Reasons for Schizophrenia Patients Remaining out of Treatment: Results from a Prospective Study in a Rural South Indian Community

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ABSTRACT

Background: A few studies have examined the factors associated with schizophrenia patients remaining untreated in India. Materials and Methods: We identified 184 schizophrenia patients in a rural community, offered the treatment with antipsychotics and followed them up in their Primary Health Centers for 1-year. Twenty-nine (15.8%) patients remained untreated at both the baseline and 1-year follow-up despite our best attempts to keep them under the treatment umbrella. They were interviewed in detail regarding the reasons for remaining untreated. This group was compared with another group of patients (n = 69) who had stopped the treatment at baseline but were successfully brought under the treatment umbrella throughout the 1-year follow-up period. Results: The reasons for remaining untreated were (n; %): (a) Unsatisfactory improvement with previous treatment attempts (19; 65.5%), (b) poor bond between the patients and the families (6; 20.7%), (c) active symptoms not allowing any treatment efforts from the family members (6; 20.7%), (d) magico-religious beliefs about the illness and its treatment (4; 13.8%), (e) poor social support (3; 10.3%), (f) adverse effects of the medications (2; 6.9%), and (g) perception of recovery and cure (1; 3.4%). For many patients, a constellation of these reasons was responsible for them remaining untreated. In contrast, the common reasons for those who restarted medications to have stopped the treatment at some time were the lack of awareness, the need to continue medications (47; 68.1%), and the financial constraints (28; 40.6%). Conclusion: The predominant reason for schizophrenia patients not remaining on the treatment in this rural community was the families’ lack of faith in antipsychotic treatment. Provision of comprehensive treatment package including medical, psychosocial and rehabilitative services, and sensitizing the community about benefits of the treatment may help in ensuring that all patients with psychosis receive the best care.

Key words: Remaining untreated, rural community, schizophrenia
INTRODUCTION

There is a huge treatment gap with nearly 50-90% persons with mental illness not being able to access the services.[1] There is a move in the National Mental Health Programme[2] to take treatment to the patients’ doorsteps. However, a proportion of patients are likely to remain untreated even if this happens. For instance, a door-to-door survey in an urban city in South India[3] reported that nearly a third of schizophrenia patients remained untreated despite the availability of the treatment services. Extra efforts may be required to provide the treatment to them. As a first step, we need to understand the factors that cause patients to refuse the treatment. Unfortunately, there are no studies in this regard in our country, especially so from the rural communities perspective. As part of a project on community intervention of schizophrenia (naturalistic follow-up study of schizophrenia patients living in a rural South Indian community: CoInPsyD), we had earlier reported that patients who continuously received antipsychotics and experienced significantly lesser disability than those who did not receive them. [4] In this paper, we explored the reasons as to why patients living in this rural community remained untreated despite making the treatment available at their doorsteps. We also compared such patients with the patients who adhered to treatment throughout the 1-year of follow-up.

MATERIALS AND METHODS

Subjects

The sample for this study consisted of schizophrenia patients recruited in an administrative block (Thirthahalli Taluk of Karnataka State) in South India. Thirthahalli Taluk consists of 1324 villages and a town that serves as the headquarters. The town has a population of 14,308 and the total population of the Taluk is 143,345. The project goals are to identify all schizophrenia patients living in this rural community, treat them and follow them up. We trained 54 village health workers to identify the patients with severe mental disorders in the community. The health workers were asked to refer all such patients, irrespective of their treatment status, to the study team. The health workers maintain community survey registers, which are updated regularly. Two trained research social workers interviewed the village health workers about the presence of persons with symptoms of psychosis in each family under their care, referring to these registers (a total of 29,432 families). Research psychiatrists screened the patients, thus, identified using International Classification of Diseases-10 (WHO 1992) criteria. They used the Mini International Neuropsychiatric Interview[5] to confirm the diagnosis. A total of 238 persons were diagnosed as having schizophrenia. The research social workers conducted a door-to-door survey in randomly selected 10% of the villages (133 villages) to look for patients who could have been missed out by our method of identifying the patients. We could identify six patients with schizophrenia by this method, giving an estimated number of about 60 (17.3%) missed cases, overall. All patients were offered treatment (described under treatment, below) and followed up. At the time of analyzing the effect of treatment on disability,[6] 215 patients had completed 1-year of follow-up. Of these 215, there were 25 dropouts (change of diagnosis = 3; withdrawal of consent = 16; death = 4; and not traceable = 2) and the information for 6 patients was missing. Of the remaining 184 patients, 29 (15.8%) had discontinued the treatment at the time of recruitment to our program, and despite our best efforts, remained out of treatment throughout the 1-year of follow-up period (the off-off group). Sixty-nine patients (37.5%) had discontinued the treatment before recruitment but were under regular treatment through the follow-up period (the off-on group). The remaining 86 (46.7%) were on treatment at the time of recruitment and continued to take the same throughout the follow-up period (the on-on group).

Treatment

At the time of recruitment into the study, patients and their family members were requested to provide all information including medical records pertaining to patients’ mental illness. The majority were prescribed antipsychotics. They were given the choice of obtaining the treatment from either the study team or from the private psychiatrists practicing in the region. The treatment details were noted. The efforts were made to impress upon the patients and their families the potential benefits of treatment. Follow-up was done in the Primary Health Centers (PHCs). For those patients who were not adherent to the treatment, the following measures were taken: Home visits, the supply of medications at home, phone calls, free consultation, and offering free inpatient care. Twenty-nine patients who remained untreated both at the baseline and at the end of 1-year follow-up period were interviewed to know the reasons for stopping medications earlier (to recruitment) and continuing to do so. We compared this group (off-off group) with patients who were off treatment at the baseline but on regular treatment at 1-year follow-up (off-on group; n = 69). The patients in the off-on group were adherent with their antipsychotics through the period of follow-up; the treatment was provided at the doorstep to them; none discontinued treatment for >1-month during the follow-up period. As all patients were staying with family members;
adherence could be easily cross-checked. A checklist was used to know the reasons for stopping medications.

RESULTS

Both groups were comparable with respect to the sociodemographic and clinical variables [Table 1]. The reasons for patients remaining untreated in the off-off group were varied and complex [Table 2]. The most common among them was that the family’s previous treatment efforts failed to show an appreciable improvement. This was followed by poor bonding between the patients and their family members and the latter’s loss of interest in their treatment. These patients were either wandering away from their homes or would to remain in one corner of the home without any active involvement with the family affairs. An equal number of patients were severely symptomatic and were without insight. They would actively resist any attempts to treat them. Two families reported poor support financial condition even to commute to the PHCs while three reported that there was no one to accompany the patient to the PHCs. Three patients had experienced adverse effects when they used antipsychotics earlier; this experience had resulted in the belief that medications are useless, and they only cause problems. One patient in the off-off group had taken medications, completely improved and was functioning well. In this case, the family was not ready to accept that there can be a risk of relapse, and hence that the patient remained untreated. One patient who also had co-morbid alcohol dependence remained untreated for a different reason: His wife reported that whenever she used to get him treated, he would remit and start earning. He would use his earnings to consume alcohol and would physically abuse his wife and children and would disturb his neighbors. His wife refused to get him treated since him remaining in a psychotic state was better for her.

In contrast, the most common reason for patients in the off-on group for stopping the treatment (before recruitment into our study) was lack of awareness about the need to continue medications ($n = 47$; 68.1%). This was followed by the financial constraints ($n = 28$; 40.6%) in continuing treatment. These were addressed by our team and consequently, all these patients remained adherent throughout the 1-year follow-up period.

DISCUSSION

Our study explored the reasons due to which rural schizophrenia patients remain untreated even when the treatment is made available at PHCs. Failure to experience an appreciable improvement with previous efforts at treatment was the most predominant reason for patients remaining off treatment, whereas lack of awareness about the need for long-term treatment and financial reasons were the main reasons for stopping treatment in those who restarted and continued the medications. This was the group for which treatment in PHCs helped a substantially.

A complex set of reasons were responsible for patients not seeking treatment in spite of extra efforts from

| Table 1 Sociodemographic and clinical variables |
| Variable | Off-off group ($n = 29$) | Off-on group ($n = 69$) | $\chi^2$ | $P$ |
| Mean age in years (SD) | 42.5 (13.4) | 41.3 (10.5) | 0.47 | 0.64 |
| Mean years of education (SD) | 5.5 (5.1) | 6.4 (4.9) | 0.73 | 0.47 |
| Socioeconomic status ($n$ [%]) | | | | |
| Low | 17 (32.1) | 36 (67.9) | 0.38 | 0.83 |
| Middle | 8 (25.8) | 23 (74.2) | | |
| High | 4 (28.6) | 10 (71.4) | | |
| Mean duration of illness in years (SD) | 12.6 (10.1) | 12.4 (10.3) | 0.08 | 0.94 |
| Mean total PANSS at baseline (SD) | 91.3 (24.5) | 81.2 (27.4) | 1.6 | 0.12 |
| Mean total ideas at baseline (SD) | 9.6 (3.0) | 8.8 (3.4) | 1.11 | 0.27 |

PANSS – Positive and negative syndrome scale; SD – Standard deviation

| Table 2 Comparison of reasons for stopping treatment |
| Reasons | Off-off group* ($n = 29$) | Off-on group* ($n = 69$) | $P$ |
| Un satisfactory improvement with previous treatment efforts | 19 (65.5) | 9 (13.0) | <0.01 |
| Actively symptomatic patient resisting all efforts to get treated | 6 (20.7) | 2 (25) | <0.01 |
| Poor bonding between patient and family members | 6 (20.7) | 0 (0) | <0.01 |
| Magico-religious beliefs about illness and treatment | 4 (13.8) | 0 (0) | <0.01 |
| Poor social support | 3 (10.3) | 2 (2.9) | 0.15 |
| Adverse effects of medications | 3 (10.3) | 0 (0) | 0.02 |
| Financial reasons | 2 (6.9) | 28 (40.6) | <0.01 |
| Perception of cure | 1 (3.4) | 0 (0) | 0.29 |
| Patient during symptoms would remain sober and consequently was less disruptive toward family and neighbors | 1 (3.4) | 0 (0) | 0.29 |
| Lack of education about the need to continue medications | 0 (0) | 47 (68.1) | <0.01 |

*Total of each cell is more than “n” as some patients had reported more than 1 factor
the treating team. This issue calls for the serious consideration from policymakers and service providers. Lack of appreciable improvement when the patient initially received the treatment emerged as an important reason for the patients' and families' reluctance to restart the treatment. This is understandable patients and families have little knowledge about the nature of schizophrenia; if patients do not experience an appreciable improvement when they make their first tentative approach to biomedical care and, instead, experience adverse effects, one can expect them to have disbelief in such treatments. It is important that when patients approach for treatment for the 1st time, concerted efforts should be made to ensure that the patients experience substantial improvement. This includes educating them about the gradual process of symptomatic response and social recovery as well as how adverse effects, if experienced, could be addressed effectively. It also includes providing the comprehensive psychosocial intervention to ensure that symptomatic remission translates into meaningful recovery. The most patients in this cohort had approached psychiatrists when the first generation antipsychotics were the mainstay treatment. If the second generation antipsychotics, which have better short-term tolerability profile, are used, the initial experience of the patients and carers could be substantially different. It could lead to better overall attitude toward continuing treatment where necessary. Some of the remedial measures may include the provision of second generation antipsychotics, especially clozapine when there is poor response to other antipsychotics, offering inpatient care at affordable costs, provision of crisis intervention team and enhancing the attitude and knowledge of the community about the mental illness. Other reasons included poor family support and severity of illness among patients. Our research team could not convince the family and the patients about the need for treatment. Ideally, some of these would have to be treated as inpatients against their will through due legal process. Our efforts to achieve this were met by a number of practical difficulties including the reluctance of the families, community members, and authorities.

In stark contrast to the reasons for nonadherence in the off-off group, patients in the off-on group had stopped medications because of lack of awareness about the continued treatment and because of financial reasons. It should be noted that nearly all patients were initially treated by private psychiatrists, and patients had to pay for consultation as well as medications. If both these expenses are addressed. As is envisaged in the District Mental Health Programme, a large proportion of apparently nonadherent patients may be encouraged to continue the treatment. We have already recorded that continuation of antipsychotic medication is strongly associated with a reduction of disability.[4]

An important drawback of our study was that we did not use any validated measures to understand the reasons due to which patients remained untreated. Future prospective studies should take into account this issue.

CONCLUSION

Various factors prevent the schizophrenia patients from receiving treatment even when it is made available at the PHC level. A number of measures including the provision of comprehensive medical and rehabilitative care from the start of treatment, raising community’s awareness regarding benefits of treatment, sensitizing authorities about legal provisions for treating patients without insight against their will, etc., are required for them to be brought under the umbrella of treatment.

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Conflicts of interest
There are no conflicts of interest.

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