

# What Do Outpatients With Schizophrenia and Mood Disorders Want to Learn About Their Illness?

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**Objective:** Psychiatric patients currently have access to a plethora of information about their illness. However, little systematic research has explored what psychiatric patients would like to learn about their illness. This study addressed the knowledge gap by asking outpatients with schizophrenia and mood disorders what they wished to learn about their illness and how they preferred to learn this information. **Methods:** An exploratory survey of psychiatric outpatients was conducted between April 2011 and June 2012. A total of 202 outpatients with a diagnosis of either schizophrenia or related disorder (*ICD-10* codes F20–F29) (N=106) or mood disorder (*ICD-10* codes F30–F39) (N=96) were interviewed after routine meetings with their psychiatrist. Interviews were conducted with open- and closed-ended questions in outpatient clinics across East London, United Kingdom. Open-ended questions were analyzed qualitatively, and closed-ended questions were analyzed quantitatively. **Results:** Over two-thirds of psychiatric outpatients (68%) reported that they would like to learn more about their illness. Overall, patients' wishes for learning were heterogeneous. However, both diagnostic groups ranked "the cause of the illness" as their top information need. Most patients preferred to learn through one-to-one conversations with their psychiatrist (schizophrenia, 92%; mood disorder, 84%). **Conclusions:** In regard to educating patients about their illness, there is no one-size-fits-all approach. Health care professionals need to be sensitive to individual learning preferences, which vary and can include group-based approaches. The results have implications for the training of psychiatrists. In particular, psychiatrists need to be equipped to address patients' questions about the cause of the illness. (*Psychiatric Services in Advance*, May 15, 2013; doi: 10.1176/appi.ps.201200382)

Since the 1970s, the consumer movement has led patients to expect more of a say in their treatment (1). Evidence suggests that most patients desire information about their treatment and want to take part in therapeutic decisions (2–5). In

mental health care, providing patients with information about the risks and benefits of medication and about treatment options can increase engagement with services (6–8).

There is a wide consensus that patients should be informed about

their illness and provided with information relevant to their own circumstance to help ensure that they become "active partners" in their care (9). Various interventions have been developed to meet patients' information needs. "Psychoeducation" (10–14) describes any program involving interaction between an information provider and patients or their caregivers that has the primary aim of offering information about the condition. Guidelines of the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom recommend psychoeducation for patients with bipolar disorder (15). For patients with schizophrenia, NICE conclusions are less clear (16). The guidelines of the U.S. Schizophrenia Patient Outcomes Research Team recommend education for patients with schizophrenia and their families (17).

No matter how effective psychoeducation is, all patients still have a right to obtain additional information about their condition. This is reflected in the assortment of patient learning initiatives that health care providers and patient groups have created in recent years. For example, "psychosis seminars" is a model that started in Germany in the 1990s and has gained popularity in other European countries (18–21). In psychosis seminars patients meet with health care professionals and family members or other caregivers with the aim of learning from each other. Everyone is regarded as an expert with respect to his or her own role and experience.

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In addition, patient groups often hold information exchange events and provide information sheets on their Web sites (for example, Florid, at [www.florid.org.uk](http://www.florid.org.uk)).

Although a variety of learning initiatives already exist, they are neither widely implemented nor standardized. This may be because it is not clear which of these interventions, if any, meets the information needs of patients. To date, little research has been conducted on precisely what psychiatric patients want to learn about their illness. Identifying the wishes of these patients is essential in designing both acceptable and effective learning opportunities. To our knowledge only one study has directly assessed the educational needs of psychiatric patients (22). In that study, patients with schizophrenia and mood disorders were asked to rank on Likert scales their interest in various educational topics. The most highly rated topics were “getting what you need from the mental health system,” “early warning signs of the illness and relapse,” and “psychiatric medications.” However, these data, which are from a relatively small sample, are now more than 20 years old.

The study reported here investigated the educational needs of patients with schizophrenia and mood disorders, because these are the most common disorders among psychiatric outpatients in secondary care. Aims were to explore what outpatients want to learn about their illness and how they would like to learn this information.

## Methods

### Study design

The study was an exploratory survey of psychiatric outpatients that used a questionnaire containing open- and closed-ended questions. The study was granted ethical approval from the East of England National Research Ethics Service Ethics Committee.

### Learning experiences questionnaire

We developed a “learning experiences” questionnaire for the purpose of this study (available on request). It

was designed with the assistance of five patients in East London who had a diagnosis of a mood disorder or schizophrenia, and it was piloted in outpatient clinics with a sample of patients who had similar diagnoses and was then refined. The questionnaire covered four general domains: patient characteristics (age, gender, occupation, race-ethnicity, education, living situation, diagnosis, and length of illness), previous experience of learning about the illness (what they have learned, whom they have learned from, and who was the most and least helpful), wishes for more learning (satisfaction with past information, wishes to learn more, and topics they would like to learn more about and from whom and in what format), and views of group learning interventions (experience of previous attendance at learning groups and willingness to consider attending learning groups in the future).

Closed-ended questions typically had multiple-choice answers, and open-ended questions asked patients to elaborate on their choices. For example, when asked, “What would you like to learn more about?” (and “From whom?” and “In what format?”), patients had the option of selecting as many topics as they liked from a list of items provided. Patients could provide additional information about topics not covered by the list. Satisfaction with past information was scored on a Likert scale, with 0 indicating very unsatisfied and 10 indicating very satisfied.

### Participants

Participants were recruited from psychiatric outpatient clinics across the three East London boroughs of Newham, Hackney, and Tower Hamlets from April 2011 to June 2012. To be considered for inclusion, patients had to be between the ages of 18 and 70 and able to provide informed consent; to be currently receiving secondary mental health care and attending an outpatient clinic; to have a primary diagnosis of schizophrenia or related disorder (*ICD-10* codes F20–F29) or a mood disorder (*ICD-10* codes F30–F39) and sufficient command of English to understand the instructions and questions.

## Procedure

Psychiatrists and administrative staff in outpatient clinics were contacted by researchers to establish whether patients with an appointment in the forthcoming week would fulfill the inclusion criteria. On the day of their appointment, eligible patients were approached by their psychiatrist about research participation. Interested patients were introduced to the researcher after their meeting with the psychiatrist. The researcher provided a complete description of the study and obtained written informed consent. Patients were guided through the questionnaire and received £10 upon completion. Qualitative data were analyzed by using content analysis. Quantitative data were analyzed with descriptive statistics. Chi square and t tests were performed to analyze differences between diagnostic groups. All data analysis was conducted with the statistical package PASW Statistics, version 18 (formerly SPSS).

## Results

A total of 290 patients were screened as eligible, and data were collected from 202 (106 with schizophrenia or a related disorder and 96 with a mood disorder), yielding a 70% response rate. The remaining 88 who did not complete the questionnaire were either too unwell to participate (N=31), refused to participate in research (N=22), did not have the time (N=15), were not approached because of clinician forgetfulness (N=13), or had other reasons (N=7). [A CONSORT diagram illustrating recruitment is available in an online data supplement to this article.]

### Patient characteristics

The characteristics of the sample are summarized in Table 1. Most patients were of white racial-ethnic background, were unemployed, had not completed college, and were just as likely to be living alone as with others. The mean  $\pm$  SD duration of illness was  $13.9 \pm 10.5$  years.

### Previous learning experiences

Patients reported moderate satisfaction with the amount of information that they currently received about

their illness. The mean score on the satisfaction scale was  $6.5 \pm 2.7$  out of 10. Although patients used the full range of scores, data were negatively skewed (median=7), suggesting that patients tended to use ratings from the higher portion of the scale rather than from consistently across the scale.

Table 2 presents data on sources of previously obtained information identified by patients. Most of the 202 patients (84%, N=170) named the psychiatrist as one of their main sources of information, and most of these patients (54%, N=92) also named the psychiatrist as the most helpful. The reasons most frequently cited were “she or he provides simple, clear explanations” (N=17), and “she or he teaches me something specific” (N=16). Of the 86 patients (43% of sample) who identified the general practitioner as an information source, 60% (N=52) also labeled the general practitioner as least helpful. The most frequent reason given was “they don’t have enough time for you” (N=14).

### Current learning needs

Over two-thirds of the 202 patients (68%, N=138) reported that they would like to learn more about their illness. The top reasons given by the other 32% (N=64) as to why they did not wish to learn more were “I am satisfied with what I know already” (N=37), and “Knowing more would be detrimental to my condition” (N=10). A significant relationship was found between diagnosis and wanting to learn more ( $\chi^2=3.78$ ,  $df=1$ ,  $p=.05$ ). Patients with a diagnosis of schizophrenia were less likely to want to learn more about their illness; 38% (N=40) of the 106 patients with schizophrenia did not want to learn more about their illness, compared with 25% (N=24) of the 96 patients with a mood disorder.

In terms of specific information, patients reported that in the past they had learned the most about the general nature of the illness (58% [N=62] of patients with schizophrenia and 72% [N=68] of those with a mood disorder) and medication (68% [N=72] and 61% [N=58], respectively). (One patient with a mood disorder reported never having learned anything

**Table 1**

Characteristics of 202 patients surveyed about their information preferences, by diagnostic group

Characteristic	Schizophrenia (N=106)		Mood disorder (N=96)	
	N	%	N	%
Gender				
Male	61	58	45	47
Female	45	42	51	53
Race-ethnicity <sup>a</sup>				
White	40	38	53	55
Black	35	33	18	19
Asian	29	27	22	23
Mixed	2	2	3	3
Occupation				
Unemployed	75	71	60	63
Employed	15	14	19	20
Retired	6	6	7	7
Volunteer	8	8	3	3
Student	2	2	7	7
Education <sup>a</sup>				
None	50	47	25	26
High school or equivalent	35	33	39	40
College graduate	13	12	16	17
Advanced degree	8	8	16	17
Living situation				
Alone	59	56	42	44
With others	47	44	54	56

<sup>a</sup> Significant difference ( $p < .05$ ) between diagnostic groups

about the illness in the past; thus the percentages are based on 95 rather than 96 in this instance.) Substantial overlap was noted between information that patients had received in the past and their current learning needs, as well as some discrepancy.

Table 3 presents data on the topics that patients reported wanting to learn more about. Patients’ wishes were mostly heterogeneous; however, the most cited information need, consistent across diagnostic categories, was to learn more about the cause of the illness (62% of patients with schizophrenia, and 57% of those with a mood disorder).

Patients were asked from what source they preferred to learn more about their illness (Table 4). Most cited a psychiatrist (74% of those with schizophrenia and 76% of those with a mood disorder), followed by a general practitioner (44% and 49%, respectively).

Patients were also asked how they would like information delivered to them (Table 5). The vast majority reported that they would prefer to learn about their illness through

one-to-one conversations with their chosen professional (92% of those with schizophrenia and 84% of those with a mood disorder). Printed leaflets and information packs followed as second and third preferences. Again, there was little difference between the preferences of diagnostic groups, although patients with a mood disorder were significantly more likely than those with schizophrenia to want to receive information via e-mail (21% versus 6%;  $\chi^2=10.11$ ,  $df=2$ ,  $p=.006$ ).

### Views of group learning interventions

Most patients reported never having attended a learning group—neither a psychosis seminar (75% [N=80] of those with schizophrenia and 91% [N=87] of those with a mood disorder) nor a psychoeducation group (93% [N=99] and 91% [N=87], respectively). Of those with no previous experience of a psychosis seminar, 48% (N=38) of patients with schizophrenia and 47% (N=41) of those with a mood disorder reported that they would consider attending one; these proportions were 58% (N=57) and

**Table 2**

Sources of previously obtained information identified by 202 patients, by diagnostic group<sup>a</sup>

Source	Schizophrenia (N=106)		Mood disorder (N=96)	
	N	%	N	%
Psychiatrist	90	85	80	83
General practitioner	41	39	45	47
Internet	16	15	36	38
Professional caregiver <sup>b</sup>	31	29	19	20
Other <sup>c</sup>	24	23	25	26
Psychologist	19	18	29	30
Family member	24	23	21	22
Printed leaflet	12	11	20	21
Other patient	8	8	7	7
Learning group	7	7	8	8

<sup>a</sup> Patients could identify more than one topic. No significant relationships were found between information source and diagnosis.

<sup>b</sup> A paid member of the patient's care team, such as a social worker or care coordinator

<sup>c</sup> Other multiple-choice options identified were books, church, friends, journals, letters, magazines, mental health charities, no one, own research, other professionals, radio, or ward visits.

60% (N=52), respectively, for considering attendance at a psychoeducation group. Among patients who had not previously attended either group, 41% in each diagnostic category reported that they would consider attending both a psychosis seminar and a psychoeducation group in the future (schizophrenia, N=31; mood disorder, N=33).

Patients who would consider attending a psychoeducation group were asked to give their top reason. To "learn and understand more" was

cited by 40% (N=23) of those with schizophrenia and 29% (N=15) of those with a mood disorder. The top reason given for wanting to attend a psychosis seminar in the future was to "share own and hear other people's experiences of the illness" (37% [N=14] of those with schizophrenia and 34% [N=14] of those with a mood disorder). Other patients, however, were put off attending either group because of "the format of the sessions" (10% [N=8] of the 84 patients

with schizophrenia who reported not wanting to attend either group and 21% [N=17] of the 81 patients with a mood disorder who reported this). Patients' dislike of the format included dislike of the group structure of the sessions, the inclusion of family members in the groups, and the didactic style of psychoeducation groups.

## Discussion

### Main findings

Most of the 202 psychiatric outpatients in this sample wanted to learn more about their illness. However, a third did not, and the proportion was higher among patients with schizophrenia. Although patients had received some information about their illness, both those with schizophrenia and those with mood disorders wished to learn more about the cause of the illness, and most patients reported that they would consider various options to obtain that information. The information delivery method cited most frequently was one-to-one conversations with their psychiatrist, followed by leaflets and information packs.

### Implications

Most of the information currently received by the outpatients in the sample was about medication and the general nature of the illness. These results are consistent with those from a study of learning preferences by Mueser and colleagues (22), which investigated topics that psychiatrists and patients tend to discuss in outpatient clinics. Our results suggest that patients are interested in learning not only about their medication but also about a range of other issues. The patients in our study were most frequently interested in obtaining more information on the cause of the illness. With respect to medication, psychiatrists can explain the known effects and side effects; however, they might struggle to outline the causes of illness. Causes are likely to be multifactorial and impossible to specify with certainty for individual patients. Indeed Baillie and colleagues (23) found that psychiatrists varied widely in their views of the etiology of mental disorders and tended to hold disorder-specific views. Therefore, patients are

**Table 3**

Topics identified by 138 patients as ones that they would like to learn more about, by diagnostic group<sup>a</sup>

Topic	Schizophrenia (N=66)		Mood disorder (N=72)	
	N	%	N	%
Cause of the illness	41	62	41	57
General nature of the illness	37	56	35	49
Other potential treatments	32	48	38	53
Medication	28	42	34	47
Available supports (social and financial)	25	38	35	49
Experiences of other patients with the same illness	31	47	27	38
Other <sup>b</sup>	24	36	27	38

<sup>a</sup> A total of 66 patients with schizophrenia and 72 with a mood disorder wanted to learn more about their illness. Patients could identify more than one topic. No significant relationships were found between topic and diagnosis.

<sup>b</sup> Includes such topics as how to cope with the illness and how to cure it, information about what the patient could do to speed recovery, specific information about the diagnosis, information about how the illness changes over time, specific questions about personal experiences, and information about "Why me?"



more likely to encounter various answers to the question of cause depending on their illness and the psychiatrist.

A clear implication of the findings is that the one-size-fits-all approach will not meet the information needs of all patients. Attempts to roll out only one approach, such as psychoeducation groups, to all patients are likely to fail because no single approach is in line with what all patients want. When established methods such as psychoeducation groups are evaluated or new initiatives developed, researchers and clinicians should be aware that each approach is likely to appeal to a limited clientele. At the same time, patients expressed a willingness to consider a range of options that they had not tried, and developing those options and making them both attractive and available to patients are challenges for services. For example, group-based approaches did not appeal to all patients but were still considered an option by up to 60% of those who had not tried them. Therefore, patients should be given greater access to such groups.

A considerable number of patients did not want any more information. This may or may not be a rational attitude, but clinicians should be aware of it and consider these wishes when communicating with patients, in particular those with schizophrenia. Future research may explore how information that is seen as acceptable and useful can be provided to these patients.

Although much information is available on the Internet or through other sources, psychiatrists—at least for the time being—were seen as the most important source of information for psychiatric outpatients. The evidence suggests that psychiatrists cannot be fully replaced as the primary source of information by the Internet or by other professionals. Patients appeared to trust that their psychiatrists would provide reliable information about their illness, which reflects the high level of trust patients have in psychiatrists found in previous studies (1,24).

The results have at least two clinical implications. First, psychiatrists should actively dedicate time to providing

**Table 4**

Sources of information preferred by 138 patients who reported wanting to learn more about their illness, by diagnostic group<sup>a</sup>

Source	Schizophrenia (N=66)		Mood disorder (N=72)	
	N	%	N	%
Psychiatrist	49	74	55	76
General practitioner	29	44	35	49
Psychologist	19	29	30	42
Professional caregiver <sup>b</sup>	22	33	15	21
Learning group	15	23	18	25
Other patient	10	15	10	14
Internet	7	11	12	17
Family member	5	8	2	3
Other <sup>c</sup>	4	6	2	3

<sup>a</sup> Patients could identify more than one source. No significant relationships were found between source and diagnosis.

<sup>b</sup> A paid member of the patient's care team, such as a social worker or care coordinator

<sup>c</sup> Other multiple-choice options identified were films, researchers, books, coworkers, conferences and workshops, and other professionals.

information in their outpatient consultations. Sufficient time must be allocated to psychiatric consultations so that psychiatrists can explain and discuss what patients want to know rather than simply referring them to leaflets and Web sites. Second, psychiatrists should be trained how to address patients' needs for information that go beyond medication and include the cause of illness. In the absence of simple explanations for the cause of schizophrenia and mood disorders, appropriate strategies to address patients' questions should be developed and included in training.

### Strengths and limitations

Patients were asked systematically about their learning experiences and preferences; the questionnaire was not focused on evaluating one specific educational approach. We included patients with schizophrenia and mood disorders. In addition, the sample was much larger than that in the only other study investigating the learning experiences of psychiatric patients (22), for which 60 patients were interviewed.

This study also had limitations. The sample was limited to outpatients in secondary mental health care in East

**Table 5**

Preferred information delivery methods of 138 patients who reported wanting to learn more about their illness, by diagnostic group<sup>a</sup>

Method	Schizophrenia (N=66)		Mood disorder (N=72)	
	N	%	N	%
One-to-one conversation	61	92	65	84
Printed leaflet	28	42	29	40
Information pack	23	35	30	42
Mixed-group discussion	18	27	24	33
E-mail <sup>b</sup>	4	6	15	21
Telephone conversation	8	12	4	6
Other <sup>c</sup>	7	11	5	7
Text message	3	5	5	7

<sup>a</sup> Patients could identify more than one source.

<sup>b</sup> Significant difference ( $p < .05$ ) between diagnostic groups

<sup>c</sup> Other multiple-choice options identified were anything, Internet, seminars, interactive workshops, books, and letters.

London. All patients were interviewed directly after seeing their psychiatrist, and patients reported that obtaining information from psychiatrists was the most frequent method of past learning. The procedure may have influenced patients' reports of the most helpful information source. It is also unclear whether outpatients in rural areas, inpatient settings, primary care, and other countries share the experiences and preferences of the patients in our sample. In this exploratory study, we did not adjust the statistical tests of difference for multiple testing.

### Conclusions

The learning needs of patients in the diagnostic groups of schizophrenia and mood disorders were relatively heterogeneous. Psychiatrists were seen as the most valued information source by these patients. Psychiatrists should consider a number of factors when providing information to their patients. They need to be aware of the learning needs of their patients; find ways to narrow the gap in regard to underaddressed issues, such as the cause of the illness; and recognize the importance of their own role in providing this information. This role may include the provision of information in various group settings. However, even though patients have many options for learning about their illness, for many patients one-to-one contact time with their psychiatrist remains central.

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