First-onset psychotic illness: patients' and relatives' satisfaction with services

GERARD LEAVEY, MICHAEL KING, ELEANOR COLE, AMANDA HOAR and ERIC JOHNSON-SABINE

Background Despite the growth in patient satisfaction studies, scant attention has been paid to the satisfaction of patients with a first episode of psychotic illness soon after presentation to services. We were particularly interested in any ethnic differences in satisfaction at this seminal stage in patient care.

Method Using a multi-item questionnaire, face-to-face interviews were conducted with patients and relatives I2 months after first contact with psychiatric services. Relatives were also questioned on support and advice issues related to after-care.

Results Most patients and relatives were generally satisfied with the treatment, and with the 'humane' qualities of psychiatric staff, but were less satisfied with the 'hotel' aspects of hospital care. Patients, and particularly relatives, were most concerned about levels of information and advice received. Relatives were dissatisfied with after-care. There were no significant differences between Black and other patients, but some differences between their relatives. Patients born abroad were significantly more satisfied than those born in Britain, irrespective of ethnicity. Compulsory detention under the Mental Health Act was also significant in determining low satisfaction for patients and especially for their relatives.

Conclusions For improved care in the community patients and their relatives need to be seen as partners in care rather than as passive recipients. The issue of information-giving by psychiatric services demands serious attention. Black patients and their relatives were not especially likely to be dissatisfied.

How patients and their relatives perceive service provision at the onset of a psychotic disorder may be a crucial determinant of compliance with care and even with clinical outcome. In previous studies deficiencies have been reported in the treatment offered to Black people (Francis et al, 1989) and dissatisfaction with treatment has been suggested as an explanation for poor compliance by Black patients (McGovern & Cope, 1991). However, in a study by McGovern & Hemmings (1994), purporting to be the first systematic survey in the UK comparing Black with White people's satisfaction with psychiatric care, it was reported that there was no difference between the two groups, despite the apparently contradictory finding in the same study that Blacks were more likely than Whites to perceive services as racist.

Previous studies suggest that demographic characteristics such as age, gender, marital status and education are not good predictors of satisfaction (Larsen et al, 1979). Svensson & Hansson (1994) reported lower satisfaction in patients with a diagnosis of schizophrenia and those who perceived that they were involuntarily admitted. Few studies have examined the satisfaction of patients' relatives as well as that of patients themselves (Ruggeri, 1994).

The aims of the present study were:

- (1) to assess patients' and their relatives' satisfaction with psychiatric care after a first episode of psychosis;
- (2) to examine factors associated with patients' and relatives' satisfaction; and
- (3) to investigate ethnic differences in satisfaction with services.

METHOD

Ninety-three patients with a first-onset psychosis who lived in a defined psychiatric catchment area in North London were recruited over a 12-month period from July 1991 (King et al, 1994). The majority of these patients were able to complete ques-

tionnaires relating to various aspects of their illness. The patients and their relatives were contacted again and interviewed as near as possible to the first anniversary of their initial contact with psychiatric services. A service satisfaction questionnaire (PSQ) was designed to explore patients' satisfaction with the psychiatric service and treatment, hospital stay and staff-patient interaction. The same questionnaire was modified (RSQ) for carers, usually a relative. The questionnaires contained a range of statements, negative and positive, relating to various aspects of care. A five-point Likert scale enabled respondents to indicate their strength of feeling concerning each item. The data were then transformed to give appropriate satisfaction scores. Thus, scores ranged from 1 to 5, with strong agreement with a positive statement or strong disagreement with a negative statement denoting high satisfaction (score=5). For the purposes of analysis we took a rating of three or more on any item as an indicator of positive satisfaction.

Relatives were also given the Family Service Satisfaction Scale (FSSS; Grella & Grusky, 1989), a standardised scale for the assessment of carers' satisfaction with aftercare services. In this scale relatives were asked about:

- (1) how much information they received about their family member's illness;
- (2) assistance received in finding community care services:
- (3) amount of information received about how to cope with crises involving their family member;
- (4) extent of contact with staff treating the patient;
- (5) understanding received about their own problems with the client; and
- (6) participation in the patient's treatment programme.

The respondents were invited to rate each of the six items on a four-point Likert scale (1, none; 2, very limited; 3, some but not as much as I wanted; 4, all that I wanted).

In order to minimise the likelihood of social desirability bias, all respondents were guaranteed anonymity and assured that the interviewers were not involved in any aspect of clinical treatment.

Analysis

Because of the relatively small sample sizes it was not possible to employ a principal-components analysis to the data to extract a manageable number of coherent factors.

Related items were grouped on face validity and tested for unidemensionality using Chronbach's alpha. Four main domains of care were established for patients and relatives:

- (1) helpfulness of psychiatric care;
- (2) information and advice;
- (3) humane qualities of staff;
- (4) hotel aspects of hospital.

The items comprising the domains were very similar for both patients and relatives, with minor variation. The alpha coefficient for these factors ranged from 0.72 to 0.86. Single items that did not appear to belong to any factor but were nevertheless considered meaningful were analysed separately, as were items of particular interest in their own right. Internal reliability of the FSSS was 0.90.

Demographic and other relevant data collected in the first-onset study were also used in the analysis (King et al, 1994; Cole et al, 1995). The data were analysed using SPSS/PC, version 5.1 for Windows. Differences in proportions of respondents in each category were tested for significance with the Chisquare test. The Mann-Whitney *U*-test for two independent samples was used to examine differences in scale scores between groups.

Sample

Sixty-eight (73%) of the original 93 patients were seen at the one-year stage. Of these, 59 were able to complete the PSQ. A close informant, usually a relative, was traced for 71 patients. In the remaining 22 cases, the patient either had no relative or their relatives lived abroad. Ten of the 71 relatives refused to participate, four relatives felt unable to comment on service provision but two relatives could not complete because of language difficulties. Fifty-five

(77%) of a possible 71 relatives completed the RSQ. There were no statistically significant differences in age, gender, marital status or ethnicity between respondents and nonrespondents. Because of the small numbers in each ethnic group, the sample has been dichotomised into Black (comprising the Office of Population Censuses and Surveys categories of Black-African, Black-Caribbean and Black-other) and other groups.

RESULTS

Satisfaction with items relating to health care is shown in Table 1. For ease of presentation, only 10 items are shown, indicating the areas of highest and lowest satisfaction for patients and relatives.

Although a high proportion of patients who were admitted, and their relatives, expressed approval of the hospitalisation itself, patients and their relatives were dissatisfied with aspects of information given by staff concerning the illness and what to do in the event of a further crisis (Table 1). Information received from doctors about the illness attracted the lowest approval rating of all items; only 12% of patients and 4% of relatives felt that they had been given enough information (Table 1). Less than one-quarter of relatives felt that they had been given sufficient information about what to do in the event of a crisis. Forty-eight per cent of relatives (26 of 54) and 51% of patients (30 of 59) felt that they received help quickly enough at the onset of the illness.

Individual items regarding the humane qualities of the staff, such as courtesy, friendliness and sympathy, attracted high satisfaction scores by patients and their relatives (Table 1).

Ward environment

Areas of low satisfaction for patients overall were items such as privacy on the ward, activities in hospital and contact with nursing staff (Table 1).

Patients and relatives

Nine individual items, which appeared to show the widest scoring differences between patients and relatives, were examined using the Mann-Whitney U-test. Five of these items showed the relatives to be significantly less satisfied than the patients: amount of time spent talking with the doctors (relatives n=55, median=2, range=3; patients n=59, median=2, range=4; U=1229, Z=-2.33, P=0.02); doctors explained treatment (relatives n=55, median=2, range=4; patients n=59, median=4, range=4; U=973.5, Z=3.8, P=0.0001); doctors were sympathetic and understanding (relatives n=55, median=4, range=4; patients n=59, median=4, range=4, U=1232, Z=-2.53, P=0.01); and information given on future crisis (relatives n=52, median=2, range=4; patients n=59, median=3, range=4, U=1011, Z=-3.20, P=0.001).

Factors associated with satisfaction

Patients

Those patients who were born abroad were significantly more satisfied on each of the four domains of care than patients born in Britain (Table 2). Patients on a Section of the Mental Health Act were generally less satisfied than voluntary patients and this was significant for the domain 'helpfulness of psychiatric care'. Age, gender and diagnosis (certainty of schizophrenia) were not related to satisfaction with care.

Table I Patients' and relatives' satisfaction with services

Item	Patients satisfied (%)	Mean score (s.d.)	Item	Relatives satisfied (%)	Mean score (s.d.)
Approval of hospitalisation	88	3.9 (1.0)	Approval of hospitalisation	74	3.7(1.2)
Ward clean and tidy	79	3.8(1.0)	Nurses: friendliness	74	3.6 (0.85)
Nurses: practical help	77	3.7 (0.77)	Doctors: respect	73	3.7(1.0)
Doctors: sympathetic	76	3.8 (0.82)	Sufficient nurses	73	3.3 (0.87)
Doctors: respect	76	3.8 (0.88)	Efficacy of medication	72	3.6(1.1)
Doctors: time talking to patients	31	2.6(1.1)	Nurses: time talking to patients	23	2.6(1.1)
Nurses: time talking to patients	28	2.6(1.2)	Information on possible crisis	23	2.2(1.3)
Privacy on ward	24	2.5(1.1)	Activities for patients	22	2.4(1.2)
Activities for patients	19	2.4(1.0)	Doctors: time talking	18	2.1 (1.0)
Information about illness	12	2.0 (0.88)	Information about illness	4	1.6 (0.74)

Table 2 Patients' satisfaction with services

	Information and advice (score 1–5 on 9 items; α=0.80)			Humane aspects (score 1–5 on 9 items; α =0.80)			Hotel aspects (score 1–5 on 9 items; α=0.80)				Helpfulness of psychiatric care (score 1–5 on 9 items; α=0.80)					
•	n	Median	Range	U	n	Median	Range	U	n	Median	Range	U	n	Median	Range	U
Born abroad	16	3.6	2.1	122**	15	4.0	2.0	118**	15	3.6	2.0	142**	15	4.0	1.3	151*
British-born	33	2.8	2.8	133**	32	3.6	2.8	118**	31	3.2	2.4		32	3.8	3.0	
Aged 16–29	29	3.3	2.4		28	3.6	3.6	0.15	27	3.6	2.2	202	28	4.0	3.0	2.42
Aged 30–54	30	3.0	2.3	249	19	3.6	3.1	265	19	3.2	2.3	203	19	4.0	3.0	248
Male	25	3.2	2.0		23	3.6	3.2		17	3.4	2.1		23	4.0	4.0	
Female	24	3.3	2.8	257	24	3.6	3.4	269	29	3.3	3.0	235	24	4.0	3.0	243
Sectioned	17	2.8	2.2		17	3.6	1.6		17	3.2	1.3		17	3.7	1.7	
Not sectioned	32	3.3	2.4	201	30	3.6	3.6	220	29	3.4	3.0	200	30	4.0	3.0	158*
Schizophrenia	24	3.1	2.2		23	3.6	3.4		22	3.5	2.9		23	4.0	3.0	
No schizophrenia	25	3.3	2.8	252	24	3.6	2.4	267	24	3.3	2.1	263	24	4.0	2.0	211
Black	15	2.8	1.9		16	3.6	3.4		15	3.6	1.7	165	16	4.0	2.0	
Other	34	3.3	2.8	229	31	3.6	3.2	236	31	3.3	2.9		31	4.0	3.0	236

^{*}P < 0.05, **P < 0.01.

Relatives

Relatives of sectioned patients were significantly less satisfied than relatives of voluntary patients on two domains: 'advice and information' and 'humane qualities of staff' (Table 3). Relatives of patients given a diagnosis of schizophrenia were significantly less satisfied with the domain 'helpfulness of psychiatric care' than relatives of non-schizophrenic patients were. No other differences between relatives were detected on the four domains of care.

Global satisfaction

Combining the four domains of care, the mean PSQ score for all patients was 2.72 (s.d.=0.39). The mean RSQ score for all relatives was 3.2 (s.d.=0.6).

Family Services Satisfaction Scale

The mean FSSS score for all items was 1.73 (s.d.=0.9), indicating low satisfaction with after-care services. Relatives of involuntary patients were significantly less satisfied with services (Table 4).

Black patients

No significant differences were found between Black and other patients in any of the four domains of care. On individual items, no difference in scoring was found between Black and other patients in their attitude towards helpfulness of medication (P=0.5). Sixty-eight per cent (13 of 19) of the Black patients and 72% (28 of 39) of other patients felt that medication had been helpful. Black patients (n=20) were as satisfied as other patients (n=39) on the item concerning the ability to get help quickly when they became ill (P=0.8).

Relatives of Black patients

Relatives of Black patients were significantly more satisfied than other relatives with the hotel aspects of care (Table 3). On individual items of interest; 68% of relatives of Black patients (13 of 19) agreed with the proposition that medication had been helpful to the patient, compared with 74% (26 of 35) of other relatives (P=0.6). Forty-seven per cent (nine of 19) of the relations of Black patients agreed that they had received help quickly enough at the beginning of the illness, compared with 49% (17 of 35) of other relatives (P=0.8).

On the FSSS, relatives of Black patients were less satisfied than other relatives, but this did not reach statistical significance (*P*=0.1). On two of the six items, however, the relatives of Black patients were more likely to answer 'none' than other relatives. First, when asked about the amount of assistance received in finding community care services,

74% (14 of 19) of the relatives of Black patients replied 'none', compared with 41% (13 of 32) of other relatives (OR=4.1, CI 1.03–17.8, P=0.02). Second, asked about their ability to participate in the patient's treatment programme, 75% (15 of 20) of the relatives of Black patients answered 'none', compared with 47% (16 of 34) of other relatives (OR=3.4, CI 1.0–14.4, P=0.04).

DISCUSSION

Previous satisfaction research has been criticised for reporting implausibly high satisfaction scores with little variation (Lebow, 1982). It may be, however, that patients and their relatives are reluctant to criticise services upon which they are so dependent. The present findings suggest that respondents give positive satisfaction ratings for general statements, for example, the personal qualities of hospital staff, but more variable responses to specific items such as advice on treatment, information about the illness, ability to get speedy help, privacy and activities on the ward.

Information

The issue of information-giving by staff is an important but complex one and this is not the first study to raise it. Thompson (1993) commented that "information and

Table 3 Relatives' satisfaction with services

	Information and advice (score 1–5 on 9 items; α=0.80)			Humane aspects (score 1–5 on 9 items; α =0.80)			Hotel aspects (score 1–5 on 9 items; α =0.80)				Helpfulness of psychiatric care (score 1–5 on 9 items; α =0.80)					
	n	Median	Range	U	n	Median	Range	U	n	Median	Range	U	n	Median	Range	U
Born abroad	18	2.9	2.1	207	19	3.6	2.5	202	15	3.3	2.6	144	16	3.9	3.0	214
British-born	33	2.5	2.8	207	33	3.6	2.8	302	28	3.0	2.2	164	28	3.9	3.5	
Aged 16-29	31	2.6	2.8	204	31	3.7	3.1	200	25	3.2	2.8	221	25	3.7	3.5	100
Aged 30–54	20	2.7	2.6	294	21	3.6	2.0	289	18	3.2	2.0	221	19	4.1	3.2	189
Male	25	2.7	2.4	2	26	3.7	2.5	201	20	3.1	2.8	210	21	4.0	3.2	212
Female	26	2.6	3.2	311	26	3.5	2.8	301	23	3.2	2.0	218	23	3.8	3.2	210
Sectioned	18	2.4	2.1		19	3.4	2.7	2.7 2.8 213*	17	3.3	2.5	183	19	3.9	3.0	210
Not sectioned	33	2.8	2.8	190*	33		2.8		26	3.0	2.1		25	3.9	3.5	
Schizophrenia	34	2.6	2.4		35	3.7	2.1		30	3.1	2.2		31	3.7	3.2	
No schizophrenia	17	2.9	2.8	239	17	3.5	3.1	285	13	3.2	2.6	167	13	4.4	2.1	117*
Black	18	2.6	2.4	270	17	3.7	2.2	202	15	3.5	1.5	1246	15	3.7	3.0	186
Other	33	2.7	2.7	278	35	3.6	283	283	28	3.0	2.8	134*	29	4.0	3.2	

^{*}P<0.05.

communication clearly affect the whole process of hospital care from pre-admission to post-discharge". Bruster et al (1994), in a nationwide survey of 5150 National Health Service patients, highlighted communication with staff as a major problem, with patients often not being given information relating to the condition, treatment, hospital routine, and important aspects of post-discharge care.

Although patients and relatives alike may complain that insufficient information is provided by staff, unfortunately there are no objective criteria by which informationgiving by staff can be assessed. It is usually the case, however, that information is provided in an informal, ad hoc way and is not the remit of any one person or profession. Unfortunately, diffuse responsibility may be no responsibility at all. Furthermore, not all patients and relatives seek advice or information and staff may wrongly conclude that none is required. Also, the unpredictable and individualistic nature of severe psychiatric disorder may limit the amount of information that can be given during one treatment episode.

The results of the FSSS should be of concern to service planners. With the advent of care in the community, relatives are increasingly relied upon to shoulder more responsibility for the care of people suffering with severe mental distress. While this

demands a stronger partnership between professional and lay carers, paradoxically the carers are being excluded from decisionmaking and discharge-planning and further denied the advice and information vital in helping them cope with a sick relative. This is not merely distressing and unhelpful for relatives, but also is an opportunity missed and one that is likely to have a negative impact on the relapse rate of patients and their access to psychiatric care. The effects of relatives' behaviour on schizophrenia has been considered in the work on expressed emotion (Leff et al, 1982). It has also been shown that the provision of educational and psychological support to relatives has a positive effect on relapse rates (Berkowitz et al, 1990). As Kuipers & Bebbington (1985) point out, however, the acknowledged importance of the relatives' role seems to have produced little change in clinical practice. Whether or not the introduction of the Care Programme Approach (Department of Health, 1990), which provides a greater consultative role for relatives, produces more satisfying results remains to be seen.

Place of birth

The most significant variable in determining patient satisfaction was place of birth. Those patients born outside of Britain consistently produced higher satisfaction scores than British-born patients, regardless of ethnicity. Those patients born abroad, including refugees, were from countries with poor or non-existing welfare services. Higher satisfaction scores in this group may be a reflection of lower expectations about service provision than in the British-born group.

Ethnicity and satisfaction

Reports of higher incidence rates of schizophrenia for Black people living in Britain,

Table 4 Family Service Satisfactions Scale score (6–24 on 6 items)

	Relatives score								
	n	Median	Range						
Black	19	8	13						
Other	32	9	18						
British-born	32	8	18						
Born abroad	19	9	18						
Voluntary	35	9	18*						
Involuntary	16	7	13						

^{*}P=0.05, Z= - 1.936, U=185 on Mann-Whitney U-test.

especially Afro-Caribbeans, have generated considerable debate concerning issues of (Fernando, misdiagnosis 1991) unsound research methods (Sashidharan, 1993). Various authors also report widespread inequalities based on ethnicity in the provision of psychiatric services (Francis et al, 1989). As a result, the relationship between psychiatry as an institution and Black people has, in recent years, become heavily politicised. This simplifies and obscures a complex set of interactions which span racism, class and culture, the media and the legal system. In a previous paper, in which we found few differences in the experiences of individuals from different ethnic groups en route to psychiatric care (Cole et al, 1995), we attempted to address some of these issues. The present study seems to confirm that, at least in the initial stages of treatment, there is considerable similarity among patients and relatives of different ethnicities in their experiences and perceptions of psychiatric care.

Of some concern, however, is the trend for relatives of Black patients to be less satisfied regarding aspects of after-care, which might indicate greater problems in coping with a sick family member and/or inadequate support from psychiatric services. This lends weight to our hypothesis (Cole et al, 1995) that the relationship between psychiatric services and Black patients and their carers begins to deteriorate over time, increasing the risk of involuntary admission into hospital, which, in itself, has a negative impact on satisfaction with care.

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LIMITATIONS

- The incidence of psychotic illness is rare in the community; even though we were able to achieve high response rates for a satisfaction survey, studies such as ours suffer from a lack of statistical power.
- The question of information-giving by hospital staff is complex. This study would have benefited from a more detailed examination of how, why and what sort of information and advice is sought, offered or denied.
- A more in-depth approach is necessary to understand how, from the consumer's perspective, psychiatric services could be made more acceptable.

CLINICAL IMPLICATIONS

- Every effort should be made by psychiatric services to include and support relatives from the very beginning of the patient's treatment.
- Lower satisfaction with after-care services among carers of Black patients may indicate greater problems in coping with a sick relative. The needs of this group require further understanding and additional support.
- The importance of information-giving to patients and relatives should not be underestimated. A more structured approach should be adopted.

GERARD LEAVY, BSc, Research Department, St Ann's Hospital, London; MICHAEL KING, MD, University Department of Psychiatry, Royal Free Hospital School of Medicine, London; ELEANOR COLE, MRCPsych, AMANDA HOAR, MRCPsych, ERIC JOHNSON-SABINE, MRCPsych, Research Department, St Ann's Hospital, London

Correspondence: Gerard Leavey, Research Fellow, Research Department, St Ann's Hospital, St Ann's Road, London NI5 3TH

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