Needs for care from a demand led community psychiatric service: a study of patients with major mental illness

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Abstract

Objective—To measure needs for care of patients aged 18-65 years with major mental illness.

Design—Identification of everyone in one area seen by a health professional within the previous five years because of a psychotic disorder. Interview of a one in three sample of patients and their main carers with the cardinal needs schedule.

Setting—Hamilton, a socially deprived district of Scotland.

Subjects—71 subjects were interviewed from the original sample of 263 patients.

Main outcome measures—"Cardinal problems" in seven clinical and eight social areas of functioning; these are defined as problems requiring action. "Needs"—cardinal problems for which suitable interventions exist but have not been tried recently.

Results—High levels of morbidity were found. 30 interviewed patients (42%; 95% confidence interval 31% to 54%) had one or more clinical needs. 35 (49%; 38% to 61%) had one or more social needs. Skills to deal with all but seven needs in the sample were available at the time of investigation. Patients not being seen by the community mental health team were similar in severity and levels of need to those who were on the community team's caseload. Care was unequivocally and severely inadequate for four patients. Shortcomings in service delivery usually arose from failure to monitor some patients at home. Problems were not due to shortage of acute psychiatric beds nor the absence of an elaborate assertive community care team.

Conclusions—Systematic assessment of needs with research instruments can give valuable insights into the successes and failures of community care of people with major mental illness. Most needs could be dealt with in these patients but in our area (and probably most other parts of the United Kingdom) this would entail diversion of resources from people with less severe disorders.

Introduction

A vigorous debate is taking place between those who maintain that reductions in the numbers of hospital beds are leading to neglect of people with severe and enduring mental disorders^{1,2} and those who remain enthusiastic about treating even the most ill patients within the community.³⁻⁵ Both sides can easily find support for their views. Many destitute homeless people are mentally ill, with a prevalence of 30% to 70% in recent studies.⁶ Self harm and infrequent violence towards others have been widely publicised,^{7,8} and individual tragedies have sometimes exposed major deficiencies in systems of care.⁷⁻⁹ On the other hand, most mentally ill people prefer to live outside hospital,^{10,11} and they and their relatives seem to prefer good quality services from

24 hour community teams, even during acute relapses.⁸ With appropriate help there need be no drift into homelessness.¹⁰ Also, community neglect still has its counterpart in the scandalous conditions in back wards of some British mental hospitals.^{12,13}

Everybody accepts that prolonged institutional care is unnecessary for nearly all patients. Controversy revolves around how to ensure a balance between hospital and community care, based on the needs of people with serious mental illness. Success with this task depends on availability of local and national data to guide policy makers.¹⁴

The cornerstone of community care, as envisaged in the NHS and Community Care Act 1990,¹⁵ is the assessment of the needs of individual patients, which will then be dealt with by health and social service providers. This apparently straightforward approach turns out to be very difficult to conceptualise, research, and put into practice.¹⁶ There is no uniformly accepted understanding of what constitutes a need and often a failure to differentiate needs for care, demands for care, and its supply. We have defined a need as a problem which requires action for which there is a suitable intervention which has not been tried recently.^{17,18}

The few research studies of the needs of people with major mental illness have not examined representative groups of patients.¹⁹ In our area we have had no systematic method for assessment of needs and no means of monitoring patients who may have become lost to follow up by the psychiatric services. As part of planned improvements in our service we established a study of needs for care of all adults under the age of 65 years with identified major mental illness.

Patients and methods

STUDY AREA

The investigation was carried out in the Hamilton district of Lanarkshire, Scotland. The total population in 1991 was 80 380 with about 45 400 aged between 18 and 65; it has scored as the 10th most socially deprived district in Scotland.²⁰ Until recently, psychiatric services throughout Lanarkshire were dominated by Hartwood Hospital, a huge isolated Victorian asylum, which is being rapidly run down. There is now a mix of NHS, social work, and non-statutory services (box), although Hamilton was still underresourced compared with recommended levels and national averages at the time of data collection (June 1993 to June 1994). A multidisciplinary community mental health team, which works during office hours, was established in 1992. It has had an explicit remit to give priority to the treatment of major mental illness. One consultant session a week is earmarked for meetings with the team but the community staff contact the senior medical staff whenever necessary.

STUDY GROUP

Subjects were aged 18-65 years, had an address in Hamilton between 1 June 1993 and 31 May 1994, and

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Main psychiatric services for 18-65 year old people in Hamilton district

- Notional acute beds in the local district general hospital (22 beds)
- Notional intensive psychiatric care beds at the Hartwood site (4)
- Rehabilitation beds (6.8)
- Long stay beds (11)
- Beds for young people with organic psychiatric disorders (3.2)
- High dependency places (4.7)
- Supported tenancies (independent sector) (6.8)
- Psychiatric day hospital
- Community mental health team

had received professional attention for a psychotic illness at any time in the previous five years. Psychotic illness was operationally defined as any of the following diagnostic categories from the *Diagnostic and Statistical Manual of Mental Disorders*, third edition, revised (DSM-III-R)²¹: depressive disorders with psychosis; hypomania, mania, bipolar disorder, mania with psychosis, bipolar disorder with psychosis (grouped as bipolar affective disorders in table 1); schizoaffective mania, schizoaffective depression, and schizoaffective bipolar disorders (schizoaffective in table 1); schizophrenia; schizophreniform and delusional disorders; and atypical psychosis. As this study was concerned with people in the community we excluded patients in the long stay and rehabilitation wards (19 of whom had a psychotic illness and an original address in Hamilton) and those who lived in the local hospital for people with learning disabilities. People with mild learning disabilities in the community fulfilling the above inclusion criteria were investigated.

Potential subjects were identified by trawls through hospital records, community nursing Kardexes, daily nursing returns, all appointment diaries, and a clinic database. Routinely collected admission and discharge

Table 1—Sociodemographic characteristics in 71 interviewed subjects with major mental illness

Characteristic	No (%) of patients
Living with:	
Partner	25 (35)
Alone	16 (22)
Parents	11 (15)
Siblings	5 (7)
Other relatives	5 (7)
Bed and breakfast hostel	2 (3)
Hospital	2 (3)
Supported accommodation or nursing home	5 (7)
Marital status:	
Single	29 (41)
Married or cohabiting	25 (35)
Divorced or separated	14 (20)
Widowed	3 (4)
Employment:	
Unemployed	49 (69)
Voluntary work	2 (3)
Part time paid work	1 (1)
Full time paid work	5 (7)
Training course or college	2 (3)
Housewife (involved in child care)	12 (17)
DSM-III-R diagnoses:	
Schizoaffective	3 (4)
Depressive disorders with psychosis	10 (14)
Bipolar affective disorders	15 (21)
Schizophrenia	29 (41)
Schizophreniform and delusional disorders	4 (6)
Atypical psychosis	10 (14)
Mean (range) age (years)	43 (18-65)

data for 1988-93 with the relevant diagnoses were supplied by the information services division of the Scottish Office. Any suggestion of psychotic symptoms led to further consideration of suitability for inclusion (see below). The 15 local general practices were contacted with the names of patients with psychosis on their lists whom we had identified. Five practices knew of no additional patients meeting our criteria. Twenty patients possibly meeting inclusion criteria were known to seven other practices, but we were not given their names to protect general practitioner-patient confidentiality. Three general practices did not provide further information.

Case notes were examined by the research psychiatrist using OPCRIT,²² which generates diagnoses according to several different classifications including the DSM-III-R system. A one in three sample of those meeting inclusion criteria was derived by using computer generated random numbers. These patients were asked to participate in an interview only if their psychiatrist, community psychiatric nurse, or general practitioner considered that contact would not jeopardise clinical management.

INTERVIEW PROCEDURE

The cardinal needs schedule^{17 23} was administered to patients and their main carer (relative or close friend in 56%; community psychiatric nurse or other key worker in 30%; no carer available for 14%). The schedule comprised five scales.

The first scale, REHAB,²⁴ is a standardised behaviour scale which rates living skills, such as communication and self care (general behaviour), and the frequency of disruptive behaviours such as violence, self harm, and shouting (deviant behaviour). Some questions were altered for use in community settings (details available from the authors). The second was the Manchester scale, a standardised rating for psychiatric symptoms²⁵; the third was the client opinion questionnaire, a structured questionnaire which elicits the patient's views on current need; and the fourth was the carer stress questionnaire, a structured questionnaire which elicits problems encountered by the main carer in helping the patient. Finally, we used the additional information schedule, a structured assessment which collates information from the case notes and the carer on medical history, forensic history, and other relevant clinical factors. The last three scales were specifically developed for the cardinal needs schedule.^{17 23}

These instruments together determine whether problems are present in seven clinical and eight social domains of functioning (listed in table 2). These become cardinal problems (a problem requiring action) if one, two, or three of the following criteria are met. Firstly, the patient is willing to accept help for the problem (the cooperation criterion); secondly, people caring for the patient are experiencing severe anxiety, annoyance, or inconvenience as a result of the problem (the caregiver stress criterion); and, thirdly, the nature and severity of the problem is such that the patient's health and safety or the health and safety of others is at risk (the severity criterion).

Criteria for deciding on the presence of a cardinal problem are not applied uniformly for each area of functioning. For example, someone who could not use community facilities such as libraries, sports centres, or public transport would not have a cardinal problem in this area if they did not want help. On the other hand, dangerous or destructive behaviour becomes a cardinal problem on the basis of severity, so that people who are behaving dangerously will receive an intervention even if they would not choose this.^{17 23}

For each area of functioning the outcome for a cardinal problem must be one of the following: a need—a

Fig 1—Explanation of decision making process in cardinal needs schedule

cardinal problem for which a suitable intervention exists but which has not been given a recent adequate trial; a suspended need—a cardinal problem for which a suitable intervention exists and this is currently under way; and a placement failure—a cardinal problem for which all suitable interventions have been tried and failed. This is summarised in figure 1.

Results

A total of 263 people (124 men and 139 women) met the inclusion criteria. Their mean age was 44.2 years. DSM-III-R diagnoses were as follows: schizoaffective 28 patients (11%), depressive disorders with psychosis 38 (15%), bipolar affective disorders 58 (22%), schizophrenia 98 (37%), schizophreniform and delusional disorders 9 (3%), and atypical psychosis 32 (12%).

There were 87 people (46 men, 41 women) in the one in three sample. Their mean age was 42.9 (range 19–65) years. Patients with schizoaffective disorders were underrepresented compared with the original group (4% v 11%), but otherwise the groups were similar.

Seventy one patients (82%) were interviewed. Of the remainder, three (3%) had moved out of the catchment area before the study year; one (1%) who had previously cooperated with treatment had gone to England unexpectedly and could not be contacted; three (3%) were too ill to give informed consent or it was deemed clinically detrimental to approach them; seven (8%) declined to participate; and two (2%) had died (probably suicide) unknown to anybody in the psychiat-

ric services. Table 1 outlines the sociodemographic and diagnostic details of the 71 interviewed subjects.

CURRENT PSYCHIATRIC SYMPTOMS AND BEHAVIOUR PROBLEMS

Scores of two or more on the Manchester scale indicate clinically relevant symptoms. Thirty nine subjects (55%; 95% confidence interval 43% to 67%) had clinically relevant anxiety or depression, or both; 32 (45%; 33% to 57%) had relevant negative symptoms of psychosis (psychomotor retardation, blunting of affect, or poverty of speech); and 35 (49%; 38% to 61%) had positive psychotic symptoms (hallucinations, delusions, or incoherence of thought). Six people had experienced suicidal ideas in the week before the interview. The mean REHAB score for general behaviour was 26.3 (20.6 to 32.0; range 0–83). Four (6%) scored above 70. Under REHAB guidelines, if those people were on a long term ward it would be doubtful that they could ever live in the community. One of these four high scorers lived in a staffed setting, two lived with relatives, and one lived alone. A further 13 (18%) scored between 51 and 70, indicating that they would probably need supervision if they lived in the community. One of these patients lived alone, two lived in staffed settings, and 10 lived with relatives. On the deviant behaviour scale 18 subjects (25%; 15% to 35%) scored 1 or above, indicating some disturbing behaviour in the previous week.

OUTCOME OF NEEDS ASSESSMENT

Table 2 shows the main results for clinical needs and for social needs. Needs in each clinical and social domain have been summed for individual patients. Forty one (58%; 46% to 69%) had no clinical needs; 21 (30%) had one such need; seven (10%) had two clinical needs; one (1.4%) had three; and one had four clinical needs. Thirty six patients (51%; 39% to 62%) had no need in the social domains, 21 (29%) had a need in one domain, 12 (17%) had needs in two social domains, and two patients (3%) had needs in three social domains. With a few exceptions (indicated in the table) the skills and the staff to deal with the identified needs were locally available. Some interventions, however, were never being used.

Valuable information was also provided by suspended needs (indicating ongoing work attempting to deal with a need) and placement failures (where all suitable interventions have been tried and failed). Thirty six people

Table 2—Clinical and social outcomes

Area of functioning	Objective problem	Cardinal problem	Suspended need	Placement failure	Need (description)
Clinical outcomes					
Psychosis	24	14	0	6	8 (5 for domestic visits; 3 for psychiatric assessments)
Side effects	47	29	0	21	8 (3 for medication; 5 for psychiatric assessment)
Anxiety or depression	39	27	11	0	16 (4 for medication; 4 for psychological intervention*; 4 for a structured programme; 3 for support; 1 for psychodynamic psychotherapy*)
Self harm or violence	10	7	1	1	5 (3 for structured programme; 1 for psychiatric assessment; 1 for medication)
Organic disorder	4	3	0	2	1 (for specialist investigation)
Health	18	13	4	6	3 (2 for specialist assessments; 1 for advice on mechanical aids)
Challenging behaviour	17	3	2	0	1 (for medication)
Social outcomes					
Domestic skills	40	13	4	4	5 (2 for remedial training; 1 for a home help; 2 for specialist assessment)
Finance and welfare	22	5	5	0	0
Transport and amenities	26	4	1	0	3 (for remedial training)
Literacy	6	2	0	0	2 (1 for detailed assessment; 1 for remedial training)
Work	64	14	5	0	9 (5 for voluntary work; 2 for paid work; 2 for job coaching*)
Social life	53	31	9	2	20 (6 for structured daytime activity; 5 for community social activity; 5 for social stimulation programme; 3 for sheltered leisure; 1 need for coping advice for patient)
Hygiene and dressing	11	6	4	2	0
Accommodation	N/A	N/A	N/A	N/A	11 (5 for move to a flat; 3 for move to similar accommodation to present; 1 for move to a nursing home; 1 for move to a staffed home; 1 for move to unstaffed group home)

*These interventions were not routinely available to the Hamilton services at the time of the investigation.

Note: a cardinal problem must have one of three outcomes, therefore the number of cardinal problems = need + suspended need + placement failure.

Table 3—Comparison of patients on or not on community team's caseload. Figures are numbers (percentage) of patients unless stated otherwise

Detail	Community cases (n = 33)	Not community cases (n = 36)	Differences in percentages/means (95% confidence interval)	Significance
Mean age (years)	42.2	43.4	1.2(−4.3 to 6.7)	$t = 0.43$; $P = 0.7$
Number of men	19 (58)	18 (50)	8%(−16 to 31)	$\chi^2 = 0.4$; $P = 0.5$
Depression or anxiety, or both, present	16 (48)	21 (58)	−10%(−33 to 14)	$\chi^2 = 0.67$; $P = 0.4$
Positive symptoms present	21 (64)	13 (36)	28%(5 to 50)	$\chi^2 = 5.2$; $P = 0.02$
Negative symptoms present	14 (42)	17 (47)	−5%(−28 to 19)	$\chi^2 = 0.16$; $P = 0.7$
Number on depot medication	20 (61)	12 (33)	27%(5 to 50)	$\chi^2 = 5.1$; $P = 0.02$
Mean REHAB deviant behaviour score	0.39	0.44	−0.05(−0.48 to 0.38)	$t = 0.23$; $P = 0.8$
Mean REHAB general behaviour score	27.9	23.7	4.2(−7 to 15.5)	$t = 0.74$; $P = 0.46$

had no social needs; two of them had placement failures and eight had suspended needs, leaving 26 people with no problems requiring intervention. Although 41 people had no clinical need, there were only 13 who had no problems requiring intervention; six had suspended needs and 22 had placement failures. This last figure reflects the often intractable nature of mental illness and highlights one of the difficulties underlying assessments of needs—many people suffer symptoms and disabilities not amenable to current therapeutic interventions. No need does not imply there is no morbidity. All outcomes of the assessment of needs must be taken into account to avoid misleading conclusions. When considering other studies which have used different methods of assessing needs, the reader should be aware that the equivalents of placement failures and suspended needs may be obscured within the data.

COMPARISON OF PATIENTS ACCORDING TO CARE BY COMMUNITY TEAM

Thirty three patients (48%) were and 36 were not on the caseload of the community team (two inpatients were excluded from the following analyses). Of those not on the team's caseload, 22 had been seen within the previous three months by a consultant or trainee psychiatrist. As shown in table 3, the two groups were largely similar, although clinically relevant positive symptoms were more common in the patients under community care, who were also more likely to be taking a depot neuroleptic medicine. Also, patients not under community care showed a trend to higher numbers of clinical needs. In a comparison of patients on the caseload of the community team and those not on the caseload 21 (64%) v 19 (53%) had no clinical needs; 11 (33%) v nine (25%) had one clinical need; and one (3%) v six (17%) had two such needs. None of the community care patients had more than two clinical needs, but one not under community care had three and another had four clinical needs (χ^2 test for trend = 3.55, $P = 0.06$). The two groups were similar in regard to social needs (numbers of community team v non-community team patients with zero, one, two, and three needs were 17 (52%) v 20 (56%), 8 (24%) v 12 (33%), 8 (24%) v 2 (6%), and 0 v 2 (6%), respectively; χ^2 test for trend = 0.33, $P = 0.56$).

SEVERE INADEQUACIES OF CARE

In our opinion, care was very seriously inadequate for four interviewed subjects. One had been doing very well two years previously and was discharged from follow up by the community team. He then stopped attending the psychiatric outpatients clinic. The research workers were the first mental health professionals to be in contact for about two years, and they elicited florid psychosis with extremely distressing hallucinations. One patient had severe self neglect at home. Another had not been visited at home

after failing to attend outpatient clinic appointments; there were, once again, severe untreated psychotic symptoms. The consultant psychiatrist had given in to a fourth patient's insistence that there should be no further home visits, but this left the family unsupported in dealing with a severe psychotic illness.

Discussion

The cardinal needs schedule accurately reflected our clinical impressions and has already guided local practice. There was no evidence that failures to deal with needs arose from insufficient acute hospital beds or the lack of an elaborate community treatment team with 24 hour care. Indeed, it became clear that recent debates on hospital versus community provision are essentially irrelevant for patients with major mental illness in our catchment area. Several interventions that should be part of good practice were unavailable because of longstanding difficulties in local recruitment. More frequently, needs for care were not being dealt with because approaches to evaluation, treatment, and follow up were unsystematic. Comprehensive care from the community mental health team was being provided to just under half of the outpatients in this sample. This input was not determined by patients' needs. If anything, there were higher numbers of clinical needs in patients not being seen by the community team. Some of the individual cases in this one in three sample (for example, the two possible suicides and those with severe self neglect or untreated distressing symptoms) illustrate the importance of prolonged monitoring at home for these groups of patients.

We have become aware that our clinical services have been almost entirely led by demand from patients, relatives, and referring agencies. For example, some patients with major mental illness have been discharged from the community team's caseload to allow treatment of the numerous referrals with more acute but less severe conditions. This is despite an explicit intention to prioritise people with the most severe and enduring illnesses. This problem seems to be encountered by community psychiatry services throughout the United Kingdom.^{2 26-29} Methods of rationing care to ensure priority for patients with the most severe disorders within a comprehensive service are now being developed in our area.

Many well meaning recommendations are made on how to provide an ideal community mental health service, but these often seem naive, or even Utopian, to those working outside demonstration projects.^{3 4 7 30} We would make one suggestion on the basis of the results of this health service research. Our single most important shortcoming has been the failure systematically to reassess patients who may not seek help. Clinicians and health services managers should consider providing sessional commitment from staff whose task is to carry out a rolling survey of needs of all identified patients with major mental disorders. Validated research instruments are available for epidemiological audit of this type. Severely ill patients who have not come to the attention of secondary services could also be targeted so long as there are additional safeguards of their privacy. This could help to deal with the widespread concerns about failures in community care,⁷ but it could remain separate from controversial legislative measures designed to help those most at risk of neglect and harm to themselves and others.³¹⁻³³ Clinicians, policy makers, and the general public must acknowledge, however, that no matter what monitoring mechanisms are put in place it will never be possible to prevent a small number of seriously ill people from avoiding all medical and social interventions.

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Key messages

- Assessment of needs is considered the keystone of care in the community
- A representative group of people with previously identified major mental illnesses showed high levels of distress and disability and most had one or more clinical or social needs
- Patients receiving rudimentary or no care from the psychiatric services had, on average, similar levels of disability and need to those receiving regular input from a multidisciplinary community mental health team
- Routine individual assessment of needs could deal with many of the concerns about the welfare of people with major mental illness who live in the community
- No matter what monitoring mechanisms are in place it will never be possible to prevent a small number of seriously mentally ill people from avoiding all medical and social care

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A worrying statistic

It had been a busy but gratifying year. In accordance with the desires of the new NHS trust we had laboured long and hard. Our acute geriatric unit of 96 beds had admitted a record 3500 patients that year and standards had been maintained even though it had been necessary to put some patients in surgical wards during the winter. We eagerly awaited the official analysis of performance in the hope of securing increased funding based on the improvement in performance.

The official statistics were provided by the region and these freely acknowledged our record throughput, which was recorded at 3469 patients. Bed occupancy was noted at 105%, but we were criticised strongly for having the worst performance in the region with an average length of stay amounting to 40.4 days.

As clinical director I knew that there had been some mistake. The statistics were queried, apparently checked, and again double checked but no error was found. The statistics were pronounced officially correct and my colleagues and I were told that computers do not make mistakes.

I pointed out that a simple "back of the envelope" calculation would prove the matter. If 3469 patients passed through 100 beds a year then 34.69 patients would occupy each bed a year. It was a simple step to divide the figure of 34.69 into the 365 days of the year in order to

obtain a figure for average length of stay. By this calculation a most respectable figure of 10.5 days was achieved, placing us as the most efficient unit. Alternatively, if 3469 patients had indeed stayed an average of 40.4 days we would have required 100% occupancy of 384 beds continually during that year. The incongruity of the data was lost upon officialdom who continued to support the regional statistics. Eventually the data were laboriously checked and the average length of stay finally amended to the figure of 10.8 days.

What had happened? Quite simply it was discovered that for two patients their date of birth had been erroneously recorded as the date of admission. Two octogenarians had been officially logged as each having spent 80 years as inpatients.

Fortunately this produced such a gross skewing of the results that it was obvious—eventually. I wonder whether such an error would have been noticed if we had been part of a paediatric unit. Mistakes occur but it takes a computer to produce a real monumental one—G PHILLIPS is a consultant physician in Liverpool

We welcome filler articles of up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk.