Disability in a Group of Long-stay Patients with Schizophrenia: Experience from a Mental Hospital

Kalita Kamal Narayan, Deuri Sailendra Kumar

ABSTRACT

Background: Recovery from schizophrenia is a complex concept. Remission of symptoms of psychotic illnesses is not necessarily linked to better functioning. Among various causes of disability, mental illnesses account for 12.3% of the global burden of diseases. Long-term hospitalization has been recognized as counterproductive and a contributory factor of disability associated with schizophrenia. Under various circumstances, many persons with mental illness are brought to mental hospitals but the measures taken for their rehabilitation and follow-up care is insufficient. Aim: In the present study we tried to find out the level of psychopathology and the associated disability in a group of patients with schizophrenia who have been staying in a mental health institution for more than 5 years due to lack of proper caregivers in the society or in their home. Materials and Methods: The study is conducted in a mental hospital of northeast India. Of the 40 patients staying for more than 5 years in the hospital, 28 fulfilled the criteria for inclusion. The Brief Psychiatric Rating Scale and World Health Organization Disability Assessment Schedule II (WHO DASII) were used for those patients. Analytical statistical methods were used subsequently. Results: Male patients were significantly older and had prolonged duration of stay. But the level of psychopathology did not differ significantly between male and female patients. Under WHODASII, understanding and communication problems are more prominent in both the groups. Of late, there are very few cases that required prolonged stay in the hospital. Many patients are fairly functional and are considered suitable for care outside hospital premises. Conclusion: Prolonged hospital stay is associated with more disability. Shorter hospital stays with proper family support is an ideal way to counteract this issue. However, due to the inadequate mandate in the Mental Health Act (MHA) 1987 and lack of other supportive facilities, patients often tend to languish in the hospital for longer duration, causing harm to the patients and draining scarce state resources. It is therefore necessary to revisit the MHA 1987 and provide adequate rehabilitative measures for the needy patients.

Key words: Disability, long stay, mental hospital, rehabilitation

INTRODUCTION

Recovery from schizophrenia is a complex concept. The scientific community may view recovery as an outcome defined by its emphasis on symptoms amelioration and ability to function independently. However for the consumer-focused activists and proponents, recovery is a process toward achieving, among other things, empowerment, hope, and respect. In contrast to clinical remission, functional recovery requires that a person be able to perform the daily activities that are required for self-maintenance. Harvey and Bellack in this context reviewed extensive literature that suggests that an improvement/remission of symptoms of psychotic illnesses is not necessarily linked to improved functioning, nor does there appear to be any close links between either of these factors and well-being.
The task of judging an individual’s functional recovery is not an easy one for health-care professionals. Using clinical judgment alone may not be enough, given the fact that the clinicians are not embedded into the natural environment of those they work with, thereby making it difficult to know how an individual functions in the real world. In psychiatric disorders, many do not achieve full functional recovery. This leads to many people living with disability. Among various causes of disability, mental illnesses account for 12.3% of the global burden of diseases, and this is forecasted to rise to 15% by 2020. As per the version 2 estimates for global burden of a disease study, schizophrenia is the sixth leading cause of Years Lived with Disability. In an Australian study, it was reported that as high as 93% of the patients with schizophrenia have some sort of activity restriction. Despite having a high level of disability associated with high economic burden on the caregivers and the society due to these disorders, their rehabilitation has not gained adequate attention. In India, Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act has been passed by the Parliament on December 22, 1995. The government notified the act on January 5, 1996, and it has been in effect since February 7, 1996. Disability due to mental illnesses was included in the act by an amendment.

Nearly one-third of the persons with psychotic disorders have significant disability. In the Study on Determinants of Outcome of Severe Mental Disorder initiated by World Health Organization, it was found that nearly 50% had only one psychotic episode while 15% had continuous unremitting illness. Thirty-three percent had two or more episodes followed by remission. In the developing countries, a complete clinical remission rate was significantly higher as compared with that of the developed countries (37% vs 15.5%). The researcher commented that ‘sobering experience of high rates of chronic disability and dependency associated with schizophrenia in high income countries, despite access to costly biomedical treatment, suggests that something essential to recovery is missing in the social fabric’. Hence the rehabilitation measures need to be molded as per the sociocultural need of the society.

In a study done in Chennai, India, it was reported that 75% of the male patients were found employed at the end of 20 years of follow-up. The authors commented that the lack of social security benefits and pressure to find work as primary wage earners may have contributed to the high rate of employment besides most patients belonging to the low or middle class with jobs in the unorganized sector as street vendor, sales staff, or domestic help. Again in a multicenter study done in India, it was found that patients with disability due to mental illness suffered more discrimination as compared with their counterparts with physical disability. They also found that there was very less awareness regarding existing law and social programs. Stigma was a major reason for underutilization of the services. So, large-scale awareness programs on mental health-related issues are also needed. This will hasten treatment, improve functioning, and reduce disability. A proper tool for the measurement of disability will help to plan services, programs, and welfare benefits for them.

A positive correlation between duration of untreated psychosis and negative treatment outcome has been replicated in many studies. Long-term hospitalization has been recognized as a contributory factor to disability associated with schizophrenia. In mental hospitals we frequently encounter patients with long duration of hospitalization leading to institutionalization. Again mental illnesses have been recognized as a major cause for homelessness. So a proper coordination between different agencies of the society is needed for proper handling of these issues.

Mental health care has improved over the last century due to advancements in many fields. The progress in scientific knowledge, development of psychotropic drugs, replacement of the hospital-centered model by community care aiming at patients’ comprehensive care, and their social reinsertion are factors that should be stressed. Among the numerous fallouts of this ‘revolution’, the most striking were the changes in patients’ profiles and goals and length of hospitalization. Consequently, old psychiatric hospitals have become general hospitals or, inversely, psychiatric wards were created inside general hospitals.

There have been legal provisions in Indiathat provide guidelines for the treatment of mentally ill persons in a hospital setup. The Indian Lunacy Act 1912 considered the mentally ill persons as ‘noncriminal lunatic’. After that, there was a change and the Mental Health Act (MHA) 1987 rephrased the term and made it more humane by replacing the term with ‘mentally ill person’. But this act is applicable only to mental hospitals and psychiatric nursing homes. There is sufficient provision through which a mentally ill person can enter into a treatment facility either voluntarily or involuntarily. But there is no proper provision for the rehabilitation of the needy persons in the said act. Again due to some orders passed by the legal authorities, it becomes problematic for the treating team to send the mentally ill person back to the community at the earliest possible time which may help in the rehabilitation process. Consequently, we see many patients staying in mental hospitals as long-stay patients.
Moreover, many homeless mentally ill persons are brought for the treatment to mental hospitals with reception order under provision of MHA 1987. Due to various reasons at times, it becomes difficult for the treating team to reintegrate the person with the family concerned. There has been no specific measure for dealing with such persons available under the provision of MHA 1987. Hence they eventually turn out to be long-stay chronic patients. This leads to lack of admission facilities for the actively ill patients for unnecessary prolonged hospitalization of this group of chronic patients. Again it bears enormous cost on the health system. In a 3-year follow-up study of 321 discharged state hospital patients, the cost of community care was found to be less than half of the estimated cost of state hospitalization.[18] Similar finding is reported by Hallam et al. in 1994 and Salize et al. in 1996.[18,19] So we need to develop a proper chain of level of treatment for them as per the need of the society in accordance with the cultural norms.[19,20]

In the present study we tried to find out the level of psychopathology and disability in a group of patients with schizophrenia without having proper caregivers staying in a mental health institution for more than 5 years and tried to figure out the possibilities of rehabilitation for them.

MATERIALS AND METHODS

The present study was conducted at Lokopriya Gopinath Bordoloi Regional Institute of Mental Health, Tezpur, Assam. It was established in 1876 as a lunatic asylum. As per the directives of the Supreme Court, it has been converted into a postgraduate teaching institute for the mental health disciplines. The Mental Health Act is followed in the hospital in the treatment of the patients. In the hospital, currently there are 40 patients who are staying in the hospital for more than 5 years. Of these 40 patients, 16 are women.

The inclusion criteria are as follows:
- Mentally ill persons having stayed in the hospital for more than 5 years
- Patients whose family is untraceable
- Patients who do not have proper family support.

The exclusion criteria are as follows:
- Patients having mental retardation.

Of these 40 patients, 6 women and 5 men have mental retardation and a female patient is dumb. Hence, 28 patients are included for the study. By the term ‘proper family support’ we meant patients who do not have their parents alive or were rejected by other first-degree family relatives due to various reasons.

The tools utilized are as follows:
- A semistructured proforma for collecting information regarding sociodemographic variables, circumstances of admission to the hospital, duration of hospital stay, availability of the family of the persons
- ICD-10 criteria for clinical description and diagnosis guidelines: International Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) is the current diagnostic guideline for diagnosing the health problems across the globe adopted by the World Health Organization, whose Chapter V (F) is related to the behavioral problems
- Brief Psychiatric Rating Scale (BPRS)[21]: It was developed by Overall and Gorham in 1962. It is an 18-item scale that measures major psychotic and nonpsychotic symptoms in individuals with major psychiatric disorders, particularly schizophrenia. It assesses the symptoms on an 8-point scale (where 0=not assessed and 7=extremely severe)
- World Health Organization Disability Assessment Schedule II (WHODAS II): It is an instrument based on the International Classification of Functioning, Disability and Health developed by World Health Organization for standardized cross-cultural measurement of health status. It has various forms from self-administered to clinician administered. In the current study we utilized the 6-item clinician proxy version that assesses disability in six domains, namely, understanding and communication, getting around, self-care, getting along with people, household/work/school activities, and participation in the society.[22]

The whole procedure was applied by a single examiner, and it was approved. Simple statistical measures were applied wherever appropriate for interpretation of the results.

RESULTS

Of the 28 recruited patients, 19 (67.86%) were men. Sixteen (57.14%) of them are illiterate; 12 of these patients have some of their family members alive and are traceable but refused to take responsibility of these patients. Families could not be traced for the rest of the patients due to various reasons despite taking help from the different agencies both government and nongovernmental. Four (14.29%) of these 28 patients were admitted after the implementation of the MHA 1987 on voluntary basis, and all of them were women. One of them was married but divorced later on. She was refused by her father’s side also. In the case of one such patient, there is no one to look after her, as her sons also suffer from the same disorder. Other patients were admitted under provision of Indian Lunacy Act 1912.
Table 1 shows the difference of age among men and women along with their duration of stay in the hospital. Although the total mean score on the BPRS is more for women, a significant difference was not observed with that of men. Table 2 shows the mean score on WHODAS II for the patients. The mean score on item CS1 differed significantly with that of the rest items. CS5 and CS6 were not assessed as the patients were staying in hospital for a prolonged period, which is self-explanatory. Twenty (71.43%) of the 28 patients had some additional physical problems. It has been shown in Figure 1.

**DISCUSSION**

In the present study we found that of the 28 patients, 19 (67.86%) were men; 84.21% of the men were single, while 66.67% of the women were single. Sixteen (57.14%) of the 28 patients were illiterate. This is in line with the findings of O’Driscoll et al.[23] The average age of the patients matches with that of the findings of Fleck et al.[24] The higher mean age for men may be due to increased rates of hospitalization. In earlier days, the male patients were brought to mental hospitals for their increased severity of the symptomatologies. Again, it is seen that the seeking of treatment in the case of female patients are less, and even if the treatment is sought it is usually at a later stage. Association of stigma cannot be ruled out in this respect.

The mean duration of hospital stay is significantly higher for men as compared with that for women, which is self-explanatory. The highest period of hospital stay formen is 55 years and for women it is 19 years. These findings are in line with those of the Brazilian study: 42.86% of the cohort had some relative alive, but they refused to take responsibility of the patients. It has been observed that since the inception of MHA 1987, only four patients turned out to be for long-term hospitalization. All of them were women, and they were either on voluntary basis or with reception order. Many patients suffer from inhuman treatment in the society, and they prefer to stay in a protected environment as found in hospitals. To counter this prejudice against the ill-treatment of the mentally ill persons, proper awareness programs need to be designed.

The institute has seen a major change in its facilities in the last 10 years. Initially it was neglected and the appointed doctors did not have qualification in psychiatry. After the order was passed by the Supreme Court, appropriate manpower were recruited and it is being converted in to a center of excellence in manpower development. Hence the quality of care for the patients improved and there has been sufficient effort done by treating team for reintegration of the patient back to the community.

Female patients had more mean value on the BPRS. It may be due to their relatively lesser duration of stay. But the difference between the two groups did not have significant difference. In a study done in Italy, the BPRS scores were grouped into three categories for the analysis: <35 (absent or mild symptoms), 35–65 (moderate symptoms), and >65 (severe symptoms).[25] If we follow that classification, then we have 11 patients who scores <35. Only one of them is a woman in the present cohort.

Again in the same study, scores on the DAS sections were collapsed into the categories of <1 (no or mild disability), 1 to <2 (moderate disability), and ≥2 (severe disability). In our study, we found that the scores in the area of understanding and communication are significantly more as compared to the scores in the other areas assessed. Thus from the above classification it can be said that in our group of cohort, severe disability is present in the area of CS1 in the WHODAS II; whereas in CS2, CS3, and CS4, moderate disability is seen. Again only 28.57% of the patients did not have any kind of physical problem. This can be attributed to the relatively older age of the cohort. In a study done in
Kuwait, it was reported that two-thirds of the long-stay patients can be successfully treated in the community and\textsuperscript{[26]} they have suggested building up of community homes accommodating 8–10 patients per home.

The MHA 1987 is silent on the issues relating to the rehabilitation of the psychiatric patients. An appropriate amendment is desirable in this aspect. Setting up of proper rehabilitation centers including community shelter homes, sheltered workshop, and foster homes at various levels will be an appropriate step for their integration into the society. Moreover, for community level rehabilitation some indigenous modes can be applied as per the capability of the patient. Our society needs many unskilled workers at our community centers. They can be employed in those centers, for example, as helpers in temples, chowkidars in markets, and helpers in cultivation.

Again proper implementation of the disability act is desirable along with awareness about it among the public. Certification and setting up of appropriate centers for rehabilitation as mentioned above is the need of the hour. Families with mentally ill person should receive certain facilities for proper assistance of the patients. Schemes such as Deendayal Disabled Rehabilitation Scheme are welcome steps taken by the government. But the roles of nongovernmental agencies are pivotal in this respect. The mental health institutes should take appropriate measures in bringing awareness among public along with proper research in this area. They should be able to attract the nongovernmental organizations to work in this field and also offer help in their activities.

The strength of this article is that it looks into the problems associated with long stay in the case of patients with schizophrenia. It also looked into the matter of destitution for the patients who were not reintegrated with the family after the abolition of the Indian Lunacy Act and implementation of the MHA 1987. The limitation of the study is that a proper evaluation of the psychopathology and disability along with quality of life at various time intervals was not done. Moreover, a study in similar group of persons after their reintegration in the community at various levels will be very informative.

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