A study of 131 patients with schizophrenia and provision for them

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One hundred and thirty-one patients came to the Institute of Biological Psychiatry at Bangor, accompanied by 161 healthy blood relatives, spouses and friends. A history was taken and a diagnosis of schizophrenia was made using DSM IIIR criteria. The patients were examined to see if they had any concurrent physical disease. Venous blood samples were taken for measurements of chemical constituents believed to be involved in schizophrenia. The population of patients is described, and the views of the patients and their relatives were noted. Recommendations are made about how provision for patients might be improved.

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Introduction

Between October 1990 and March 1993, 131 patients diagnosed here as schizophrenic, accompanied by 161 healthy relatives or friends and 33 healthy subjects, came to the Schizophrenia Association of Great Britain at Bangor, Wales (Table I). Other patients who came were diagnosed as not schizophrenic, and are not discussed here. The aims of this study were:

- to establish the diagnosis, so that blood samples were examined only from patients with schizophrenia, rather than from patients with any other psychiatric, neurological or medical disease. This was to try to detect any specific biochemical lesion in schizophrenia;
- to take detailed histories, to find out if particular factors precipitated the initiation or relapse of the condition;
- to examine patients clinically to see if they had any concomitant physical disease;
- to hear from the patients and their relatives how they felt towards treatment and provision for them, and how it could be improved, if necessary;
- it also proved to be a useful exercise to survey the difficulties of research in the biological basis of schizophrenia, several of which are shared with other mental illnesses;
- finally, it was felt possible to make a number of general recommendations, designed to improve the treatment and life styles of patients with schizophrenia.

The fact that the patients, their relatives and friends, and the healthy subjects, were volunteers meant that none of the groups could be considered random samples of their populations; therefore, they could not be used for statistical studies. However, one could compare the biochemistry of the blood of the following four groups:

1 the patients who were being treated with neuroleptics;
2 the patients who were not being treated with neuroleptics;
3 the first-degree relatives of the patients;
4 the healthy control subjects, including non-blood relatives.

Some patients of group (2) did not want to be treated with neuroleptic drugs; others said that they had not taken neuroleptics for the past three months or longer.

The chemistry of the blood from the patients who met the DSM IIIR criteria for schizophrenia (American Psychiatric Association, 1987), and that from healthy blood relatives and healthy control subjects, who were not taking drugs or dietary supplements which could affect the concentration in their blood of the substances being measured, were compared. The results of the analyses of the blood samples have been published elsewhere (Ramchand *et al.*, 1992 a,b; Wei *et al.*, 1992 a,b).

Methods and procedure

The fact that the patients travelled long distances voluntarily had the effect of excluding those who were acutely or severely ill. An arbitrary but useful scale was designed to indicate the seriousness of the patients' clinical state at the time of their visit to the Association:

1 was severely ill;
2 was ill but living at home, with occasional relapses;
3 was stable, but having symptoms;
4 was capable of working part-time or working full-time;
5 was feeling well, and working full-time or retired.

These were relatively simple states on which different observers would agree.

The patients, relatives and volunteers travelled to Bangor, Wales, from all parts of the UK. They did not eat or drink (except water) from 22.00 on the day of arrival, until the blood samples were taken between 08.00 and 09.00 on the morning of the following day. They were asked to fill in forms indicating that they did not have bacterial or viral infections. They then signed consent forms for blood samples to be taken, if they fulfilled the criteria for being schizophrenic, healthy blood relatives or control subjects; some also agreed to give skin biopsies.

Samples of 20-25ml of blood were taken from the ante-cubital veins, and the blood, plasma and sera were stored, whole or separated, at

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–20°C, until analysed. The patients, relatives and subjects, were then asked to give urine samples for "Multistix" dip tests (Ames Ltd) for the presence of urobilinogen, blood, bilirubin, ketones, glucose, proteins, and approximate values for pH and specific gravity; they were then given breakfast.

Table I
Persons from whom blood samples were taken. Full histories were taken, and clinical examinations were made, only on the patients

	Number of persons	Age in years (s.d.) %
Patients meeting DSM IIIR criteria for schizophrenia	131	36.0 (11.0)
Male	92	35.7 (10.8)
Female	39	36.5 (11.2)
Healthy first-degree relatives of schizophrenic patients	144	52.6 (11.2)
Male	81	53.7 (14.1)
Female	63	50.1 (17.6)
Healthy spouses of schizophrenic patients	17	47.9 (11.6)
Male	8	51.1 (12.8)
Female	9	45.1 (9.6)
Healthy control subjects	33	37.9 (12.5)
Male	12	31.7 (8.2)
Female	21	41.4 (14.5)

A history was then taken from the patients in the presence of their relatives or friends, followed by questions designed to find out how many of the DSM IIIR criteria they fulfilled. They were asked about their general health, their family histories, the age of onset of the schizophrenia, their subjective state of health on the day they were attending, what drugs they were taking, any side effects from which they were suffering, any family history of mental disease, how much they smoked, how many alcoholic drinks they imbibed, and whether they had ever taken drugs of addiction. They were not asked whether they had been abused sexually.

They were then told that information was being sought about the current provisions for schizophrenic patients, how their general practitioners, psychiatrists, hospital nurses, community psychiatric nurses and communal organisations had helped them. They were also invited to comment on the helpfulness of (+1), the neutral assessment of (0) or the dissatisfaction with (–1) the various personnel with whom the patients and their families had been in contact. Frank and spontaneous but confidential comments were sought in an effort to understand the strengths and weaknesses of current provision for the patients. Of course, since the patients and their relatives, who had volunteered to come to the Schizophrenia Association, were not random, the opinions expressed can only be regarded as those of the more articulate schizophrenic patients and their relatives. However, it is hoped that it may be useful to publish this information as a guide to how the "consumers" of the services for schizophrenic patients perceive the provisions, and how they would like to see them improved. Nevertheless, one has to bear in mind that some of the patients' complaints arose from the nature of their illness. The patients were always interviewed in the presence of relatives or friends, whenever they were accompanied.

All patients, but not the relatives or control subjects, were then given a simple clinical examination, to find out if they had concurrent physical disease. Their vision, blood pressures, temperatures, heights and weights were also measured. At the time when they visited the Association, three of them were in-patients, three were not being, and had never been, treated by a psychiatrist, but all the rest were having psychiatric treatment, mostly with neuroleptic drugs. No treatment or advice about treatment was given to them, but general advice was proffered (Appendix 1).

Skin biopsies were taken only from patients and healthy control subjects. The forearm skin was anaesthetised by injection of 0.5ml of 1 per cent xylocaine subcutaneously, and a 4mm diameter punch sample was taken. The intention was to grow fibroblasts and keratinocytes in tissue culture, to see if any biochemical abnormalities present in the brains of schizophrenic patients might also be found in their fibroblasts and keratinocytes grown in tissue culture (Giller, 1980; Grosshong *et al.*, 1978; Mahadik *et al.*, 1991; Schallreuter *et al.*, 1992).

The patients, relatives and control subjects were informed if any abnormalities were found in their urine samples, or on clinical examination of the patients. We also wrote immediately to their general practitioners, if they wished us to do so.

With the patients' permission, photographs were taken of the front and side views of the patients, and of their hands, to identify the patients, and to note their postures and the shape of their fingers. Neither of the latter two were abnormal in the first 70 patients, and so these were not pursued or reported. Patients and those accompanying them were asked if they had any queries about the research being done on their blood samples or biopsies. They, and their closest relatives or friends who could observe them, were given stamped addressed envelopes to write to us, if the patients should have a relapse, describing their own and the observers' experiences in their own words (Strauss, 1989).

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Not enough replies were received to permit useful analysis.

Patients and their relatives were interviewed for 2.5-3.5 hours, including the clinical examination.

Problems of research

The patients and their relatives came in response to advertisements and were not a random population. Whenever possible, brothers and sisters of the patients were sought, but often the patients were accompanied by their parents, who were, of course, a generation older than themselves; therefore, it was difficult to derive conclusions about blood chemistry which changed with age. However, the blood relatives who were healthy were close genetically to the patients. Some of the patients were taking neuroleptics and some were not, and we also had a group of healthy spouses and control subjects. Thus, one could derive statistically significant results from the biochemical measurements, but not the data in this paper, since it was collected only from, or about, the patients, without a control group for their clinical conditions.

The information given by the patients and their families was not always reliable. Their memories for past admissions, symptoms and drug treatments were not always good. When persons gave a single number to represent their smoking or drinking habits, or indicated that they had suffered a symptom, it was difficult to establish how that single number could accurately represent the habit or symptom of a lifetime.

Another problem was that they had heard the leading questions, such as those used in the diagnosis of schizophrenia, many times before. They had "learned" to answer them, and their answers were often affected by their mood at the time. Often relatives would give a different answer to a question than the patient would. One did not know how reliable the patients were in their information about compliance with drug treatments. Furthermore, one only interviewed the patients and the accompanying persons once, due to the expense and difficulties of their travelling to the Schizophrenia Association at Bangor.

A few patients and their relatives found that travelling long distances, staying overnight at a hotel, the prospect of interviews about their illness, the circumstances of the interview, giving the blood samples, and the biopsy of the skin, were stressful and this could have affected the biochemistry of the blood.

Blood

As can be seen in Table I, 131 schizophrenia patients were accompanied by 144 healthy first-degree relatives and 17 spouses; the spouses and 33 healthy subjects together acted as a control group. Their ages are given, and it can be seen that many of the relatives were older than the patients. There were about twice as many men as women in our sample. The age of onset of the illness was 22.0 ± 6.4 years in the 92 male, and 22.4 ± 9.1 years in the 39 female patients; the duration of the illness at the time of attendance was 13.0 ± 9.3 years, and 13.8 ± 8.9 years, respectively. The number of admissions of male patients were from 0-20, and of female patients 0-7 times (Table II). Although data were collected originally about whether admissions were voluntary, it was not clear how accurate the information was, nor how often the patients were admitted "voluntarily", because they had been told that they would be "sectioned", if they did not "volunteer". Therefore, they are not divided into two such groups. The severity of the illness at the time when the patients visited the Association was assessed when the blood samples were taken to examine their biochemistry (Table III).

The educational achievements of the patients are given in Table IV, and show the high academic level of those who came here.

The drugs and the doses that the patients and their relatives said had been prescribed, and were taking, are listed in Table V. Thirty-three patients had never taken any neuroleptic drugs at all, or had not taken them during the three months prior to their visit. Flupenthixol, procyclidine, trifluoroperazine, chlorpromazine, fluphenazine, haloperidol and sulpiride, were the drugs most commonly used. Side effects reported included

Table II
Number of admissions of patients to hospitals, reported by the patients and their relatives

Number of admissions	Male number of patients	Female number of patients
0	9	2
1	20	12
2	24	4
3	6	8
4	8	4
5	10	5
6	7	3
7	5	1
>7	3	0
Number of patients	92	39

Table III
The severity of the illness at the time the patients were seen. The scale is given in the methods and procedures section. It will be noted that no severely ill patients, of severity 1, were seen

Severity	Male number of patients	Female number of patients
1.5	9	2
2.0	10	5
2.5	17	7
3.0	25	10
3.5	16	7
4.0	11	5
4.5	1	1
5.0	3	2
Number of patients	92	39

Table IV
Highest educational achievements of schizophrenic patients

Examinations passed	Male number of patients	Female number of patients
None	13	5
City and Guilds	6	3
GCSE or 'O' levels (1-10 subjects)	21	12
'A' level (1-4 subjects)	24	9
Diploma or degree	25	9
No information	2	1
Total	91	39

tiredness, "twitching legs", inability to concentrate, increased weight, blurred vision, amenorrhea and impotence, but they were very rare. Five of the patients who took no drugs expressed fear of toxic or side effects. Of the patients, 58 were also taking vitamin supplements, such as Multivite, cod liver oil, B_{12}, folic acid, ascorbic acid, or minerals, such as Mg^{2+}, Zn^{2+} or Fe^{2+}.

The male schizophrenic patients drank and smoked very much more than the females, although about half of the patients either did not drink or did not smoke at all (Table VI). About the same proportion of patients had never taken drugs of addiction, although those who admitted doing so may have taken them once, regularly or frequently (Table VII). Of those who took such drugs, cannabis was by far the commonest one used. On the information they gave us, women took these drugs less frequently than men.

Schizophrenia was diagnosed by the presence of the first 12 symptoms listed in Table VIII, so it is not surprising that they occurred

Table V
Drugs and dosages reported by the patients. The compliance was not known. Many patients were taking more than one drug. The number of male or female patients taking most of the drugs was too small to make it useful to indicate their genders

	Dose range	Number of patients
Neuroleptic drugs		
None		33
Benperidol	0.75mg/d	1
Benzhexol	10-15mg/d	2
Chlorpromazine	50-700mg/d	18
Clopenthixol	30-500mg/14d; 20mg/d	4
Clozapine	150-600mg/d	3
Fentazine	12mg/d	1
Flupenthixol	12.5mg/21d-300mg/7d	37
Fluphenazine	12.5mg/21d-100mg/7d	14
Fluspirillene	3mg/7d	1
Haloperidol	3-60mg/d	9
Lofepramine	140mg/d	1
Loxapine	80mg/d	1
Maprotiline	75mg/d	1
Mianserin	20mg/d	1
Orphenadrine	150-500mg/d	3
Perphenazine	8mg/d	1
Pimozide	4-12mg/d	2
Pipothiazine	100mg/14d-50mg/2d	4
Procyclidine	5-30mg/d	27
Prothiaden	25mg/d	1
Remoxipride	150mg/d	1
Sulpiride	200-600mg/d	9
Thioridazine	50-600mg/d	7
Trifluoroperazine	2-40mg/d	19
Other psychotropic drugs		
Amitryptyline	25mg/d	1
Benztropine mesylate	2mg/d	1
Clomipramine	5-10mg/d	2
Diazepam	30-60mg/d	2
Fluoxetine	40mg/d	1
Imipramine	50mg/d	1
Lithium carbonate	120-1,000mg/d	5
Propanolol	10mg/d	1
Temazepam	10-60mg/d	3
Trimipramine	10mg/d	1

frequently in this population, where they were in approximately equal incidence in males and females. About one-third of the patients had been violent to other people or property, and about 65 per cent had been unable to work due to their illness. The incidences of first-degree family histories of schizophrenia or manic depression, or of diabetes were also high, but the way in which the population was recruited may have contributed to this.

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The patients and their families were told: We would like to know from you confidentially how helpful the various different people and services have been to you recently, both in good and bad respects. We would like you to suggest ways in which provision might be improved, so we are going to ask you about each of the main persons and services with which you have come into contact. We will mark those as +1 satisfied or good, 0 neutral, –1, dissatisfied or bad. We will then ask you for any comments or suggestions about how the provision for schizophrenic patients can be improved.

The answers to these questions are summarised in Tables IX-XIII. In Tables X-XIII, the answers were free and unstructured; they were classified and their incidence counted subsequently.

Table VI
Drinking and smoking habits reported by 92 male and 39 female patients. Four of the latter took short as well as long drinks

	Drinking			Smoking	
Drinks (per week)	Male number of patients	Female number of patients	Cigarettes (per day)	Male number of patients	Female number of patients
0	52	31	**0**	40	20
<2.5	21	2	**–5**	12	2
2.5-5	4	2	**–10**	4	3
5-7.5	4	0	**–15**	7	3
7.5-10	0	0	**–20**	15	5
10-12.5	3	1	**–25**	4	3
12.5-15	2	0	**–30**	5	1
15-17.5	4	1	**–35**	1	1
17.5-20	2	0	**–40**	2	1
			–45	0	0
			–60	1	0

Table VII
Drugs of addiction taken at any time of their lives by schizophrenic patients

Drug addiction	Male number of patients	Female number of patients
None	57	25
Cannabis	37	14
Lysergic acid diethylamide	9	3
Amphetamine	6	1
Methylamphetamine	3	1
Morphine	2	0
Mescaline	1	1
Cocaine	1	1
Psilocybin	1	0
Heroin	1	1
Barbiturate	1	0
Chloroform	1	0

Table VIII
Symptoms which the 131 patients complained of at some time during their illnesses, and family history of psychosis and diabetes mellitus

Symptom	Male number of patients	Female number of patients
Fear or dread	71	33
Period of silence or withdrawal	68	37
Depressed easily	57	27
Strange fantasies	53	31
Voices in head	63	31
Hallucinations	50	31
Feeling that people are against patient	63	29
Controlled from outside or by others	48	20
Thoughts broadcast to outside	47	21
Thoughts transferred into brain	36	19
Thoughts taken out of brain	23	10
Sleep disorder	40	17
Tired much of the time	26	14
Poor concentration	5	3
Violent to other people or property	37	14
Police involvement for misdemeanour, drug offences or being found wandering	35	9
Multiple jobs in the past	31	20
Has stopped the patient working now	59	26
First-degree family history of schizophrenia or manic depression	40	8
First-degree family history of diabetes mellitus	24	5
Total number of patients	92	39

Bearing in mind that those who volunteered to travel all the way to Bangor are likely to have been more articulate than other schizophrenic patients and their families, the following general points seem to arise from Tables IX-XIII. Between 25 and 40 per cent of patients gave a positive assessment of their treatment by the four agencies, and about an equal proportion were dissatisfied. There was a tendency for dissatisfaction with psychiatrists in the treatment of both male and female patients. A fairly high proportion of the men would not or could not give us information about their relationships with the different personnel and institutions with whom they were in contact (Table IX). Many of the men had previously had no contact with social services.

A number of the patients and relatives did not think that their general practitioners knew much about mental illness, that they did not have enough time for patients with mental illness, and that they did not listen to patients (Table X); more made similar comments about psychiatrists (Table XI). In both

Table IX
Assessments of schizophrenic patients and their families about the helpfulness of the different personnel who have treated the patients: +1 is positively helpful; 0 is neutral; –1 is positively unhelpful. No contact means the patient has had no contact with those personnel. No information means the patient would not comment

	Male				Female			
Assessment	General practitioner	Psychiatrist	Nurses	Social services	General practitioner	Psychiatrist	Nurses	Social services
+1	41	30	30	38	23	11	13	13
0	10	9	19	9	3	8	7	1
–1	31	43	27	14	12	19	14	14
No contact	2	1	5	22	0	0	4	9
No information	8	9	11	9	1	1	1	2

Table X
Comments of patients and their families about general practitioners

	Number of patients, families or friends commenting
Their general practitioners:	
Do not know much about mental illness	8
Do not have enough time for patients	5
Unaware of the side effects of the drugs they prescribe	5
Do not care about the patients	4
Do not listen to patients	4
Refused to visit patients	3
Would not speak to relatives	3
Do not tell patients or relatives about schizophrenia	3
Do not understand patients	2
Do not take patients seriously	2
Did not get psychiatric treatment readily enough	1
Insensitive to effects of schizophrenia on family	1
General practitioner was abusive	1

Note:
A comment made by several people in respect of one patient is regarded as made by one person. All the comments in Table X were unstructured and spontaneous

cases, they seemed to be wanting more time with their doctors, to be listened to by them, and for the doctors to answer the patients' questions more often (Table XII). Many patients and relatives pointed to a shortage of nurses both within the hospital and the community. Some of their comments were similar to those about the doctors. Patients often also had problems in respect of not finding the company of like-minded people in hospitals, and of being bored with life as in-patients.

The predominant theme about their comments on community provision, and the social services, concerned those people who needed care after release, and the lack of employment and educational opportunities for them (Table XIII). This may be partly a reflection of the general unemployment in the UK at this time. The same themes of lack of purposeful activity and desirable company were expressed in respect of the patients' own predicaments (Table XIV), but another important point was also made. If patients on illness or unemployment benefit take any part- or full-time paid employment, they lose their benefit and, if they cannot stay in that employment, it takes several weeks for them to receive the previous benefits again. This has the effect of discouraging patients from seeking paid employment.

We had news of three patients who committed suicide some months after interview here, and one died of a heart attack.

It will be seen that the advice we gave the patients concerned their diagnosis, the desirability of them taking the drugs prescribed, living healthy lives, and exploiting abilities they had (Appendix 1). The questions which the patients and their relatives asked are listed (Appendix 2), and they reflected a desire to know more about the disease, its prognosis and a likelihood of a cure being found. Question 7 was the most difficult to answer. Often the illest patients were the most unwilling to seek treatment, yet the relatives and friends were naturally reluctant to force them to be treated against their wishes. Patients could be severely ill and disruptive, but might not be sent into hospital against their will, unless they were a danger to their own lives or those of their families. We were often asked about the efficacy of unorthodox treatments.

We also answered questions over the telephone about the symptoms of schizophrenia We always advised patients, their relatives or friends, to see their general practitioners, who would refer them to psychiatrists, if necessary. We never advised treatment, nor made diagnoses over the telephone.

Discussion

The population studied

The disadvantages of studying this population are that our patients were not a random

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sample of schizophrenic patients in Britain, that there were more than double the number of male patients than females (Table I), that no severely or acutely ill patients came to Bangor, that there was no way of confirming much of the information given by the patients (particularly that in Tables V-VII), and that there was no control population for the study of the patients here; this was because we did not question the relatives, friends or control subjects in depth about themselves, nor did we examine them, although blood samples and skin biopsies were taken from the latter groups. The uncertainty about the veracity and accuracy of information given by patients is a common problem in mental illness, somatic medicine, sociological and psychological studies, but it is assumed that most errors in the information given about patients will be random and, as such, would have relatively little impact on conclusions.

The advantages of the present study are that a period of 2.5-3.5 hours in a relaxed atmosphere, and in the presence of their relatives and friends, gave the patients and those accompanying them much more opportunity to impart information; often the parents or friends would modify answers to questions, and sometimes they would enter into a dialogue with the patients, which they had not done for a long time. The patients and those accompanying them were pleased to talk about the illness at length, and to ask us about it (Appendix 2). The satisfaction they often expressed and the letters received afterwards suggested that the visit to the Association may have helped them. The patients and their relatives were pleased to be able to express their satisfaction or dissatisfaction with those whom they came into contact, and to suggest how provision for them might be improved (Tables IX-XIV). These opinions must be viewed in the light of knowledge of the nature of schizophrenia. All those who treat and care for patients should try to differentiate between, first, difficulties due to the disease; second, difficulties due to inadequate resources; and third, inadequacies and inefficiency of those who look after them. The first requires optimal effort in diagnosis and treatment; the second requires pressure of public opinion; and the third necessitates doctors and nurses listening to patients and their carers in order to make a conscious effort to meet the reasonable desires and expectations of the patients, their friends and their families.

Table XI
Comments of patients and their families about psychiatrists

	Number of patients, families or friends commenting
Their psychiatrists	
Do not listen to patients or relatives	13
Do not communicate with patients	13
Do not talk to patients	10
Do not spend enough time with patients	10
Do not treat acutely ill patients urgently	8
Not enough psychiatrists	7
Too many different psychiatrists seen	5
Too many injections or drugs, not enough psychotherapy	5
Do not take the side effects of drugs seriously	4
Do not tell patients or relatives about condition	4
Psychiatrists aggressive	3
Sometimes do not allow relatives to visit	3
Not interested in nutrition or food allergies	3
Not enough co-ordination with general practitioners	2
Language barrier between patient and psychiatrist	2
Miscellaneous other individual comments	7

Note:
A comment made by several people in respect of one patient is regarded as made by one person.

Table XII
Comments of patients and their families about nurses and hospitals

	Number of patients, families or friends commenting
Comments about their nurses and hospitals	
More nurses needed in hospitals	9
More community psychiatric nurses needed	6
Not enough like-minded people to talk to in hospitals	6
Boring life in hospital	6
Nurses do not care about patients	3
Nurses do not answer questions of patients or relatives	3
Nurses allowed wards to get out of control	2
Patients need company when they are acutely ill	2
No toilet facilities in restricted cells	1
Patient said he was beaten in hospital	1

Note:
A comment made by several people in respect of one patient is regarded as made by one person.

Characteristics of this population

A remarkably high proportion of the population studied here had reached degree or diploma standard (Table IV), although clearly their status as volunteers would tend to select these people from the population at large. At interview, the patients often referred to their interest in writing, music, art and electronics, and we put them in touch with others with similar interests. We also encouraged them to pursue amateur or professional studies in these subjects.

The range of neuroleptic drugs and their dosages, which the patients reported taking, was large (Table V). With the exception of drugs given by injection, such as clopenthixol, flupenthixol and pipothiazine, it was difficult

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to know how good the compliance was, unless the patients lived at home and the relatives or spouses supervised the treatment. Patients reported side effects so rarely that they could not be tabulated, but many of them were treated successfully by procyclidine (Table V). Fear of toxic or side effects of drugs was sometimes given as a reason for not taking them, and we always encouraged patients to tell their doctors about any side effects as well as if they were varying treatment on their own initiative.

Approximately, 50-60 per cent of the men and women did not smoke or drink (Table VI); there are no figures for these habits in healthy unemployed persons of the same age available for comparison, but it can be seen that young men smoked heavily. Of the male patients, 57 out of 91, and 25 of 39 female patients had never taken drugs of addiction. The others said that they had taken some occasionally. Cannabis appeared to be the most popular drug, and intravenous drugs were hardly mentioned at all (Table VII). The incidence and the popularity of cannabis in the patients seemed to be similar to those found in the British population as a whole (National Audit of Drug Misuse in Britain, 1992). It would be useful to study in depth whether addiction triggers the manifestation of latent schizophrenia, or actually causes it itself.

It is not surprising that patients who were diagnosed as schizophrenic on the basis of their having symptoms listed in DSM IIIR should exhibit these symptoms frequently (Table VIII). However, of the first 14 symptoms, a mean of 46 out of 92 men, and 23 out of 39 women had each symptom; thus each patient had about half the list of symptoms. It will be seen that fear or dread, silence or withdrawal, voices and paranoia were the commonest symptoms. Schizophrenia had prevented about 65 per cent of the men and women from working. About 43 per cent of the males and 20 per cent of the females reported first-degree relatives with schizophrenia or manic depression. This fits in with the view that there is a genetic contribution to schizophrenia (Gottesman, 1991; Gottesman and Shields, 1982; Pollin *et al.*, 1969; Slater and Cowie, 1971), and a smaller, but remarkably high incidence of diabetes mellitus was also found in the families (Table VIII).

Table XIII
Comments of patients and their families about community provision for them

	Number of patients, families or friends commenting
Community provision and social services	
Not enough provision for patients when carers are not able to look after patients or are in hospital	6
Little provision of holidays for patients and carers	5
More workshops needed for patients	3
More training and education needed for patients	3
Mixing only with ill people not conducive to recovery	3
Social services are rationed	3
More employment opportunities needed	3
Services are rationed	3
More half-way houses needed for patients discharged from hospital	3
No day centre for patients in the area	2
Churches could help more	2
More help needed for divorced parents of patients	1
More resources needed for mental health	1
Children at schools should be taught about mental health	1
Patients would like their own accommodation	1

Note:
A comment made by several people in respect of one patient is regarded as made by one person.

Table XIV
Comments of patients and their families

	Number of patients, families or friends commenting
Their own predicaments	
They need something to do all day	7
Day centres are boring	6
Other people in day centres are mentally ill, hopeless, or boring	8
Patients lose benefits if they earn money	5
Cannot communicate with general practitioners or psychiatrists	5
Need education, training, or skill	5
Partner does not understand mental illness	5
Cannot often go on holiday	4

Note:
A comment made by several people in respect of one patient is regarded as made by one person.

Treatment and provision for patients

It is expensive to keep patients in hospital, and not quite so expensive to provide for them in the community (Knapp *et al.*, 1992; 1993). It is desirable for patients to stay in hospital only when their treatment requires it, and it has been British government policy since the 1980s to close down mental hospitals (Department of Health, 1989; 1992). Some of the problems mentioned by our patients and their families arise from insufficient personnel and resources devoted to treating and caring for the patients, while others are the responsibility of staff, and can be addressed by listening to what the patients and their relatives have said, as classified in Tables IX-XIV. These are best summarised in a series of recommendations.

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Recommendations

1 General practitioners need to be made more aware of the early symptoms of schizophrenia (and other psychoses), so that they may diagnose patients and refer them for treatment sooner. They should always be prepared to see the patients' families and concerned friends. Our experience is that despite some initial embarrassment, it is advantageous to interview the patients with their families or friends, because the interview is then much more productive. General practitioners should also be less unwilling to certify patients under the Mental Health Act (1983). Usually, this is not done until the patients are dangerous to the lives of themselves or others, when they are too psychotic to accept treatment voluntarily.

2 Some psychiatrists are still unwilling to see members of the patients' families, either because they feel that parents may have contributed to the illness by inappropriate upbringing or physical or sexual abuse. The psychiatrists may not have time to see the patients. After an initial interview for an hour, the patient may only be seen for 15-20 minutes every 1-6 months, which is clearly not enough. The shortness of the interview is exacerbated by the fact that a patient may see a different psychiatrist at each visit; obviously, the personality of the psychiatrist, and the establishment of rapport between patients and their families with their general practitioners and psychiatrists, are important in treatment and drug compliance (Piatkowska and Farrell, 1992).

3 Patients and families often complained of the unwillingness of general practitioners, psychiatrists and nurses, to explain to them the nature of schizophrenia or the rationale of the particular drug treatment, and sometimes to answer questions at all. This perceived lack of responsiveness of medical staff was sometimes part of the disease, but sometimes arose from the hostility engendered by some organisations towards the drug treatment of schizophrenia. At times, however, it seemed to arise from the behaviour of the medical staff itself.

4 The patients and their families often mentioned that they thought that the lack of attention was due to there being too few psychiatrists, ward nurses and community psychiatric nurses to give enough time to individual patients. Certainly, the patients were often sympathetic to the fact that each member of staff was often too busy to give them the attention they wanted.

5 A few schizophrenic patients who had been in hospital several times before mentioned that they had an agreement with the psychiatrist to admit them rapidly when they felt that they were going into relapse. However, many others complained that it was sometimes difficult to obtain admission when they felt they needed it. Some patients and their families are aware that they are becoming iller, but others are not. Considerable research has gone into identifying prodromal symptoms (Birchwood *et al.*, 1989; Chapman and Chapman, 1987; Doherty *et al.*, 1978). Earlier treatment of those patients who recognise the onset of a relapse themselves, or in whom the relatives can see it coming, is highly desirable, but such recognition has to be by lay people and based on simple observations, if it is to be practicable. It should be accompanied by greater willingness and ability of hospitals to admit patients immediately who show prodromal symptoms. The thinking behind this is that those patients in whom a relapse can be anticipated may be kept on lower maintenance doses of neuroleptics, but the doses may be increased immediately a relapse appears imminent.

6 Patients often found little or nothing for them to do in hospital. That, together with the lack of contact with nurses, often made them feel bored. Perhaps they could be encouraged to do such communal activities as sports, plays, concerts, art exhibitions, etc. Some of them could teach others writing, reading, languages, skills, etc. A culture of activity involving many of the patients would probably mean more occupational therapists, but it is likely that families of patients would be prepared to help to organise such activities.

7 Patients and their carers often need holidays, either together or separately. The burden of looking after chronically ill patients would be much relieved if they could be admitted to a hospital or a half-way house for a 2-3 week period, or if they could be adequately looked after and supervised, while the carers went on holiday. Of course, the patients should also have their own holidays, with or without carers.

8 It would be highly desirable to reform the social security system to encourage patients, who have been ill, to take part-time paid posts, without loss of benefit, because this would assist them to recover more quickly. It would also help the patients very much, if their benefits could

be restored rapidly if they failed to keep down a paid job, so that it would be no financial disadvantage for them to try to work.

9 Toilet facilities should be provided in secure rooms.

In conclusion, it is worth mentioning perhaps the most difficult problem which we have encountered. The patient, who is not ill enough to be in hospital, who is not dangerous enough to be sectioned and often lives far from relatives or carers, is often unwilling to be treated. He or she is usually paranoid, and quite hostile to the appeal of friends, family, general practitioners, community psychiatric nurses and others, to seek help. Often, such patients have no family or friends nearby, and they live rough. Some take drugs. If a general practitioner, an approved social worker or even a member of their family, seeks to help them, they often run away. Sometimes their paranoia leads them to violence or suicide. This problem needs to be addressed by psychiatrists, governments and carers.

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Appendix 1.
Advice about the patients given to them and to the persons accompanying them

1 Whether they were schizophrenic.
2 Information about any abnormalities found on physical examination.
3 That they should comply with treatment given by their general practitioners and psychiatrists, whom they should always consult if they wish to vary it.
4 That they should report side effects of drugs to their general practitioners and psychiatrists.
5 That they should give up smoking, excessive drinking and eating, if possible.
6 That they should stop taking drugs of addiction, seeking professional help to do so, if necessary.
7 That they should have exercise.
8 That they should seek employment as soon as they could.
9 What educational and training opportunities are available to them.
10 That they should take part in as much social and communal activity as they can.

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11 That they should seek the advice of geneticists on the likelihood of offspring being schizophrenic.
12 What benefits are available to them and their carers.
13 That they should join appropriate support groups, if they think that this will help them.
14 That they should exploit any creative abilities they may have in writing, painting, electronics, computing, etc.
15 That they should avoid seeking expensive biochemical measurements, and ineffective treatments, especially from unorthodox practitioners.
16 The respective roles of the schizophrenic Association of Great Britain (research), Mind (support group for all mental illness), National Schizophrenia Fellowship (local support groups) and SANE (telephone help line).

Appendix 2
Questions asked by patients and persons accompanying them

1 Is the patient schizophrenic?
2 What is the long-term prognosis?
3 Should they continue to take particular drugs prescribed?
4 What are the risks of their offspring being schizophrenic?
5 What is the role of nutrition in schizophrenia?
6 What likelihood is there that research will produce a cure?
7 Can the Association help them to obtain treatment (which is at present inadequate), how can they induce an unwilling patient to seek treatment, or how can the authorities be persuaded that the behaviour of a patient is due to schizophrenia, and not due to criminal intent?
8 Can the Association advise them about unorthodox treatments?