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# Schizophrenic Patients and their Families
## A Survey in a Psychiatric service based on a DGH Unit

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Summary: We identified the population of schizophrenic patients under 65 in a geographically defined area. The number using psychiatric services based on a new District General Hospital unit in the course of one year was 364, a prevalence of 2.2 per 1000 adult population. Half the patients lived in supportive private households, most often with spouses or mothers. More women than men married and retained supporters. Patients and their primary supporters were interviewed separately. The PSE Catego programme classed 47 per cent of patients as psychotic. Supporters reported disturbed behaviour in 65 per cent of patients, and restricted social performance in 78 per cent. There was evidence of hardship (emotional and physical ill-health, problems with children) in 90 per cent of households. Supporters' subjective distress was directly related to the presence of psychosis and disturbed behaviour and inversely related to the duration of the illness. Drop-out and failure to take medication appeared to be causes of the relatively high prevalence of psychosis.

For over twenty years, mental health policy has been based on the assumption that a declining need for long-stay beds would allow the replacement of large mental hospitals by smaller units in District General Hospitals, supplemented by psychogeriatric units and community-based social and medical services (DHSS, 1975). Progress in changing the system has been slow, but by 1977 33 per cent of all psychiatric admissions were to DGH units, compared with 15 per cent in 1964 (DHSS, 1980). Such a shift in patterns of care has particular implications for the patients, most of them with schizophrenic illnesses, who previously occupied long-stay beds. Although many still have chronic, relapsing disorders, they and their families are now dependent on care given by a variety of medical and social agencies. Effective co-ordination of these services may be very difficult (Jones, 1978), and the central role of families in providing long-term care is not in dispute.

In the period following the 1959 Mental Health Act, several studies were carried out on the effects of a community care policy on patients and their families (Sainsbury and Grad, 1966; Hoenig and Hamilton, 1969). Brown *et al* (1966) focussed specifically on whether a community service could meet the needs of the most seriously handicapped patients. Their five-year follow-up of three cohorts of schizophrenic patients showed that some two-thirds had been continuously ill or had suffered episodic relapses throughout the period of follow-up. The patterns of community care then in existence appeared ineffective in preventing social crises or providing rehabilitation for patients or support for relatives. In 1974, Creer and Wing made a detailed, though not representative, study of community care for schizophrenic patients from their relatives' point of view. They concluded that many patients continued to be disturbed and handicapped and that, in general, services were unreliable and inadequate. However, Cheadle *et al* (1978), in a survey of a large sample of schizophrenic patients in Salford, found that many of them were in touch with psychiatric services and about three-quarters were maintained on long-term neuroleptics which successfully contained psychotic symptoms. Neurotic problems and social handicaps were common, however, and no information was available on the problems of relatives.

The Health District of the present study has a population of 308,000 but there are only 100 beds in a new DGH unit for all psychiatric patients under 65, with very limited access to a mental hospital. We decided to study the care received in the new service by schizophrenic patients, and in particular the extent to which the new service was able to meet the needs of families caring for a schizophrenic family member. To do this, we identified all schizophrenic patients aged 16–65 from part of the catchment area who received any service from the DGH unit during one year, and noted which were living with a supporter. We defined a 'supporter' as someone living in the same household as the patient and connected to the patient by ties of blood, marriage or friendship. The 'primary supporter' was the supporter who spent most time with the patient and felt most responsible for him/her. We then monitored contacts with psychiatric, social and G.P. services, and help received from informal sources, during the following year.

This paper describes the clinical and social situations of the identified schizophrenics. It goes into greater detail on those living with supporters, considering the extent of the patients' psychiatric symptoms, disturbed behaviour and restricted social performance; the hardships experienced by the supporting families; and the distress and strain experienced by primary supporters.

## Methods

We wished to identify all schizophrenic patients aged 16–65 with an address in the city (pop. 208,000), or with no fixed address, who had contact with psychiatric services based on the DGH unit between 1st February 1981 and 31st January 1982. We therefore monitored points of entry to the service and the psychiatric case register in order to detect the first contact of the year in each case. Case records were checked to identify cases of schizophrenia and to establish which of these patients were living in private households with someone who met the operational definition of a supporter. Clinical and social information was collected from case records for all schizophrenic patients.

Patients were counted as schizophrenic if they met at least one of the following criteria:

1. A firm diagnosis of schizophrenia by the responsible consultant.
2. Evidence in the case notes of first-rank symptoms of schizophrenia.
3. Evidence of persistent non-affective delusions.
4. Evidence of persistent non-affective auditory hallucinations.

Patients were excluded if there was clear evidence of organic brain disease, or if schizophrenic-like symptoms occurred only transiently in association with alcohol or drug abuse.

Schizophrenics living with a supporter formed the sample chosen for interview. All such patients and their supporters were sent separate letters within a week of the index service contact, inviting their participation in the study. Our social and psychologist interviewers then made separate arrangements to call on supporters and patients respectively. Interviews normally took place within two weeks of the first service contact. The primary supporter was identified during the visit to the household.

### *Interviews with patients*

For interviews with patients we used the Present State Examination (PSE) of Wing *et al* (1974). The data were processed by the Catego programme. Where the PSE revealed no current psychotic symptoms, or no PSE data were obtained, a syndrome check-list was completed from the case notes of any previous psychotic episode. This allowed us to allot each case tentatively to a Catego class, provided that the case record was sufficiently detailed and accurate.

### *Interviews with supporters*

The scaled version of the General Health Questionnaire (Goldberg and Hillier, 1979) and the Social Behaviour Assessment Schedule (Platt *et al*, 1980) were given to primary supporters.

The Social Behaviour Assessment Schedule (SBAS) is a standardized semi-structured interview which was developed to assess the disturbed behaviour and altered social performance of patients from an informant's point of view, while at the same time evaluating adverse effects upon the household and the subjective distress experienced by the patient's main supporter. The schedule is in three parts, which investigate:

I. The patient's behaviour in the last month (22 items)
II. The patient's performance in social and domestic roles (12 items)
III. The patient's effect on the supporter's health, on children in the household, and on other household circumstances (18 items)

For each item there are two rating scales; an objective one measuring the severity of occurrence of the item and a distress scale measuring the informant's emotional reaction to it. The scale points are predefined and ratings of distress are based entirely on informants' verbal answers to standardized questions. The distress scale is:

| | |
|---|---|
| 0 | no distress |
| 1 | resigned |
| 2 | some distress |
| 3 | severe distress |

### *Reliability of interview technique*

At different stages during the year of the study the social interviewers tape-recorded 30 interviews, and these were rated independently by the two interviewers. The statistic *weighted kappa* (Hall, 1974;

TABLE I

*SBAS: Agreement between rater pairs (n = 30)*

| | Weighted κ |
|---|---|
| *1. Disturbed behaviour* | |
| Objective scale | .978 |
| Supporter's distress | .977 |
| *2. Social performance* | |
| Objective scale | .850 |
| Supporter's distress | .829 |
| *3. Hardship* | |
| Objective scale | .945 |
| Supporter's distress | .977 |

Cicchetti, 1976) was used to evaluate inter-rater reliability on each of the three objective and three distress scales (see Table I).

To test for any order effect (since the section on behaviour is normally administered first), 36 cases, divided between two interviewers, were randomly allocated so that half had the section on social performance administered first. There were no differences in the mean scores on the objective or distress scales when the order of administration was varied.

## Results

We identified 364 schizophrenic patients, of whom 25 were first-ever referrals, 23 were new to the local service, 38 were re-referrals who had been out of contact for at least a year, and 278 were in continuing treatment. We excluded from further study 47 additional patients occupying long-term beds in the mental hospital outisde the city. This gave a prevalence of 2.2 per 1000 population for the age group 16–65, and an incidence of first-ever referrals of 0.15 per 1000.

### *Domestic circumstances*

We found that 50 per cent of schziophrenic patients were living in private households with a supporter. Another 13 per cent were alone in private households; 2 per cent had only children for company; 10 per cent were in group homes supervised by hospital staff and a voluntary agency; 13 per cent were in large hostels run by the Church or Salvation Army, an overnight shelter or the DHSS reception centre; and 4 per cent had no fixed address at the time of their index contact, usually because they had recently drifted to the city, sometimes on discharge from another hospital. The remainder were in a variety of more or less accompanied situations, but lacked a supporter who met our research criteria. These data are summarized in Table II.

TABLE II

*Living circumstances of schizophrenic patients in the community*

| | Number | % |
|---|---|---|
| With supporter | 183 | 50 |
| With children only | 6 | 2 |
| Alone in private household | 46 | 13 |
| Group home | 38 | 10 |
| Hostel, reception centre, etc. | 46 | 13 |
| Boarding/lodging house | 11 | 3 |
| No fixed abode | 16 | 4 |
| Other | 17 | 5 |
| Not known | 1 | |
| *Total* | 364 | 100 |

TABLE III

*Age and sex of schizophrenic patients with and without supporters*

| | Supported | | Unsupported | |
|---|---|---|---|---|
| Age | M | F | M | F |
| 16–24 | 12 | 6 | 8 | 5 |
| 25–34 | 29 | 21 | 40 | 10 |
| 35–44 | 24 | 24 | 33 | 15 |
| 45–54 | 13 | 25 | 28 | 10 |
| 55–65 | 7 | 22 | 15 | 17 |
| *Total* | 85 | 98 | 124 | 57 |

TABLE IV

*Interview response rate of supported schizophrenics and their supporters*

| | Supporters | Patients |
|---|---|---|
| Interviewed | 166 (91%)* | 143 (78%) |
| Refused interview | 10 (5%) | 31 (17%) |
| Not traced | 3 (2%) | 4(2%) |
| Excluded (no English) | 3 (2%) | 4 (2%) |
| Excluded (other) | 1 | 1 |
| *Total* | 183 (100%) | 183 |

*Includes three supporters and two patients who did not provide complete interviews

### *Demographic factors*

There were 209 male and 155 female schizophrenics. The mean age was 40.2 years. The women were significantly older than the men, nearly half being over 45 compared with less than a third of the men (see Table III). Of the 364 patients, 54 per cent have never been married, 26 per cent were currently married, 2 per cent were widowed and 18 per cent divorced or separated. Women were significantly more likely to have married at sometime (70 per cent of women compared with 27 per cent of men) and to be still married (40 per cent of women, 13 per cent of men).

### *Supported and unsupported patients compared*

Significantly more women than men were living with supporters: 63 per cent compared with 41 per cent (P <.001). There were no significant age differences between supported and unsupported groups, but unsupported patients were significantly more likely to be single (66 per cent compared with 43 per cent) and to have a broken marriage (30 per cent compared with 10 per cent). When geographical distribution of patients throughout the city was examined, patients with supporters were fairly evenly distributed among the 15 wards, whereas patients without supporters were over represented in the inner city area: 45 per cent of unsupported patients with addresses were living in the two inner city wards, compared with 14 per cent of supported patients. This finding reflects the geographical distribution of the hostels and lodging houses where so many unsupported patients were accommodated, rather than cultural causative factors.

### *Supporting households*

Table IV shows the response rate of supported patients and their supporters. We compared interviewed and missing cases with respect to the patients sex, age, marital status, relation to supporter, clinical category, supporter's age and size of household. Only the last showed a significant difference, with missing cases occurring more often in two-person households (P <.02).

Table V shows the relationships between patients and their primary supporters. Mothers living with son-patients and husbands with wife-patients predominated. Twenty-five per cent of all the primary supporters were aged 65 or over; 11 per cent, nearly all mothers, were over 75. About 30 per cent of the primary supporters were living alone with the patient: this proportion increased with the supporters age, so that 38 per cent of supporters over 65 were alone with the patient, and 45 per cent of supporters over 75. In such circumstances the patient was often an important prop to the parent. Twenty-six per cent of the households contained one or more children under 16, and 8 per cent contained children under five (compared with 13 per cent of the local population). The households were very stable, with 71 per cent of supporters and patients having lived together for more than ten years and only five per cent for under a year. Over-crowding was not noticeable, but compared with the local population more patients' households were in old property lacking basic amenities. Among supporters social classes IIIM (skilled manual), IV (partly skilled) and V (unskilled) were over-represented. (The social class of supporters was judged from the last occupation for male supporters and single women, and from the husband's last occupation for married women). This may reflect a real social-class difference in prevalence, or a greater tendency in working-class families to keep their schizophrenic members at home. One third of the households contained no working member.

TABLE V

*Primary supporters of men and women patients*

| | Patient | |
|---|---|---|
| Primary supporter | M | F |
| Husband | — | 61 |
| Wife | 25 | — |
| Mother | 45 | 18 |
| Father | 8 | 4 |
| Sibling | 5 | 7 |
| Child (17+) | 0 | 5 |
| Other | 2 | 3 |
| *Total* | 85 | 98 |

### *Supported patients' education and employment*

Only 27 per cent of supported male patients were in full- or part-time work, compared with 80 per cent of men under 65 in the local population: 12 per cent of supported women patients were in work compared with 57 per cent locally, but 59 per cent had some recognised status and occupation as housewives. Sixty-eight per cent of the patients had left school without any qualifications, but 23 per cent had O levels, CSEs or apprenticeships, and 9 per cent had A-levels or better.

## Clinical characteristics

### *Supported patients*

The PSE was completed in 141 cases. Sixty-six patients (47 per cent) were classed by the Catego programme as *psychotic:* 43 were assigned to S (schizophrenia), 17 to P (paranoid), 4 to M (manic) and 2 to D (depressive). Two of the manic patients had had clear-cut schizophrenic episodes in the past, the other two had had predominantly affective illnesses with episodic schizophrenic features. The two depressive patients had previously had non-affective delusions and hallucinations.

A further 17 patients (12 per cent) had *neurotic* symptoms, mostly depressive, of sufficient severity to qualify as cases.

The remaining 58 patients (41 per cent) had few or no PSE symptoms and failed to qualify as cases. All but two had had an undoubted prior schizophrenic episode: the two had an inadequately documented history of possible schizophrenia.

TABLE VI

*Frequency of psychotic symptoms in patients with supporters*

| | Patients with psychotic symptoms | | |
|---|---|---|---|
| Time since First contact | Total | No regular medication | Re-referrals |
| 0–1 yr (*n* = 22) | 15 (68%) | – | – |
| 1–5 yrs (*n* = 33) | 15 (45%) | 12 | 3 |
| >5 yrs (*n* = 124) | 46 (37%) | 20 | 13 |

Examination of the case records of the 38 patients who did *not* complete the PSE showed that ten (26 per cent) had active psychotic symptoms (eight schizophrenic and two paranoid). The remainder had no psychotic symptoms at the index contact, although all had had previous schizophrenic or paranoid episodes.

Combining the data from PSEs and case records shows that 42 per cent of supported patients had frank psychotic symptoms at the index contact. The proportion of patients with psychotic symptoms was found to vary inversely with the length of time since their first-ever psychiatric contact (see Table VI). Table VI also shows the infrequency of medication in those with psychotic symptoms: the vast majority (95 per cent) of patients *without* psychotic symptoms were receiving regular antipsychotic medication. We judged the *clinical poverty syndrome* to be present when, in the absence of psychotic or marked PSE depressive symptoms, the primary supporter rated at least three of the following six behaviours as present during the preceding month: social withdrawal; slowness; underactivity; self-neglect; few or no spare-time activities; lack of emotional response. This syndrome ('negative symptoms') was present in 24 per cent of patients whose first contact had occurred 1–5 years previously, and in 49 per cent of those for whom it was more than five years ago.

### *Patients without supporters*

Scrutiny of case notes showed that 77 (42.5 per cent) of the patients without a supporter had psychotic symptoms at the time of the index contact (56 schizophrenic, 13 paranoid, 6 probably schizophrenic, 2 of uncertain nature). Most of the 104 patients without positive symptoms had a previous history of definite schizophrenia or paranoid psychosis. In five cases no diagnosis could be made from the information available. Eighty-five (82 per cent) of the non-psychotic patients were receiving antipsychotic medication.

TABLE VII

*Frequency of disturbed behaviour in supported schizophrenics in previous month* (n = *163)*

| | None | Moderate | Severe |
|---|---|---|---|
| *A* Harmful, threatening, noisy | 51% | 27% | 22% |
| *B* Deluded/hallucinated | 59% | 21% | 20% |
| *C* Possibly schizophrenic | 23% | 31% | 46% |
| *D* Other | 24% | 25% | 51% |

## Information from supporters

### *Patients' behaviour (SBAS Part I)*

The 22 behavioural items in the SBAS were condensed into four categories derived from Brown *et al* (1966):

A. Harmful, threatening, noisy behaviour (including night disturbance, over-activity, unpredictable behaviour, rudeness, violence, parasuicide, offensive behaviour and heavy drinking).
B. Hallucinations or delusions expressed to the informant.
C. Possibly schizophrenic behaviours (including slowness, forgetfulness, underactivity, withdrawal, self-neglect, odd behaviour).
D. Depression, worry, fears, indecisiveness, irritability, obsessionality, clinging and bodily complaints.

The frequency of these types of behaviour in the previous month is shown in Table VII. Nearly half the patients had displayed harmful, threatening or noisy behaviour; 41 per cent had displayed hallucinations or delusions, 20 per cent to a degree which made them appear to be completely out of contact with reality; over three-quarters displayed behaviours in categories C and D. Taking all behaviour into account, 18 per cent of supported schizophrenics were rated as severely disturbed and 47 per cent as moderately disturbed. Only 35 per cent appeared to be free or almost free from all disturbed behaviour.

Behaviours which caused most distress were offensive behaviour, rudeness and violence, which occurred in only a minority of patients but caused distress to over 95 per cent of their supporters. Another eight behaviours—misery, odd ideas, irritability, overactivity, self-neglect, odd behaviour, parasuicide and heavy drinking—were distressing to over 80 per cent of supporters affected. In general, the behaviours most likely to cause severe distress were those directed at the supporters (such as rudeness and violence) or were the product of active psychosis (such as unpredictability and odd ideas). Supporters were more able to become resigned to chronic negative symptoms.

*Correlation with PSE.* There was a significant correlation between the patient's total symptom score on the PSE and the mean behavioural score on the SBAS ($r$ = .426, P <.001). Of patients rated on the SBAS as having moderate or severe behaviour distur bance, 70 per cent had a PSE ID-level of at least 5 (i.e. they qualified as cases), compared with 39 per cent among those rated as less disturbed on the SBAS $\chi^2 = 11.67$ d.f. 1, $P < .001$). Thus there was significant agreement between the patient's clinical symptomatology as elicited by the PSE interview and the informant's report of behavioural disturbance, even though many of the behavioural items are not necessarily psychiatric symptoms.

### *Patient's social performance (SBAS Part II)*

Eighty-six per cent of patients were playing only a limited part in household care and management. Over 70 per cent had limited spare-time activities and gave little support, affection or sexual love (where appropriate) to the supporter. However, nearly half of the patients who worked or had responsibilities for children were able to maintain full performance in those roles.

Although deficits in social role performance occurred more frequently to a moderate or severe degree (in 78 per cent of cases) than disturbed behaviours, they caused less distress to supporters. Supporters did not seem to mind carrying executive responsibility for the patient: only about a quarter were distressed by the patient's playing little part in decision-making or household management. People supporting parent-patients were able to adapt to the patient's playing a limited parental role in about half the affected cases. Unsatisfactory sexual relationships caused less distress than lack of support, affection or daily interchange. Patient's work problems were actively distressing to three-quarters of the supporters affected.

### *Adverse effects on the household (SBAS Part III)*

Supporters had symptoms of emotional or physical ill-health in 72 per cent of cases. Children in the household were adversely affected in 63 per cent of cases. The household had been disrupted by frequent arguments or someone leaving in 42 per cent. The supporter's work had been affected in 41 per cent and his/her social life in 44 per cent. Financial hardship had occurred in 39 per cent, and the patient had caused disruption outside the household in 14 per cent.

Friction in the household, personal emotional problems such as depression and anxiety, and odd, naughty or clinging behaviour in children caused distress to 90 per cent of supporters experiencing them. Financial problems, reduced performance at work, physical ill-health and disruption outisde the household were distressing to 80 per cent of those affected. However, children having time off school or being away from home caused distress to less than half the supporters affected, probably because these events had often been deliberately arranged.

TABLE VIII

*Mean SBAS scores, with standard deviations in brackets (n =163)*

| | Objective mean | Informant's distress |
|---|---|---|
| Patients' behaviour | 0.36 (.29) | 1.55 (.86) |
| Patients' social performance | 0.87 (.54) | 0.85 (.74) |
| Family hardship | 0.42 (.29) | 1.44 (.84) |

### *Conclusion from SBAS ratings*

Patients who had been in psychiatric treatment for longer than a year displayed significantly less disturbed behaviour, but levels of restricted social performance and family hardship did not decrease significantly with length of illness. Table VIII shows the mean SBAS Part-scores and the mean distress score for each. Patients' disturbed behaviour and hardship to the family caused more subjective distress to the primary supporters than deficits in social role performance, although such deficits were more common.

### *General Health Questionnaire*

Another measure of the emotional distress experienced by primary supporters was provided by their scores on the 28-item GHQ: 68 per cent had scores between 0 and 4, i.e. below the threshold score suggested by Goldberg and Hillier (1979), but 32 per cent had scores between 5 and 24. By comparison Goldberg and Hillier found that 41 per cent of 553 general practice attenders had scores in this range. The factor 'anxiety and insomnia' had the highest score, followed by somatic symptoms, with depression lowest. New supporters, living with patients who had been ill for less than a year scored above the threshold more often (45 per cent compared with 28 per cent). Scores on the GHQ were significantly associated with the total distress score recorded on the SBAS ($r = .50$ $P < .001$).

### *Strain on supporters*

The overall distress score on the SBAS was used as an index of supporters' strain. Scores ranged from 0 to 8.7, with a mean of 3.8 (s.d. 1.9). The scores were distributed as follows: no strain/slight strain (score 0–3) 44 per cent; moderate strain (score 4–5) 35 per cent; severe strain (score 6 and over) 12 per cent. In 9 per cent of cases data was missing.

We first examined various characteristics of the supporters—age, sex, relationship to patient, marital status and social class—to see if they had an effect on the amount of strain experienced. There were no significant differences in mean distress score between supporters over and under 45; male or female;

TABLE IX

*Supporters' mean distress scores by presence of psychotic symptoms in patient and length of illness*

| Years of illness | Patient not psychotic | Patient psychotic |
|---|---|---|
| Under 1 | 4.55 ($n$ = 7) | 4.81 ($n$ = 14) |
| 1–5 | 3.70 ($n$ = 17) | 4.36 ($n$ = 15) |
| Over 5 | 3.26 ($n$ = 68) | 3.97 ($n$ = 43) |

Numbers of patients in brackets

spouses, parents or others; married, single or other marital state; nor between social classes. However, supporters in households containing children expressed more distress (P <.06), and supporters living alone with patients less distress (P <.08).

We then examined some characteristics of the patients in relation to the level of the supporters' distress. There was no significant difference connected with sex or marital status, but patients under 45 caused more distress than older ones (P = .05). The most important determinants of supporters' distress, however, were the patients' clinical characteristics. Patients with an ID level of at least 5 on the PSE caused significantly more distress, and the total symptom score on the PSE was significantly correlated with the supporter's distress ($r$ = 0.38, P <.001). Table IX shows how supporters' distress varied with the presence or absence of psychotic symptoms and the length of time since the patient's first psychiatric contact which was also important. Three-quarters of the patients who had been ill for less than a year caused moderate or severe strain to their supporters, compared with only 46 per cent of those who had been ill for more than five years.

## Discussion

We hoped to get a representative picture of the needs of schizophrenic patients and their supporters in a new service based on a DGH unit by studying the total population of such patients in any form of psychiatric treatment. Schizophrenic people who did not use any psychiatric services during the year were of course missed.

Our sample differs considerably from that of Creer and Wing (1974): only 14 per cent of the relatives in their study were spouses, compared with 47 per cent in ours; and their typical patient was a young man living with parents, whereas wives outnumbered sons in our sample of patients. The differences are probably due to the fact that Creer and Wing drew most of their sample from members of the National Schizophrenia Fellowship.

When our sample of supported and unsupported patients is compared with that of Cheadle *et al* (1978), there are more men but no large differences in age or marital status. Cheadle's study did not include transient patients, who are disproportionately male. There are also major differences in the clinical findings between the two samples. The findings are not directly comparable in all respects, because Cheadle *et al* did not use the Catego programme to process their PSE data, but only 27 of their 157 patients (17 per cent) showed 'schizophrenic or paranoid symptoms', while 60 of our 141 patients (43 per cent) were classed as 'schizophrenic or paranoid cases'. The difference cannot be explained by our use of the PSE being confined to patients living with a supporter, since our scrutiny of case notes showed that a similar proportion of unsupported patients had psychotic symptoms.

An important methodological difference between the two studies was in the timing of the PSE interviews. In Salford the interviews did not begin until 13 months after the end of the year in which the index contact had occurred, so no new or recent cases were interviewed. However, even if we exclude from our sample all patients whose first psychiatric contact occurred less than 13 months before their index contact, the proportion of the remaining cases in Catego classes S or P is *still* high—almost 40 per cent (49 of 123 patients). There again, because our PSE interview was conducted as soon as possible after the index contact, it was more likely than Cheadle's to coincide with a recrudescence of psychotic symptoms. Indeed, in 13 of the 49 psychotic cases (27 per cent) the index contact was a re-referral, following a lapse of contact with the service. Our repeat PSE study, carried out approximately a year after the index contact, may show a prevalence of schizophrenic and paranoid symptoms more like that found in Salford. Even so, the Salford psychiatric service may have been more effective than the one we studied, perhaps offering more intensive and persistent follow-up and having greater success in maintaining anti-psychotic medication.

In the new DGH-based psychiatric service only a small minority of all schizophrenic patients under 65 are mental hospital inmates: 90 per cent receive their psychiatric care from the DGH unit. Half are living with close family members in private households. Women are able to maintain residence with a supporter more frequently and for a longer time than men, partly because they marry at a rate similar to the general population of women (though more divorce), while male schizophrenics are much less likely to marry. Less than one third of the patients who no longer live with close supporters are able to maintain independent lives in private households, and the impoverished alternatives available at present seem strong reason for trying to maintain supporter–patient households for as long as possible.

The prevalence of behavioural problems and limited social performance reported by relatives in the present study is close to the findings of Creer and Wing (1974). About two-thirds of their patients displayed 'socially embarrassing' behaviour to a moderate or marked degree in the previous year, and 90 per cent showed 'socially withdrawn' behaviour. Levels of unsatisfactory social performance were also similar. However, 19 per cent of Creer and Wing's relatives reported no adverse effects on themselves in the previous year, whereas only 10 per cent of the present sample gave no evidence of family hardship. ('Hardship', the prevalence of predefined household problems, is a broader concept than 'burden', which refers to that element of hardship explicitly attributed to the patient).

We found that levels of subjective emotional distress and scores on the GHQ were highest among new supporters: this effect may be explained in two ways. Supporters may become progressively more resigned or detached as they learn their roles by trial and error and become more skilled. Alternatively, long-term supporters may be a selected group, the strongest survivors who have always coped well. Distress is not the same thing as relatives' 'expressed emotion', which has been considered to have a causal effect on schizophrenic relapse (Leff *et al*, 1982). However, a relative experiencing severe distress in response to a disturbed patient is likely to behave in ways that exacerbate the situation. The need for long-term follow-up of schizophrenics and prompt availability of psychiatric care at times when symptoms are beginning to reappear is clear.

There was evidence, which we shall test further during the follow-up, that drop-out and failure to persist with medication are major causes of relapse. More systematic and co-ordinated services for patients with relapsing, psychotic disorders will have to be developed in the community as hospital beds become increasingly scarce resources (Freeman, 1981).

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