

An Assessment of the Educational Needs of Chronic Psychiatric Patients and their Relatives

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Both psychiatric patients and their relatives benefit from learning about mental illness and how to cope with it, but the specific interests of these consumers remain unclear. To determine specific educational needs and to compare the needs of different consumers, a questionnaire survey was conducted with a sample of patients with schizophrenia and affective disorder and their relatives. Both patients and relatives reported strong interest in learning more about psychiatric illness and strategies for coping with common problems, but patients with schizophrenia were less interested than patients with affective disorder and both sets of relatives. Discriminant analyses revealed that needs differed as a function of patient diagnosis, patient/relative status, and relatives' membership of a self-help and advocacy organisation. Consumers of mental health services are capable of specifying their own educational needs, and educational programmes should be tailored to meet these.

The discovery of antipsychotic medication, the accumulation of evidence supporting a genetic basis for schizophrenia, and the ineffectiveness of early therapies aimed at correcting 'pathological' family interactions, have gradually led to the abandonment of early theories postulating an aetiological role for the family in the development of schizophrenia and other chronic mental illnesses (Mueser, 1989). Whereas the family is no longer viewed as the *cause* of severe psychiatric disorders, the impact of the family on the course of illness, as well as the effect of the illness on family functioning, have become an important focus of research and treatment. A consistent body of research has emerged suggesting that negative affect in the family directed towards the patient, 'expressed emotion' (EE), has a deleterious effect on the course of schizophrenic and major affective illnesses (Brown *et al*, 1972; Miklowitz *et al*, 1988). Relatives of the mentally ill have objected to the concept of EE, arguing that it is pejorative and fails to attend to the legitimate concerns of family members, such as the management of disruptive patient behaviour and the availability of treatment resources in the community (Hatfield *et al*, 1987).

The increase in caring responsibilities of families following deinstitutionalisation has underscored the importance of assessing and alleviating the burden of chronic mental illness on primary family members (Fadden *et al*, 1987). Families have expressed dissatisfaction with the treatment they receive from mental health professionals (Dearth *et al*, 1986). Surveys indicate families have a strong desire for more information about the disorder as well as practical advice concerning how to cope with the patient (e.g. Spanoil *et al*, 1987). This conflict

between the perceived needs of family members and theories regarding the influence of EE has led to a fruitful dialogue between families and mental health professionals, although differences in perception persist (Mintz *et al*, 1987).

Over the past 15 years a variety of family treatment models have been developed to improve the ability of the family to manage the ill relative at home, lessen the burden of the illness on family members, and decrease negative affect in the family (Falloon *et al*, 1984; Leff *et al*, 1985; Anderson *et al*, 1986; Tarrier *et al*, 1988). These interventions differ in both theoretical orientation (in that they can be behavioural or systems-strategic) and in the format in which treatment is delivered (e.g. individual families v. family groups). Common to all the family treatments, however, is the provision of basic information about the patient's psychiatric disorder, such as the diagnosis, characteristic symptoms, effects of medication, and course of illness.

Just as family members benefit from learning about a relative's psychiatric illness, patients themselves need to be educated about the disorder, to enable them to become more active partners in the management of their own illness (Swezey & Swezey, 1976). The education of patients has focused primarily on teaching patients early warning signs of an impending relapse (Herz & Mellville, 1980) and on medication effects (Wallace *et al*, 1985), although programmes providing other information have also been established (Bisbee & Lee, 1988).

Despite the widespread clinical practice of educating patients and relatives about psychiatric illness, relatively little is known about the specific educational needs of these people. The curriculum of most

educational programmes has been established by treatment providers, based on their own beliefs as to what information about the illness and its treatment patients and families need to know, rather than on objective data collected from the consumers themselves. In their development of a treatment service model, Smith & Birchwood (1990) stressed the importance of needs-led, goal-defined interventions for psychiatric patients and their relatives.

Only a few objective surveys of mental health consumers have been conducted, and these have studied the needs of relatives who are participants in self-help and advocacy groups, such as the Alliance for the Mentally Ill (Hatfield, 1981; Holden & Lewine, 1982; Spanoil *et al.*, 1987). In general, the results indicate that relatives are most interested in learning basic information about the illness and advice for coping with common problems. However, these surveys leave open many questions. Do patients and relatives have the same needs? How do needs differ according to diagnosis? Are the needs of relatives who participate in self-help groups different from those of other relatives? The present survey study was conducted in order to assess the educational needs of patients and relatives from their own perspectives, and to compare differences in the perception of need as a function of respondent (patient v. relative), diagnosis, and membership in a self-help group (for relatives).

Method

The subjects for the study comprised 60 psychiatric out-patients, 46 with schizophrenia or schizoaffective disorder and 14 with major affective disorder, and 108 relatives and 27 close friends of these patients. Most of the relatives were parents (74%) or siblings (14%); 3% were spouses.

All patients were symptomatically stable and were currently receiving out-patient treatment at one of two hospitals in the Philadelphia, Pennsylvania area. To be included in the survey, patients were required to have at least four hours per week of contact with a relative, which was assessed by self-report. Their DSM-III-R diagnoses (American Psychiatric Association, 1987) made for the purpose of this study were based on the most recent chart diagnosis.

Relatives of patients at the two hospitals were asked to complete the survey. In addition, the members of two chapters of the Alliance for the Mentally Ill, a self-help and advocacy organisation for relatives of the mentally ill, also participated in the survey. Where a relative was not related to a patient included in the survey, the patient's diagnosis was based on the report of that relative. Fifty-eight per cent of the relatives were members of self-help organisations, 36% were not, and this was unknown for 8%. Patients and relatives were approached in person and invited to participate in the survey, which required about 15 minutes.

The number of persons who declined to complete the survey was not recorded, but approximately 15% refused.

A questionnaire was developed by the authors to assess educational needs. Forty-five items pertaining to different areas of educational need were generated by ten professionals, five family members, five patients, and previous surveys (Spanoil *et al.*, 1987). The items generated could be classified into six general domains: basic facts about mental illness (13 items, e.g. symptoms, medication, genetics); coping with patient symptoms (11 items, e.g. negative symptoms, persistent hallucinations, delusions, anxiety, anger); enhancing social functioning (6 items, e.g. improving social relationships, independent living skills); community resources (6 items, e.g. alternative living situations, patient and relative self-help groups); coping with stress and family problems (6 items, e.g. stress management, family problem solving); and miscellaneous (3 items, dealing with weight gain, coping with stigma, planning for when a parent dies).

Patients and relatives participating in the survey rated their interest in learning more about each item on a five-point Likert-type scale, with 1 denoting "not interested" and 5 denoting "very interested". A copy of this questionnaire is available from the first author upon request.

Results

Preliminary analyses were conducted to evaluate whether chronicity of the illness varied as a function of diagnosis, patient/relative status, or membership in a self-help group. *T*-tests were computed comparing the length of illness between patients with schizophrenia and those with affective disorder (mean 10.5 v. 7.3 years, respectively), between the relatives of patients in each diagnostic group, and between relatives who held membership in a self-help organisation and those who did not. None of these tests was statistically significant ($P > 0.05$).

The statistical analysis of educational needs was conducted in two general steps. Firstly, analyses were performed to examine general patterns of response across the items on the educational needs questionnaire and among different groups of subjects. Secondly, analyses were conducted to determine which, if any, items discriminated between the different subject groups.

General response patterns

To evaluate whether the items on the questionnaire could be combined into different factors based on similar patterns of responses, a principal-components factor analysis (Kleinbaum *et al.*, 1988) was performed using all 45 items from the total sample of 195 subjects. The first factor had an eigenvalue of 16.82 and accounted for 37.4% of the variance of the sample. Nine additional factors had eigenvalues over 1.0, but no factor accounted for more than 6% of the remaining variance. A scree test (Cattell, 1966) indicated that a single-factor solution was most parsimonious. Of the 45 items, 44 had a factor loading over 0.50 on the first factor; 'dealing with weight gain' had a factor loading of 0.43.

Table 1
Educational topic ratings for schizophrenia and schizo-affective disorder group

Question	Patients		Relatives	
	Rank	Mean ¹	Rank	Mean ¹
Getting what you need from the mental health system	1	4.17	2	4.51
Early warning signs of the illness and relapse	2	4.11	11	4.33
Psychiatric medications	3	4.02	10	4.36
What happens when parent dies	4	3.96	5	4.39
Strategies for solving problems	5	3.91	9	4.36
Genetics and vulnerability to illness	6	3.91	12	4.32
Symptoms of the illness	7	3.89	29	4.02
Side-effects of medications	8	3.85	1	4.56
Stress and the illness	9	3.83	19	4.16
Recent research on mental illness	10	3.80	8	4.36
Enhancing leisure and recreation activities	11	3.80	24	4.11
Applying for financial assistance	12	3.78	34	3.84
Coping with stigma of mental illness	13	3.78	14	4.25
Improving communication with relatives	14	3.78	13	4.32
Ways of managing stress more effectively	15	3.78	6	4.39
How psychiatric diagnoses are made	16	3.76	15	4.23
Improving social relationships	17	3.72	4	4.39
Persistent delusions	18	3.70	35	3.83
What the illness is like for the person with it	19	3.67	7	4.37
Relatives' support and advocacy organisations	20	3.59	32	3.86
Patients' self-help organisations	21	3.54	28	4.03
Persistent hallucinations	22	3.54	37	3.80
Vocational rehabilitation	23	3.54	18	4.18
Alternative treatment approaches	24	3.52	17	4.19
Lack of interest and motivation	25	3.50	22	4.12
Coping with depression and suicidal thoughts	26	3.50	30	4.02
Managing 'burnout'	27	3.50	38	3.73
Setting limits on the patient's behaviour	28	3.50	3	4.47
Problems with concentration	29	3.48	25	4.09
Loss of pleasure	30	3.48	31	3.90
Social isolation, avoidance/withdrawal	31	3.48	21	4.13
Anger, violence, assaultive behaviour	32	3.48	36	3.81
Biological theories	33	3.48	23	4.11
Improving independent living skills	34	3.46	16	4.21
How common the illness is and what tends to happen when a person has it	35	3.43	27	4.06
Alternative living situations	36	3.41	20	4.14
Dealing with weight gain	37	3.39	44	3.62
Anxiety and panic attacks	38	3.33	42	3.67
Planning/coping with holidays	39	3.28	41	3.68
Day treatment	40	3.24	26	4.07
Sleeping problems	41	3.22	40	3.68
Admission to psychiatric hospital	42	3.15	43	3.63
Improving grooming and hygiene	43	3.07	33	3.85
Involuntary commitment to hospital	44	3.04	39	3.70
Drug/alcohol abuse	45	2.78	45	3.17

1. High means denote greater interest, on scale of 1-5

The factor analysis indicated that subjects' responses to the educational needs questionnaire reflected a single dimension of general interest in learning more about psychiatric illness. There was no evidence that subsets of questions were answered with higher consistency, which would suggest the existence of meaningful subscales of items.

Analyses were conducted to compare the general interest level across the different groups of subjects. Firstly, a mean interest rating for each subject was computed across the 45 questions. Then, an analysis of variance (ANOVA) was performed to evaluate whether interest level was related to diagnosis (schizophrenia or schizoaffective disorder v. major affective disorder), respondent (patient v. relative), or the diagnosis \times respondent interaction. The overall ANOVA model was significant ($F(2,190) = 4.77, P < 0.009$). The diagnosis \times respondent interaction was significant ($F(1,190) = 3.38, P < 0.03$), as was the main effect for respondent ($F(1,190) = 7.50, P < 0.007$). The main effect for diagnosis was not significant ($F(1,190) = 2.34$). A *t*-test comparing the interest level of relatives who were members of a self-help organisation with relatives who were not was not significant ($t(123) = 0.27$).

The analyses indicated that the patients with schizophrenia or schizoaffective disorder were on average *less* interested in the educational topics (mean = 3.58) than those with affective disorder (mean = 4.26), or than the relatives of patients with either diagnosis (means = 4.08, 4.07, respectively). Membership of a self-help organisation was not related to degree of interest. The average level of interest was quite high for all respondents, with most ranging between "somewhat interested" (3) and "very interested" (5).

Subject differences in specific educational needs

The differences and similarities in the self-reported educational needs of patients and relatives for the two diagnostic groups are contained in Tables 1 and 2.

Three educational topics were among the most interesting to all four groups of subjects: medication, side-effects of medication, and getting what you need from the mental health system. Several additional topics were among the most interesting for three out of the four subject groups: early warning signs (except relatives of schizophrenics), strategies for solving problems (except relatives of affective patients), stress and the illness (except relatives of schizophrenics), stress management (except schizophrenics), personal experiences of patients (except schizophrenics), and recent research on mental illness (except affective patients). Four topics were among the *least* interesting to all four groups of subjects: drug/alcohol abuse, hospital admission, coping with holidays, and dealing with weight gain. Additional topics that were among the *least* interesting for three out of four groups included: coping with persistent hallucinations (except schizophrenics), improving grooming and hygiene (except relatives of schizophrenics), and involuntary commitment (except relatives of affective disorder patients).

In order to identify which specific educational needs most distinguished the different groups of subjects, stepwise multiple discriminant analyses (MDAs) were conducted

Table 2
Educational topic ratings for major affective disorder group

Question	Patients		Relatives	
	Rank	Mean ¹	Rank	Mean ¹
Ways of managing stress more effectively	1	4.93	7	4.52
Side-effects of medications	2	4.93	1	4.93
Early warning signs of the illness and relapse	3	4.86	8	4.52
What the illness is like for the person with it	4	4.79	3	4.67
Stress and the illness	5	4.79	10	4.44
Strategies for solving problems	6	4.71	11	4.41
Patients' self-help organisations	7	4.71	19	4.19
How common the illness is and what tends to happen when a person has it	8	4.71	9	4.44
Enhancing leisure and recreation activities	9	4.64	28	4.00
Coping with stigma of mental illness	10	4.57	25	4.15
Anxiety and panic attacks	11	4.57	20	4.19
Improving social relationships	12	4.57	21	4.19
Recent research on mental illness	13	4.57	6	4.56
Psychiatric medications	14	4.57	2	4.74
Problems with concentration	15	4.50	24	4.15
Genetics and vulnerability to illness	16	4.50	13	4.37
Getting what you need from the mental health system	17	4.50	5	4.63
Applying for financial assistance	18	4.43	17	4.30
Loss of pleasure	19	4.43	39	3.70
Alternative treatment approaches	20	4.43	16	4.30
Anger, violence, assaultive behaviour	21	4.43	29	4.00
What happens when parent dies	22	4.36	40	3.81
Sleeping problems	23	4.36	37	3.63
Biological theories	24	4.36	14	4.37
Improving independent living skills	25	4.29	26	4.11
How psychiatric diagnoses are made	26	4.29	4	4.67
Day treatment	27	4.29	41	3.81
Lack of interest and motivation	28	4.29	23	4.15
Coping with depression and suicidal thoughts	29	4.29	12	4.41
Social isolation, avoidance/withdrawal	30	4.21	22	4.19
Improving communication with relatives	31	4.21	18	4.22
Symptoms of the illness	32	4.21	15	4.37
Managing 'burn-out'	33	4.21	36	3.56
Setting limits on the patient's behaviour	34	4.21	27	4.11
Planning/coping with holidays	35	3.93	34	3.37
Relatives' support and advocacy organisations	36	3.93	30	4.00
Persistent delusions	37	3.86	45	2.85
Vocational rehabilitation	38	3.71	31	4.00
Drug/alcohol abuse	39	3.64	32	3.11
Persistent hallucinations	40	3.57	44	2.74
Admission to psychiatric hospital	41	3.50	38	3.67
Involuntary commitment to hospital	42	3.21	42	3.81
Improving grooming and hygiene	43	3.21	33	3.15
Alternative living situations	44	3.21	43	3.96
Dealing with weight gain	45	2.86	35	3.48

1. High means denote greater interest, on scale of 1-5.

(Kleinbaum *et al*, 1988). This analysis identifies which educational needs were *uniquely* different for the groups of subjects, while controlling for the moderately high correlations between all of the questions. A total of five MDAs were performed comparing the following groups: schizophrenic patients with their relatives; patients with affective disorder with their relatives; schizophrenic patients with affective disorder patients; relatives of schizophrenics with relatives of patients with affective disorder; and relatives who were members of self-help organisations with non-member relatives. A probability level of $P < 0.05$ was set for a variable to enter the multiple discriminant equation.

No variables were significant for the MDA comparing the patients with affective disorder with their relatives, indicating similar educational needs. The remaining four MDAs were highly significant, with between one to four variables discriminating the different groups. These analyses indicate that a relatively small number of educational needs distinguished the different groups of subjects. The statistics for the MDAs and the items that discriminated the groups are summarised in Table 3.

Schizophrenic patients and their relatives differed only in that the relatives were more interested in "setting limits on patient's behaviour". The patients with schizophrenia and those with affective disorder differed on several topics: those with affective disorder were more interested in the prevalence of the illness, stress management, and self-help groups, whereas schizophrenic patients were more interested in dealing with weight gain and alternative living situations. The relatives of schizophrenics were more interested than the relatives of those with affective disorder in learning about coping with persistent hallucinations, whereas the relatives of those with affective disorder wanted to learn more about coping with depression and suicidal thoughts. Finally, non-members of self-help organisations were more interested than members in learning about relatives' support groups and drug/alcohol abuse, whereas the members of self-help groups were more interested in vocational rehabilitation and coping with depression and suicidal thoughts. Since a slightly higher proportion of members of self-help groups had relatives with schizophrenia (65%) than did non-members (50%), these differences in interest do not appear to be due to differences in the patient's diagnosis.

Discussion

The survey indicated that, on average, relatives were quite interested in gaining more information about psychiatric illness and strategies for managing common problems. This is consistent with previous surveys of relatives who are members of self-help organisations (Hatfield, 1981; Holden & Lewine, 1982; Spanoil *et al*, 1987) and extends the findings to family members who are not members of such organisations. Several differences emerged when the educational needs of members of self-help groups were compared with the needs of non-members. Non-members were more interested in relatives'

Table 3
Summaries of stepwise discriminant analyses predicting diagnosis, patient status, and membership of a self-help organisation from educational needs questions

Groups discriminated ¹	Variables entered at $P < 0.05$	Direction of effects	Partial r^2	F	Significance
SP/SR	Setting limits on patient's behaviour	SP < SR	0.13	23.12	$P < 0.0001$
AP/AR	No variables were significant	-	-	-	-
SP/AP	How common is illness	SP < AP	0.13	8.62	$P < 0.005$
	Stress management	SP < AP	0.07	4.18	$P = 0.045$
	Dealing with weight gain	SP > AP	0.07	4.42	$P = 0.040$
	Patients' self-help groups	SP < AP	0.10	6.09	$P = 0.017$
	Alternative living situations	SP > AP	0.10	6.29	$P = 0.015$
SR/AR	Persistent hallucinations	SR > AR	0.08	11.53	$P < 0.001$
	Coping with depression and suicidal thoughts	SR < AR	0.07	10.48	$P < 0.001$
SHO/non-SHO	Drug/alcohol abuse	SHO < non-SHO	0.06	8.59	$P = 0.004$
	Coping with depression and suicidal thoughts	SHO > non-SHO	0.07	9.01	$P = 0.003$
	Vocational rehabilitation	SHO > non-SHO	0.04	5.16	$P = 0.025$
	Relatives' support groups	SHO < non-SHO	0.05	6.78	$P = 0.010$

1. SP = schizophrenic patients; SR = relatives of schizophrenic patients; AP = affective disorder patients; AR = relatives of affective disorder patients; SHO = member in self-help organisation (relatives only).
With the exception of AP/AR, each of the discriminant models was significant at $P < 0.0001$. Wilks' lambdas for the models were as follows: SP/SR = 0.87; AP/AR = NS; SP/AP = 0.61; SR/AR = 0.85; SHO/non-SHO = 0.79.

support groups, suggesting they would like to be members if given the opportunity. Non-member relatives were also more interested in drug/alcohol abuse than members. These differences may reflect socioeconomic factors, but these were not evaluated in the present study. Members of self-help groups were more interested than non-members in vocational rehabilitation and coping with depression and suicidal thoughts, which may be due to their stronger desire to be involved in the active treatment of their relative's psychiatric illness. The present results suggest that membership of a self-help organisation may reflect different needs and interests regarding the management of a relative's mental illness.

The strong interest of relatives in the educational topics was matched by the patients with major affective disorder, but not by the patients with schizophrenia and schizoaffective disorder. This could reflect anhedonia, a core symptom of schizophrenia (Meehl, 1975); while some interest is present, impaired hedonic capacity may attenuate respondents' curiosity about their illness and strategies for managing common problems. Cognitive impairments including deficits in information processing (Nuechterlein & Dawson, 1984) could also contribute. It is important to recognise that although the interest expressed by schizophrenic patients was significantly lower than that of other groups, the absolute magnitude of the difference was small – less than one Likert-scale point; these patients were, on average, between “somewhat” and “rather” interested in the educational topics.

The needs of patients with schizophrenia differed significantly from those of patients with affective

disorder; the former were more interested in learning how to deal with weight gain and alternative living situations, while the latter were more interested in stress management and self-help groups. The differences in concern with weight gain may be because neuroleptic medications potentiate more weight gain than antidepressants. While a variety of interpretations can be offered to account for the other differences, the results support the utility of assessing patients' own perceptions of their needs (MacCarthy *et al*, 1986).

In contrast to the two sets of patients, relatives reported needs similar to each other, and the few differences were limited to their interest in learning how to cope with characteristic symptoms of each disorder: the relatives of the schizophrenic patients were more interested in coping with persistent hallucinations, whereas the relatives of patients with affective disorder were more interested in learning how to cope with depression and suicidal thoughts.

Finally, contrasts between the educational needs of patients and relatives revealed no significant differences within the affective disorder group, and only one difference within the schizophrenia group: relatives of schizophrenics were more interested in learning how to set limits on the patient's behaviour than were the patients themselves. Despite this difference, it is noteworthy that this topic was not among the least interesting topics for the schizophrenic patients (it was ranked 28th). This finding is consistent with the different levels of interest in learning about the illness reported by relatives and schizophrenic patients, and suggests

that, on average, patients and relatives may have compatible educational needs.

In general, all groups of respondents were most interested in learning basic information about the illness (e.g. medication, early warning signs) and generic coping strategies (e.g. stress management); this is similar to other surveys of relatives' educational needs (Spanoil *et al*, 1987). The interest in learning more about the illness was most pronounced for the schizophrenic patients, for whom the topics of primary interest related to basic information, including identifying the symptoms of the illness. The topic that was of greatest interest to all respondents was learning how to get their needs met from the mental health system. The interest in this topic echoes the dissatisfaction of many consumers with the standard treatment they receive and with the poor coordination of treatment services in many areas (Walsh, 1985).

The comparatively low level of interest in strategies for coping with specific problems may reflect the fact that only a minority of patients suffer from each particular problem (e.g. persistent hallucinations, depression and suicidal thoughts). Tailoring educational materials to the expressed needs of family members and patients, then, appears vital (Smith & Birchwood, 1990), especially in terms of practical advice for coping with problems.

Both patients and relatives were relatively uninterested in one topic that is of particular concern to professionals in the mental health field: drug and alcohol abuse. In a survey of relatives who are members of the Alliance for the Mentally Ill, Spanoil *et al* (1987) also found a low interest level in dealing with patients' drinking. This is surprising in light of the prevalence of substance abuse in schizophrenia and affective disorders (Christie *et al*, 1988; Mueser *et al*, 1990), and suggests that when substance abuse is prominent, the clinician may need to galvanise the family and patient to address the abuse as an important focus of treatment. The low interest level could also reflect that substance abuse was a current problem for only a minority of the patients surveyed.

This survey of psychiatric patients' and relatives' educational needs emphasises the importance of assessing the specific needs of different diagnostic groups, as well as the value of distinguishing between the needs of patients and family members and between persons who are/are not members of self-help organisations. Patients and family members are capable of identifying their educational needs, and these perceptions need to be accommodated in order for providers to overcome the dissatisfaction of mental health consumers with current treatments. If we are to promote the growing dialogue between patients, families, and mental health professionals

(Tarrier & Barrowclough, 1990), we would be advised to design educational programmes which are based on objective data collected from specific subject groups and which, therefore, match the interests of the mental health consumer.

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