Pattern of burden on the family of patients with schizophrenia and bipolar disorder: A comparative study

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In psychiatry “burden refers to the presence of problems, difficulties, or adverse events that affect the lives of psychiatric patients.”[1] Objective burden refers to the physical burden of care resulting from changes in behavior of patients with psychiatric disorders and their effects on the caregiver’s social life and to disturbances in the family due to the patient’s illness that are apparent and demonstrable. Subjective burden refers to general ratings of distress, including emotional reactions, stress, reduced morale, anxiety, and depression, felt by the caregiver as a result of the patient’s illness.[2] The notion of burden has some features in common with social performance, for one person’s burden is another person’s poor social performance. Both concepts are relative to social expectations which are likely to vary. As it has been emphasized with regard to psychiatry “burden refers to the presence of problems, difficulties, or adverse events that affect the lives of psychiatric patients.”[1]

ABSTRACT

Background: The concept of burden of care came from the realm of behavioral sciences primarily in the context of looking after a psychiatrically ill person. Caregivers of schizophrenia and bipolar affective disorder (BPAD) have to take over the totality of patient care since most of these patients are treated at home. As a result of this, they are exposed to negative consequences of caregiving. Aim: This study aims to assess and compare the pattern of burden among the families having patients with schizophrenia and bipolar disorder. Materials and Methods: This cross-sectional, observational study was conducted on the outpatient department level at Ranchi Institute of Neuropsychiatry and Allied Science. This study included 30 patients with schizophrenia and equal number of age- and sex-matched patients with bipolar disorder. The diagnosis was made as per criteria of International Classification of Diseases 10 diagnostic criteria for research. Their caregivers who gave consent for their participation in the study and satisfy the inclusion and exclusion criteria were included in the study by purposive sampling. Tools administered were socio-demographic datasheet and family burden inventory schedule. Statistical Analysis Used: Chi-square test, Fisher’s exact test, and Mann–Whitney U test. Results: Total caregiver burden, financial burden, disruption of routine family activities, family leisure, family interaction, and subjective burden felt by caregiver were significantly more in caregivers of schizophrenia patients compared to caregivers of BPAD. There was no significant difference in the two areas of burden, i.e., effect on physical health of the caregivers and effect on mental health of caregivers. Conclusion: Caregivers of schizophrenia patients have significantly higher family burden as compared to caregivers of subjects with BPAD.

Keywords: Bipolar disorder, caregivers, schizophrenia

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social performance, measurement of burden can never be entirely satisfactory, and it always remains open to criticism. There is no universally accepted definition for family burden, but many eminent persons related to this field have tried to define it in their own. Treudley first used this term in relation to the consequences for those in close contact with the psychiatric patient. The burden of the caregiver is defined as a psychological state that arises as a result of the amalgamation of physical work, emotional effort, social pressure, and economic restrictions that occur due to looking after the patients.

Different theories have attempted to explain the essential theoretical framework for the concept of family burden. The role theory considers everyone to be an actor of social relationships. Groups of people with some similarities are called positions: Father, mother, son, and others. Persons in a particular position demonstrate a set of expectations (called role sector) about the manner in which they are going to behave with others in a similar position. As expected, patients with serious psychiatric illnesses are unable to fulfill their family expectations on many occasions causing discomfort to the members of their family. The stress theory proposes that adversities resulting from the disorder, environmental stressors, and changes in the caregiver are the reasons for the burden. The systemic theory posits that even though burden is a family phenomenon, to fully comprehend this notion it is essential to think about family in its social context. Family is a dynamic system which is influenced not only by its subsystems but also by external systems with a continuous input and output of information. The family burden is generated by inputs from both internal and external systems.

Schizophrenia and bipolar disorder are severe and potentially incapacitating mental illness, each affecting about 1% of the global population. These disorders often have a chronic course requiring long-term care. In developing countries, there is almost a complete lack of halfway homes or rehabilitation services. Due to the unavailability of community-based support, the responsibility of caregiving falls completely on the family. As a result, there is an enormous burden on the families of these patients. Studies have shown that families of schizophrenia patients become isolated, stigmatized, and suffer discrimination.

A number of studies have been carried out in developed countries to assess the existence and nature of burden experienced by families of patients with psychiatric disorders, but comparatively few studies have been carried out in developing countries. Studies in South Asia are comparatively less and have given contradictory results. Few studies have reported that caregivers of schizophrenia patients experience more burden than those of bipolar disorder. On the other hand, few studies revealed that patients with schizophrenia and bipolar disorder impose similar level of burden on their caregivers, while one study reported that caregivers of bipolar disorder patients had a higher burden than caregivers of schizophrenia. In view of the contradictory results studies, the present study was undertaken to assess and compare the burden among the families having patient with schizophrenia and bipolar affective disorder (BPAD).

**MATERIALS AND METHODS**

This hospital-based cross-sectional, observational study was conducted at Ranchi Institute of Neuropsychiatry and Allied Science (RINPAS). The proposal for the study was submitted to the institutional ethical committee and approval obtained. All the subjects gave written informed consent.

**Sample**

Based on the purposive sampling technique, a sample of 30 patients of either sex with schizophrenia and equal number of age- and sex-matched subjects with BPAD, between the age range of 20 and 50 years, were selected from the outpatient unit of RINPAS Kanke, Ranchi. Patients were diagnosed with schizophrenia and affective disorder according to the International Classification of Diseases-10 diagnostic criteria for research. The study was conducted on 30 caregivers of schizophrenia, and 30 affective disorder respectively selected by purposive sampling, and were willing to give written informed consent for the same. Duration of living of caregiver with the patient was minimum 5 years. Only stable patient coming for routine outpatient follow up were included who had minimum 1 year duration of illness. Patients with comorbid medical illnesses were excluded from the study. Families having another member with chronic psychiatric disorder or chronic medical illnesses were also excluded from the study.

**Tools**

**Sociodemographic and clinical data sheet**

This self-made questionnaire consisted of questions to obtain personal information from the subjects on such themes as age, address, gender, education, religion, caste, marital status, tribal/nontribal, education, monthly income and occupation, and clinical details of the patients.

**The family burden interview schedule**

The family burden interview schedule (FBIS) is a semi-structured interview schedule consisting of 24 questions grouped under 6 areas of burden comprising...
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of financial burden, disruption of family routine activities, family leisure, and family interaction, effect on physical health and on mental health of others. Guidelines for the assessment of burden for each item are provided. The burden for each item is recorded as absent (scored zero), moderate (scored 1) or severe (scored 2). The FBIS has satisfactory reliability and validity. The authors of the FBIS reported that inter-rater reliability of all the items was more than 0.78. Validity of the FBIS was assessed by correlation of burden ratings on the schedule with subjective burden reported by caregivers, which was 0.72.\(^{[12]}\)

### Procedure

The current study included caregivers of patients with schizophrenia and BPAD being reviewed in the Psychiatry outpatient department of a tertiary care hospital who were stable on medications. Caregivers were explained the purpose of the study, and only those who gave written informed consent were included in the study. They were interviewed and then assessed with the help of socio-demographic datasheet. The family burden was assessed using the FBIS a popular tool constructed for Indians having acceptable reliability and validity.

### Table 1: Sociodemographic details of the patients having schizophrenia and bipolar affective disorder

| Variables                  | Schizophrenia, n (%) | BPAD, n (%) | Chi-square test | P       |
|----------------------------|----------------------|-------------|-----------------|---------|
| Sex                        |                      |             |                 |         |
| Male                       | 24 (80)              | 20 (66.6)   | 1.364           | 0.243 (NS) |
| Female                     | 6 (20)               | 10 (33.3)   |                 |         |
| Age range                  |                      |             |                 |         |
| 20-30                      | 11 (36.6)            | 14 (46.6)   | 4.131           | 0.127 (NS) |
| 30-40                      | 7 (23.3)             | 11 (36.6)   |                 |         |
| 40-50                      | 12 (40)              | 5 (16.6)    |                 |         |
| Marital status             |                      |             | Fisher’s exact test | 0.019 (S) |
| Married                    | 24 (80)              | 14 (46.6)   |                 |         |
| Unmarried                  | 2 (6.6)              | 10 (33.3)   |                 |         |
| Others (widow, separated)  | 0                    | 2 (6.6)     |                 |         |
| Education                  |                      |             |                 |         |
| Illiterate                 | 13 (43.3)            | 5 (16.6)    | 11.188          | 0.0107 (S) |
| Matriculation              | 12 (40)              | 10 (33.3)   |                 |         |
| Inter                      | 3 (10)               | 14 (46.6)   |                 |         |
| >Inter                     | 2 (6.6)              | 1 (3.3)     |                 |         |
| Occupation                 |                      |             |                 |         |
| Employed                   | 4 (13.3)             | 1 (3.3)     | 9.061           | 0.107 (S) |
| Unemployed                 | 20 (66.6)            | 12 (40)     |                 |         |
| Others                     | 6 (20)               | 17 (56.6)   |                 |         |
| Monthly income (Rs.)       |                      |             |                 |         |
| 1000-3000                  | 19 (63.3)            | 23 (76.6)   | 1.314           | 0.518 (NS) |
| 4000-6000                  | 9 (30)               | 6 (20)      |                 |         |
| >6000                      | 2 (6.6)              | 1 (3.3)     |                 |         |
| Religion                   |                      |             |                 |         |
| Hindu                      | 25 (83.3)            | 23 (76.6)   | Fisher’s exact test | 0.616 (NS) |
| Muslim                     | 4 (13.3)             | 6 (20)      |                 |         |
| Christian                  | 1 (3.3)              | 0 (0)       |                 |         |
| Sikh                       | 0                    | 1 (3.3)     |                 |         |
| Domicile                   |                      |             |                 |         |
| Urban                      | 16 (53.3)            | 14 (46.6)   | 1.689           | 0.429 (NS) |
| Rural                      | 4 (13.3)             | 8 (26.6)    |                 |         |
| Semi-urban                 | 10 (33.3)            | 8 (26.6)    |                 |         |
| Age of onset (years)       |                      |             |                 |         |
| 14-25                      | 11 (36.6)            | 14 (46.6)   | 4.131           | 0.127 (NS) |
| 26-37                      | 7 (23.3)             | 11 (36.6)   |                 |         |
| 38-49                      | 12 (40)              | 5 (16.6)    |                 |         |
| Duration of illness (years)|                      |             |                 |         |
| 2-5                        | 20 (66.6)            | 22 (73.3)   | 0.318           | 0.853 (NS) |
| 6-9                        | 5 (16.6)             | 4 (13.3)    |                 |         |
| 10-13                      | 5 (16.6)             | 4 (13.3)    |                 |         |

S – Significant; NS – Not significant; BPAD – Bipolar affective disorder
The inventory was scored as per instructions in the test manual.

**Statistical analysis**

Data were tabulated into Excel sheet. Statistical analysis was undertaken using appropriate statistical tests. Chi-square or Fisher’s exact test was used for frequency data. Mann–Whitney U test was used to assess differences in scores of the FBIS.

**RESULTS**

The schizophrenia and bipolar disorder patients were matched in age and gender distribution.

Patients with schizophrenia had significantly less education and income compared to BPAD patients [Table 1]. The sample of caregivers included 30 caregivers, each of schizophrenia and bipolar disorder patients. The two groups well matched in age, gender, education, occupation, relation with the patient, and duration of stay with the patient [Table 2]. The amount of objective and subjective burden felt by caregivers of schizophrenia and BPAD patients is shown in Table 3. Analysis of the experience of burden among the family of schizophrenia and BPAD patients revealed that family of schizophrenia patients have a significantly higher burden as compared to family of bipolar disorder patients in terms of total burden, financial burden, disruption of routine family activities, disruption of family leisure, and disruption of family interaction. There is no significant difference in respect to other aspects of burden among the family members of both the groups. A subjective burden was also significantly higher in the caregivers of schizophrenia compared to the BPAD group.

**DISCUSSION**

In the current study, the total objective burden score of the family members of schizophrenia patients was significantly higher than BPAD patients, but the global objective burden was not significantly different in the two groups. Although the global objective burden of caregivers was similar in the two groups, the subjective burden perceived by caregivers of schizophrenia was significantly higher than that in caregivers of BPAD patients. Further analysis of the pattern of burden in the two groups revealed that the burden was statistically significant more in families of schizophrenia patients in the following areas of FBIS–financial burden, disruption of routine family activities, disruption of family leisure, and disruption of family interaction. However, there is no statistically significant difference in effect on the physical health of others and effect on mental health of others.

**Table 2: Sociodemographic details of the caregivers of schizophrenia and bipolar affective disorder patients**

| Variables          | Range       | Schizophrenia patients, n (%) | BPAD patients, n (%) | χ²  | P      |
|--------------------|-------------|-------------------------------|----------------------|-----|--------|
| Relation with patients |             |                               |                      |     |        |
| Parents            | 12 (40)     | 8 (26.6)                      | 5.665                | 0.226 (NS) |
| Siblings           | 12 (40)     | 9 (30)                        |                      |     |        |
| Spouse             | 3 (10)      | 10 (33.3)                     |                      |     |        |
| Children           | 1 (3.3)     | 2 (6.6)                       |                      |     |        |
| Niece              | 2 (6.6)     | 1 (3.3)                       |                      |     |        |
| Age range of caregivers (years) |             |                               |                      |     |        |
| 20-30              | 10 (33.3)   | 6 (20)                        | 2.6                  | 0.272 (NS) |
| 30-40              | 17 (56.6)   | 17 (56.6)                     |                      |     |        |
| 40-50              | 3 (10)      | 7 (23.3)                      |                      |     |        |
| Education          |             |                               |                      |     |        |
| VIII-X standard    | 15 (50)     | 18 (60)                       | 4.416                | 0.219 (NS) |
| Matriculation      | 8 (26.6)    | 2 (6.6)                       |                      |     |        |
| Intermediate       | 3 (10)      | 4 (13.3)                      |                      |     |        |
| >Intermediate      | 4 (13.3)    | 6 (20)                        |                      |     |        |
| Occupation         |             |                               |                      |     |        |
| Employed           | 1 (3.3)     | 7 (23.3)                      | 5.201                | 0.074 (NS) |
| Unemployed         | 6 (20)      | 5 (16.6)                      |                      |     |        |
| Others             | 23 (76.6)   | 18 (60)                       |                      |     |        |
| Marital status     |             |                               |                      |     |        |
| Married            | 6 (20)      | 6 (20)                        | 0                    | 1 (NS)    |
| Unmarried          | 22 (73.3)   | 22 (73.3)                     |                      |     |        |
| Others             | 2 (6.6)     | 2 (6.6)                       |                      |     |        |
| Duration of stay with the patient |             |                               |                      |     |        |
| 5-10               | 3 (10)      | 6 (20)                        | 2.601                | 0.457 (NS) |
| 10-15              | 3 (10)      | 4 (13.3)                      |                      |     |        |
| 15-20              | 5 (16.6)    | 7 (23.3)                      |                      |     |        |
| >20                | 19 (63.3)   | 13 (43.3)                     |                      |     |        |
| Family structure   |             |                               |                      |     |        |
| Joint              | 16 (53.3)   | 14 (46.6)                     | 0.267                | 0.605 (NS) |
| Nuclear            | 14 (46.6)   | 16 (53.3)                     |                      |     |        |

NS – Not significant; BPAD – Bipolar affective disorder
The findings of the present study are similar to earlier Indian studies that compared relatives of schizophrenia and BPAD patients by using the FBIS. They also observed significantly higher subjective burden in the relatives of patients with schizophrenia. On objective burden the total burden as well as burden in the areas of finances, family routine, family leisure, and family interaction, was significantly more in caregivers of schizophrenia patients. Similar findings were also reported by few other Indian studies. In the present study, 90% of caregivers of schizophrenia patients reported moderate to severe family burden. This finding is in agreement with earlier studies which reported that 82%–90% of families of persons with schizophrenia experience moderate-to-severe burden. A probable reason for this observed difference could be the fact the while most of the BPAD patients were in remission, but most of the schizophrenia patients continued to have residual symptoms. Further, the patients with schizophrenia had lower level of functioning than patients with BPAD. The longer duration and chronic course of schizophrenia are likely to increase the objective burden. Caregivers of BPAD patients are better able to cope with the situation due to the episodic nature of the disorder and near-normal functioning between episodes. On the other hand, in schizophrenia patients, even when the acute symptoms of the disorder have been controlled, patients may continue to have negative or residual symptoms due to which caregivers are unsure of the patient’s ability to resume normal work life, social life, and leisure activities.

Limitations
The current study has few limitations. It was a cross-sectional hospital based study, and sample size was modest, which makes it difficult to generalize the result. Blind ratings were not done, which may have caused rater bias.

CONCLUSION
Family members of schizophrenia patients experience significantly higher burden in the areas of financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interaction, and subjective burden felt by caregiver, as compared to family members of BPAD.

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Conflicts of interest
There are no conflicts of interest.

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