

Schizophrenic patients who were never treated – a study in an Indian urban community

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ABSTRACT

Background. A significant number of patients with severe psychiatric disorders remain untreated in the community although health services are available. The factors related to non-treatment are not well understood.

Method. A door-to-door survey was conducted on an Indian urban population of 100 000 using standardized screening and clinical instruments as a part of a larger epidemiological study. Treatment status was determined from multiple sources of information.

Results. Nearly one-third of 261 schizophrenia patients were found never to have received treatment. They were older in age and ill for a longer duration than those who had been treated and were more symptomatic and severely disabled. They were more often uneducated and divorced and lived with larger extended/joint families. This last factor was considered as being the important factor in determining whether the patient received treatment.

Conclusion. The larger extended/joint family, which was able to compensate and cope with the dysfunctional member, seemed to be the crucial factor related to non-treatment of the schizophrenic patient.

INTRODUCTION

It has been emphasized that the study of untreated psychiatric disorders is an important issue in psychiatric epidemiology (Dohrenwend & Dohrenwend, 1982). It has been observed that a substantial number of patients in the community even with severe psychotic disorders, like schizophrenia, do not receive antipsychotic drugs. The clinical characteristics of untreated patients with schizophrenia and the reason why they have remained untreated are not well understood (Geddes & Kendell, 1995).

It was opined that most schizophrenics in developed countries would eventually end up in psychiatric treatment settings (Ødegaard, 1952). In the future, prolonged periods of initially untreated psychosis are unlikely to be

encountered in a research context, other than very occasionally (Waddington *et al.* 1995). The growing rarity of studying untreated schizophrenics may not apply to the non-Western countries (Sikanartey & Eaton, 1984). Reports from countries like India have shown that several patients did not receive any treatment, despite being severely ill for many years (Isaac *et al.* 1981). Though this was attributed to poorly developed psychiatric services and their low accessibility, especially in the rural areas, it was seen that there were a number of patients living in and around a large towns and cities who were untreated for many years despite easy availability of health services (Isaac *et al.* 1981).

This paper is based on an analysis of data gathered during a community survey conducted in an urban population in the city of Madras (renamed Chennai), which identified a substantial number of schizophrenia patients who had never received any treatment from the onset of the illness. This analysis was done with the

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objectives of identifying the characteristics of these untreated schizophrenia patients and the factors that could explain why they remained untreated despite easy availability of health services.

METHOD

Background

The survey in the urban community was conducted in 1985–6 with the study centre at the Department of Psychiatry, Government General Hospital, Madras. One objective of the study was to measure the prevalence of 'functional' psychoses in the community. The 'functional' psychoses were those defined by the ICD-9 (WHO, 1978), which did not have an organic basis. They were: schizophrenia, affective psychoses, paranoid psychoses and other non-organic psychoses (ICD-9 categories 295 to 298). The ICD-9 criteria used were appropriate at the time that this study was done. The study involved a door-to-door survey covering a population of nearly 100 000 in two residential areas of the city of Madras. The prevalence rates observed were reported (Padmavathi *et al.* 1988). The re-analysis of the data regarding untreated patients with schizophrenia was done at the Schizophrenia Research Foundation (India).

Catchment area

The two residential areas surveyed were located adjacent to the study centre with the farthest point being about 6 km from the hospital. No particular religious or community group predominated in the areas studied. The occupational activities of the population resident in the areas included white-collar jobs, service/trade activities, skilled and unskilled manual labour and fishing. For purposes of the survey, a population of 100 000 was taken as the target. As the total population of the two areas exceeded the target, the total population of one area and a part of the other area adjacent to the research facility were surveyed.

Psychiatric services

The psychiatric health service were available for the population from four state-run general hospitals and a large mental hospital located within 10 km from their residences. All of these

centres have been present for more than 30 years. Psychiatric consultation can be sought from any of the 50-odd psychiatrists in private practice in the city and any number of general practitioners practising within their locality. The choice of the facility depended mainly on the affordability of the consumer.

Survey method

The survey was conducted in two stages. The first stage was a door-to-door survey of all the households in the study area in order to detect probable cases of functional psychosis with the use of a short screening instrument. The second stage was a detailed evaluation of all the probable cases detected using standardized instruments.

Door-to-door survey

Each head of the household was interviewed about psychological health problems in the family, using the screening instrument. If there was a positive response on the screen, the probable patient was interviewed in detail by the psychiatrist.

Instruments used

For purposes of screening for probable cases of functional psychosis, the Indian Psychiatric Survey Schedule (Carstairs & Kapur, 1974) was used. Before the start of the survey, the survey team was trained in the use of the screening instrument. The reliability was tested using a clinical population wherein a high inter-rater reliability coefficient of 0.92 was measured. Validation was carried out using the target population. A total of 800 households screened were examined in detail by the author (R.P.), who was blind to the screening result. It was seen that the instrument had no false positive responses and had false negativity of 6.3% as it had missed one out of 16 cases detected during detailed evaluation (Padmavathi *et al.* 1988). The probable patients identified during the survey were interviewed by the psychiatrist using the Present State Examination (PSE: Wing *et al.* 1974), Psychiatric History Schedule (PH) and the Social Description Schedule (SD) (WHO, 1973) and Disability Assessment Schedule (DAS: WHO, 1988). A proforma to assess health service utilization was used, which

assessed the awareness of the family about the illness, the psychiatric health services known to them and their utilization.

Treatment status

The patients' lifetime exposure to anti-psychotic medication was determined through discussion with the head of the household and other family members as well as with the patient, examination of prescription sheets and the available medical records. We were satisfied that accurate medication histories were obtained, especially in those who had never received such medication. In this regard it is to be noted that a psychiatric consultation and taking anti-psychotic medication is an important event in the lives of the patients and their families for two reasons. One was the cost involved and the second was the stigma and hesitation in seeking such help. Hence a history of taking such treatment for whatever period would not easily be forgotten.

Analysis

Comparison was made between the patients who were never treated and those who had received anti-psychotic drugs on their socio-demographic, clinical and health service utilization factors using chi-square and Student's *t* test of significance. The SPSS/PC+5.0.1 version (Norusis, 1992) and Epi Info (version 5.01b) (Dean *et al.* 1990) was used for the analysis of data.

RESULTS

The survey covered a total population of 101 229 (male: female ratio = 1.06:1). Almost 43% of this population lived in slum areas, 66% lived in nuclear family settings and 91% were Hindus. About 18% had received no schooling at all and 70% of the families had incomes of Rs. 1000 or less per month. From the total population, 66281 were over 15 years of age and of these 265 were diagnosed as suffering from schizophrenia.

The data on four of the patients with schizophrenia were incomplete. In the cohort analysed ($N = 261$) there were 154 males and 107 females. Their mean age was 36.02 years (s.d. = 12.24) with 7 (2.7%) patients being less than 20 years of age and 96 (37%) 40 years and over. The mean duration of the illness was 11.64

years (s.d. = 17.32). The illness was present for less than 1 year in 16 (6%) patients and for more than 15 years in 65 (25%) patients. Nearly one-third of them had never been to school ($N = 84$, 32%). A little more than half of them lived in slum areas ($N = 146$, 57%), with 68% of their families having monthly income of less than Rs. 1000. Half the number of patients ($N = 135$, 51%) lived in a nuclear family setting and the rest with extended/joint family units. None of the patients was living alone or in other types of living arrangements. Sixty-one per cent ($N = 159$) had been married, but of them 63 (40%) were divorced/separated. The employment status assessed in the males showed that 69 of them (45%) were employed. The treatment history of the patients showed that 75 (28.7%) had never received any psychiatric treatment at all (the untreated (UT) group). The remainder (186, 71.3%) had received anti-psychotic drugs at some period during their illness and/or was under treatment (the treated (TT) group).

The UT group was significantly older (39.26 years, s.d. = 12.17) than the TT (34.75 years, s.d. = 12.0; $t = 2.72$, $P < 0.01$). They were also significantly older at the onset of the illness (UT = 28.7 years, s.d. = 9.25; TT = 26.2 years, s.d. = 9.31; $t = 1.97$, $P < 0.05$) and were ill for a longer duration than the treated group though not to a significant level (mean = 15.3 years s.d. = 21.95 *v.* 10.17 years s.d. = 14.88). But on closer analysis it was seen that a larger number of the UT group (29, 39%) was ill for 15 years or more compared with 36 (19%) ($P < 0.01$) of the TT group.

Table 1 shows the other factors that characterized the UT group: uneducated status, living in an extended/joint family, having a broken marriage. The UT group was more often symptomatic than the treated at the time of evaluation, the global disability was severe in almost all of them and in the episode of onset without any remissions and relapses. The PSE symptoms of sleeplessness, self-neglect, blunted affect, non-social speech and lack of insight were more in the UT patients. It was noted that the family members living with them were less aware of the psychiatric nature of the illness. The variables that did not separate the two groups were sex of the patient, type of residential setting, being ever married, mode of onset of illness, PSE symptoms other than listed above.

Table 1. Comparison between untreated (UT) and treated (TT) patients

Variable	UT (N = 75)	TT (N = 186)	P	Odds ratio (95% CI)
Sex (male)	43	111	< 0.73	0.91 (0.51–1.62)
Age (years) > 40	36	60	< 0.01	1.94 (1.08–3.48)
Illiterate	33	51	< 0.01	2.08 (1.15–3.78)
Broken marriage	27	36	< 0.01	2.34 (1.24–4.44)
Employed (males)	15	54	< 0.12	0.57 (0.26–1.24)
Slum life	47	99	< 0.16	1.47 (0.82–2.65)
Extended/joint family	46	80	< 0.01	2.10 (1.17–3.77)
Family aware of psychiatric nature of problem	41	134	< 0.01	0.47 (0.26–0.85)
Illness onset insidious	55	119	< 0.15	1.55 (0.82–2.93)
Illness continuous	57	70	< 0.001	5.25 (2.75–10.10)
Illness duration > 15 years	29	36	< 0.001	2.63 (1.40–4.94)
Clinical status				
Symptomatic	74	117	< 0.001	43.64* (7.17–1771.54)
Severe global disability	74	129	< 0.001	32.70* (5.35–13331.27)
PSE symptoms				
Blunted affect	68	126	< 0.001	4.63* (1.96–12.6)
Speech poverty	61	107	< 0.002	3.22 (1.61–6.50)
Self neglect	68	124	< 0.001	4.86* (2.06–13.22)
Poor insight	64	101	< 0.001	4.90 (2.32–10.54)
Insomnia	32	52	< 0.02	1.92 (1.06–3.48)

* Exact confidence limits.

DISCUSSION

The analysis of the data from a survey conducted in 1985–6 in a community living in a metropolitan city revealed some interesting facts. Nearly one-third of the patients with schizophrenia was found to have never received anti-psychotic treatment. It was surprising to find such a substantial proportion of patients remaining absolutely untreated despite the nearness and the affordability of the facilities for treatment that had been available over many years.

Were the patients untreated because their illness was different in nature and severity from that of the treated patients? Do they fit into that category of patients who should not be treated with neuroleptics, referred to by Buckley (1982)? The patients deemed not to require any treatment were those with milder forms of illness and were amenable to non-drug therapies (Davis, 1975) and featured often in therapeutic communities. The untreated patients studied here were, on the contrary, more severely ill for a long duration often experiencing a continuous illness and severe disability. The observations did not support the impression that when more malignant forms of psychosis, like schizophrenia, are present to a severe degree the

likelihood of receiving treatment is higher (Wing *et al.* 1981).

If the issues of health service availability and clinical status were not related to non-treatment of schizophrenia patients were the social factors related to it? The sex of the patient was seen to have no role in deciding who received treatment. In the community studied there was no predominance of either sex with regard to receiving treatment. Considering the age factor, it was seen that the untreated patients were older and had their illness later in life. Younger persons and those who had some education had the benefit of treatment, probably because of their higher potential productivity. Though the treatment facilities were present for many years families were possibly less hesitant to seek treatment in more recent times. This could also account for the observation that patients who received treatment were younger. The socio-economic status, as reflected by the type of housing of the patients, did not seem to influence the need to seek treatment, as the patients from the poorer stratum living in the slums were no more likely to be untreated.

The primary social supports of the patients were studied. Among the untreated patients there were more who had been separated/divorced. A poor marital outcome was a factor

shown to be related to a poor course and outcome in schizophrenia (Sartorius *et al.* 1977; Thara & Srinivasan, 1997). It was seen here that poor marital outcome could be related to seeking treatment.

The family structure of the patients was seen to be significantly different with more of the untreated living in larger extended/joint type family units. The extended/joint family system frequently seen in developing countries, was considered therapeutic to the patients as they provided a very effective umbrella of care and protection to the severely mentally ill patients and a better outcome in them (Leff *et al.* 1990; Thara & Rajkumar, 1992). The present analysis showed that the same family system was associated with the status of the patients having never received treatment. It could only be surmised that the same compensatory support mechanisms from these larger families, implicated in better outcomes of schizophrenic patients in countries like India, were the probable reason for the patients remaining untreated. This impression drew strength from the interviews with the families of many of the patients. The families expected little from the patient in the way of contribution to the family and other members were able to compensate for lack of participation by the patient.

It may be said that some of the factors, e.g. poor marital status, symptomatology and disability are an effect of being untreated. Skirting aside the cause-effect issue, the question that needed an answer was why these severely ill patients continued to remain untreated for many years? Of all the factors considered the crucial one seemed to be the type of family – a large extended/joint family with multiple care-givers and wage-earners was able to take care of the chronic continuously severely ill patient without any medical treatment. To get the untreated to treatment one should take into account the family's participation in the effort. This is more relevant in societies like India where the family plays a major role in patient management.

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