patient Outcomes Research Team (PORT) developed treatment recommendations for the care of persons with schizophrenia.<sup>1</sup> These recommendations were derived from an extensive review of the treatment literature, emphasizing rigorously conducted scientific research studies. Recommendations covered both psychosocial and psychopharmacologic treatments. Three recommendations addressed family psychosocial interventions.

- (i) Patients who have on-going contact with their families should be offered a family psychosocial intervention which spans at least nine months and which provides combinations of
  - (a) education about the illness,
  - (b) family support,
  - (c) crisis intervention and
  - (d) problem solving skills training.
- (ii) Family interventions should not be restricted to patients whose families are identified as having high levels of 'expressed emotion'.
- (iii) Family therapies based upon the premise that family dysfunction is the etiology of the patient's schizophrenic disorder should not be used.

These recommendations do not prescribe one specific family intervention. Rather, the first recommendation details the necessary components of an effective family psychosocial intervention. Nor do the recommendations assert that all families must participate in a family psychosocial intervention to optimize care. Families should be offered these services. However, the recommendation allows for the fact that families may or may not choose to participate. The proportion of families who would choose to participate in what kind of intervention is unknown. Notably, other efforts to define standards for best practices such as the American Psychiatric

Association practice guidelines (APA)<sup>2</sup> and the Expert Consensus Guideline Series<sup>3</sup> recommend that families receive education and support. Beyond the United States, an international group of family psychoeducation researchers and other leaders of the family movement recently convened under the sponsorship of the World Schizophrenia Fellowship and developed a description of the critical elements and principles of family interventions.<sup>4</sup>

## Family Psychoeducation Research: What are the data?

The PORT treatment recommendations are based on well-designed and rigorous research on family psychoeducation programs.<sup>5</sup> Randomized controlled trials by McFarlane *et al.*,<sup>6,7</sup> Randolph *et al.*,<sup>8</sup> Tarrier *et al.*<sup>9</sup> and Hogarty *et al.*,<sup>10,11</sup> among others,<sup>5,12</sup> demonstrate decreased relapse rates among patients whose families received family psychoeducation when compared to individual therapy. Data also modestly suggest that family psychoeducation improves the functional status of patients and family well-being. These psychoeducation programs have the elements listed in the recommendations. They assume that schizophrenia is a brain disease and that the family is a partner with the providers. Family psychoeducation is delivered with psychopharmacologic treatment. The effect sizes demonstrated in family psychoeducation are comparable to the effect sizes observed in psychopharmacologic trials of antipsychotic medications in schizophrenia. The majority of these trials were conducted in the USA, Great Britain and Australia, and the results may be most generalizable to the industrialized countries. However, three studies have been conducted in China, one of which had over 3000 subjects.<sup>12</sup>

## Beyond Family Psychoeducation: What Are Some Other Family Service Models?

While family psychoeducation programs have been the subject of extensive treatment trials, family members and family organizations have endorsed a variety of other models of services. The family education and consultation models are most prominent.

Family education shares many of the same goals and strategies as family psychoeducation, i.e., providing education and support to family members and helping family members to cope more effectively with their ill relative. However, Solomon<sup>13</sup> described some critical differences between the two models. While psychoeducation tends to be clinic based and delivered by mental health professionals, family education can be community based and delivered by families to families. Family education is typically delivered in a peer-to-peer format. It is not necessary for the ill family member to be receiving treatment in order for the family member to participate.

Further, the conceptual underpinnings of family psychoeducation and education differ.<sup>13</sup> Most psychoeducation programs are at least partially derived from theories of

expressed emotion (EE). The EE framework emerged from observations that family members' negative and critical comments toward the ill member were associated with psychotic relapse. Reduction of EE should therefore reduce relapse. In contrast, family education is based on theories of stress, coping, adaptation and support.

Family education programs also tend to be shorter in length with programs lasting weeks rather than months or years. The primary outcome of family education is family well-being. The well-being and/or status of the ill family member are secondary or not considered. In contrast, family psychoeducation tends to be more patient-focused, with patient as well as family outcomes critical. Finally, family psychoeducation programs are generally diagnosis specific, while family education is used for families of persons with a variety of diagnoses.

Perhaps the best known example of a family education program is National Alliance for the Mentally Ill Family to Family Education program, formerly called the Journey of Hope. Developed by Joyce Burland, a psychologist and family member of a person with mental illness, this is a 12-week family educational program taught exclusively by family member volunteers using a highly structured scripted manual. In weekly two-hour sessions, family members receive information about mental illnesses, are exposed to problem solving strategies and receive support from other family members. Using a train-the-trainer model, family members train other family members to conduct the program, and thus the model sustains itself. A program evaluation found that participants were highly satisfied and reported increased knowledge of mental illness, improved management of their ill relative's behavior and increased awareness of the mental health system.<sup>14</sup> However, this evaluation lacked a comparison condition, and results are thus difficult to interpret.

The consultation model has been viewed as a subset of family education.<sup>13</sup> In this individual family format, a family meets with a consultant who can be a professional or a family member. Education can be provided, but the main focus of the interaction is for the consultant to provide whatever is needed (e.g., advice and support), tailored to the specific needs of the family. A consultation is open ended and can lead to referral to another program on ongoing individual family work or terminate after one session.

Family support and consultation models may fit better in societies with more traditional cultures such as India. Previous research has suggested that persons with schizophrenia have a more benign course in less industrialized countries, and this may be in part due to the benign and tolerant attitudes of families in such cultures.<sup>15</sup> Susser and colleagues observe that in developing countries families tend to be much more involved with and responsible for caregiving, due to cultural norms and because of inadequate resources in the systems of care. They suggest that this kind of family involvement with the care system may be partially responsible for the reduced impairment and disability associated with schizophrenia in developing countries.<sup>16</sup> Shanker<sup>15</sup> describes little desire for information in a group of Indian caregivers,

and thus developed an individualized program that aims to guide the family in facilitating optimum recovery for the patient and to provide support to caregivers to enhance their caregiving ability. This program does not typically include the formal multiple family psychoeducational group.

Research on family education and consultation models has not been as rigorous as research on family psychoeducation. Control groups are generally lacking. No consistent findings have been reported, although isolated studies have found increased knowledge, self-efficacy and greater satisfaction with treatment among families who have participated in family education programs.

## The Current State of Affairs

### *Are Families Receiving Services?*

Remarkably little is known about the extent to which families actually receive appropriate services. Previous studies have tended to focus on selected cohorts of family members, e.g., members of the National Alliance for the Mentally ill or families receiving services at one institution. There are virtually no large-scale data on penetration of family services to families in usual community settings.

Data from the Schizophrenia PORT provide some insights into the current status of services to families.<sup>1,18</sup> Categories of data included administrative claims from both Medicare and Medicaid and primary interview data from a cohort of 719 persons receiving treatment for schizophrenia in two different states. The limitations of these data also suggest directions for future research.

The PORT accessed Medicare claims for a 5% sample ( $N = 16\,480$ ) of persons with a schizophrenia diagnosis in 1991. Only 0.7% of that cohort had a billing for family therapy. In contrast, 51.4% had a claim for individual therapy. The Medicaid data represent a single southern state and also include all persons with a diagnosis of schizophrenia in 1991. A total of 6.9% of the Medicaid sample of 6066 persons had a billing for family therapy compared to 67.4% who had a claim for individual therapy.<sup>18</sup>

The PORT interview field study asked clients a number of questions about the extent of contact they had with their family and services received by their families.<sup>17</sup> A total of 539 (75%) patients reported having family contact. Patients were asked 'Did anyone in your family receive information about your illness or your treatment or advice or support for families about how to be helpful to you?'. Of patients reporting that they had family contact, 165 (30.6%) reported that their families had received such help. A total of 44 (8.2%) of patients responded affirmatively to the question 'Did your family member attend any kind of educational or support program about schizophrenia and treatment?'

Claims data are obviously limited by billing and reimbursement practices. Claims tell us nothing about the type or quality of service received. Patients' self-report data are also limited; patients may be unaware of services their families have received. Further, while the patient report is somewhat more specific about the type of service families

received, it is impossible to ascertain how close the particular family service received is to the type of service described in the PORT treatment recommendation. Nevertheless, the paucity of family services reflected by claims and patient report is startling.

In a recent survey of state mental health authorities in the USA, 80% (35/44) of respondents indicated that the state funds or sponsors a family support intervention.<sup>19</sup> The majority of such states (27/35, 77%) reporting funding or sponsorship provides this funding to the National Alliance for the Mentally Ill Family to Family program, the Journey of Hope or other NAMI efforts. Three states fund family psychoeducation of the type that has had significant experimental research. The amount of money dedicated to family programs was very modest during the last year and ranged from \$11 500 to \$150 000 per year.

### *Are families satisfied with services?*

Previous research has consistently revealed that families have high levels of dissatisfaction with mental health services.<sup>20–29</sup> Greater dissatisfaction has been related to less information and support available to families from mental health professionals,<sup>30</sup> greater client symptomatology,<sup>31,32</sup> female caretakers and less family involvement with the system.<sup>23</sup> However, in the study by Grella and Grusky,<sup>23</sup> service system characteristics were the most important predictor of satisfaction. In particular, the more case managers interacted with families, the greater the families' satisfaction with services. In the post-discharge study by Solomon and Marcenko,<sup>25</sup> the majority of families reported being not at all satisfied on 12/13 dimensions surveyed. Families were more satisfied with services provided by the case management team than mental health agencies and hospitals.

### *Do mental health services improve family outcomes?*

An emerging body of literature is now accumulating to demonstrate an association between the nature of mental health services delivered to patients and family outcomes. A review of family psychoeducation interventions finds evidence that these models not only consistently and robustly reduce patient relapse, but also improve family well-being.<sup>4</sup> Poor family relationships with providers and lack of provider support have been associated with caregiver depression<sup>32</sup> and strain.<sup>28</sup> Conversely, provision of information and advice to families has been found to reduce family distress.<sup>33</sup> Solomon and colleagues found enhanced self-efficacy among families receiving brief family education.<sup>28</sup> Poor interaction with the mental health system has been found to be one of the two greatest sources of family burden.<sup>34</sup>

### *Why are services provided to families so limited?*

If family psychoeducation is effective, why do all the data suggest that it is scarcely offered?<sup>34</sup> Even use of family

education programs, which are perhaps easier to deliver and cheaper, is limited. Some answers to these questions may be found in evaluations of efforts to disseminate family psychoeducation models. The Schizophrenia PORT sponsored a dissemination of William McFarlane's multiple family psychoeducational group. One obstacle to implementation was lack of programmatic leadership at agencies. Another was conflict between the philosophy and principles of the family model and typical agency practices. Dissemination efforts of the MFPG model are under way in the states of Illinois and Maine.<sup>35</sup>

Internationally, the World Schizophrenia Fellowship Strategy Development Group identified the following barriers to implementation of family psychoeducation programs: stigma; psychoeducation treatments seen as not important; conflicts in relationship between users and carers; different models of family interventions; inadequate training of the professional work force; costs and structural problems in many mental health services.<sup>4</sup> Bergmark<sup>36</sup> noted the persistence of psychodynamic theories which families perceived as blaming and inhibited effective collaboration between professionals and families.

Wright<sup>37</sup> explored the impact of attitudinal, occupational and organizational factors on mental health professionals' involvement with clients' families and found that attitudes were not predictive of frequency of contacts with their clients' families. Rather, job and organizational factors were critical. Being a social worker or therapist and working on day or evening shift were associated with increased involvement with families.

Family education and self-help efforts clearly have different barriers to dissemination and implementation than formal professional services. Further research needs to focus on what motivates help-seeking behavior in formal and informal settings.

## **Challenges for the Future**

Four main areas of research are necessary to achieve progress in providing services to families and persons with serious and persistent brain diseases such as schizophrenia.

- (i) We need a better understanding of the current state of affairs, including systematic exploration of what kinds of service different kinds of families are receiving or not receiving and from whom. Research on treated populations is not sufficient. Billing records alone will not account for the informal clinician/family contacts, which are valued. This research must include the patient, family and clinician perspectives as well as incorporating systemic factors such as financing and organization of services.
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maximal value in first-break patients. How can the acceptability of psychoeducation to families and clinicians be maximized? Are there ways to capitalize on the best of clinician-run and family-run models to create hybrid models? Does family psychoeducation shift costs toward or away from families?

(iii) How can successful family services models be disseminated effectively? Although it is still necessary to know more about the current status of services to families, it is quite clear that the best researched psychoeducation programs have limited, if any, penetration in typical communities. Approaches that combine grassroots participation of clinicians and family members as well as efforts with senior administrators and payers are likely to yield the greatest success.

(iv) More research is necessary on the role of families and other caregivers in recovery and course of illness. This research must be driven by an appreciation of the biopsychosocial model and be empirical rather than ideological. Such an approach will optimally protect families from their own tendency to self-blame and from the tendency of the medical models prevalent in industrialized countries to find blame, fault and pathology.

The gap between what we know and what we do for families of persons with schizophrenia appears to be large.<sup>16</sup> Our research agenda must increase what we know by a greater understanding and closing of this gap.

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