

Caregivers Burden of Patients with Schizophrenia and Bipolar Disorder: A Sectional Study

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ABSTRACT

Background: Caregiving has been identified as a basic component of human nature and a primary element of close relationship. This study aims to assess the extent and pattern of burden felt by the caregivers of patients with schizophrenia in comparison with bipolar disorder. **Materials and Methods:** Fifty-two patients with schizophrenia and fifty-one patients with bipolar disorder attending the outpatient department were assessed in the study. The burden among the caregivers was assessed using Burden Assessment Schedule. **Results:** The caregivers of schizophrenia group had significantly higher total burden score as compared to caregivers of bipolar disorder. Caregivers of schizophrenia experienced significantly higher burden in area of external support, caregivers routine, and other relations. **Conclusion:** The extent of burden among families of schizophrenic patients is more than those of bipolar disorder. The families of patients with bipolar disorder do also experience considerable burden. The pattern of burden among families of schizophrenia and bipolar disorder is almost identical in most of the domains except for external support, caregivers routine, and other relations.

Key words: *Bipolar disorder, caregivers burden, schizophrenia*


INTRODUCTION

Caregiving has been identified as a basic component of human nature and a primary element of close relationship. In India, since professional services both in public and private sectors are not adequately developed due to shortage of trained human resources and infrastructure, the family support system plays a major role in caring for people with mental illnesses. Most of the studies in this area during the past 5 decades across the world have focused on the families of patients with schizophrenia and found that the families experience

significant burden due to the illness.^[1-11] Later studies on caregivers of depression showed that the relatives of patients with depressive illness also experience significant distress.^[12,13]

A study involving caregivers of bipolar disorder has shown that 93% of caregivers report moderate level of burden and 54% caregivers report severe level of burden.^[14] The burden on the relatives of patients with manic and depressive symptoms is significant and at similar level;^[15] severity of symptoms, difficulties in the relationship with the patients, lack of support, and stigma attached to the illness are important predictors of caregiver burden in bipolar disorder.^[16]

Apart from documenting the burden due to the individual disease, few authors attempted the comparative study of burden among caregivers of schizophrenia and bipolar disorder. Both the objective and subjective burden is more in relatives of schizophrenia compared to caregivers of bipolar patients.^[17] Caregivers of

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schizophrenia patients experience more burden than those of bipolar disorder.^[18] In another study, Chadda *et al.*,^[19] revealed that patients with schizophrenia and bipolar disorder impose similar level of burden on their caregivers and they use similar types of coping methods to deal with the burden. There are not many studies which have compared the burden in the families of patients with schizophrenia and bipolar disorder; more so during the stable phase of the illness. Therefore, we studied the extent and pattern of burden felt by the caregivers of patients with schizophrenia in comparison with bipolar disorder. The null hypothesis of the study being the extent and pattern of burden is similar among the caregivers of patients with schizophrenia and bipolar disorder.

MATERIALS AND METHODS

Participants

The study was conducted in Asha hospital, a tertiary care hospital in Hyderabad, Andhra Pradesh, in southern part of India. The study was approved by institutional ethical committee. The sample was selected from consecutive outpatients attending the psychiatry service of the hospital. Patients of either gender, ranging between 18 and 55 years of age, fulfilling Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV)^[20] diagnosis of schizophrenia and bipolar disorder, with a minimum of 1 year of illness, and clinically stable for 3 months (clinical stability was defined as “no major changes in medication and no hospitalization in the 3 months preceding the screening”). The “caregiver” was any healthy primary caregiver of the patient, aged 18 years and above, and staying with the patient during last 1 year prior to the assessment. Those patients with chronic physical and other comorbid axis-I psychiatric illness, staying away from the family for a period of more than 3 months for any reason during the last 1 year, and families with other family members having psychiatric or chronic physical illness were excluded from the study.

Measures

A sociodemographic proforma specially designed for the study was used to collect the demographic and clinical details. Socioeconomic Status Scale^[21] (Tiwari *et al.*, 2005), developed for both rural and urban communities in India, was used for assessing the socioeconomic status. The reliability of the scale was high with a correlation coefficient of 0.998. To measure caregiver burden, Burden Assessment Schedule (BAS)^[22] was used. It is a 40-item structured instrument in English, which assesses both the objective and subjective burden experienced by the caregiver of chronic mentally ill patients. BAS is reported to have good interrater reliability (k 0.80) and satisfactory face value in terms of relevance of the

items in measuring the caregiver burden. The criterion validity of this instrument was computed against the family burden schedule of Pai and Kapur^[2] and was found to have good correlation for most of the items and ranged between 0.71 and 0.82. To measure global functional level, Global Assessment of Functioning scale,^[23] a 100-point single item scale with values ranging from 1 to 100 representing the hypothetically sickest person to the healthiest, was used. MINI International Neuropsychiatric Interview,^[24] a short, structured diagnostic interview, designed to diagnose DSM-IV and ICD-10 psychiatric disorders was used to confirm the diagnosis and detect any comorbid conditions. It is a relatively brief instrument and has good validity and reliability. Psychopathology in schizophrenia patients measured using Positive and Negative Syndrome Scale (PANSS).^[25]

Procedure

The information regarding the primary caregiver of patients was assessed from the accompanying person. In case of nonavailability or nonconsent, the next close relative was chosen for the study. After obtaining informed consent from both the patients and the caregivers, sociodemographic and disease variables were recorded. Later, MINI was administered to patients for confirmation of the clinical diagnosis and to rule out other comorbid psychiatric illnesses. Later, schizophrenia patients were assessed using Positive and Negative Syndrome Scale. Following this, caregivers were interviewed on Burden Assessment Schedule and Global Assessment of Functioning scale (GAF). All the assessments were done by the first author, Vasudeva Sadinamne.

Statistical analysis

Statistical analysis was done using SPSS version 16. Data normality was assessed using histograms and Shapiro-Wilk test statistic. Pearson's Chi-square test was used to assess the difference between the categorical variables. Independent “*t*” test and Mann-Whitney U test were used to assess the difference between the parametric and nonparametric continuous variables, respectively. Effect sizes for BAS were reported as Cohen's *d*. The total burden score was calculated excluding spouse-related domain. The level of significance was set at $P < 0.05$ (two-tailed).

RESULTS

Sample characteristics

The total intake consisted of 150 patients and their caregivers (77 of schizophrenia and 72 of bipolar disorder), out of which 47 patients and caregivers were excluded (25 from schizophrenia and 21 from bipolar disorder group) due to not meeting inclusion/exclusion

criteria. Finally, 103 patients and caregivers (52 of schizophrenia and 51 of bipolar disorder) were included in the final analysis. The sample characteristics are summarized in Table 1.

The mean age of patients with schizophrenia was 34.50 (standard deviation (SD): 8.65) years, which was comparable to that of bipolar disorder (37.59, SD: 11.42) years. There was no difference between the patients in terms of gender, education years, marital status, employment, age of onset of illness, duration of treatment, and number of hospitalizations. The median duration of illness was significantly higher in bipolar patients as compared to schizophrenia ($P < 0.05$), whereas the median duration of untreated illness was significantly higher in patients with schizophrenia ($P < 0.001$). The mean GAF score was significantly higher in patients with bipolar disorder ($P = 0.001$). The mean score on PANSS in patients with schizophrenia was 61.15 (SD: 16.10).

Among caregivers, the mean age was 48.32 (SD: 11.65) years and 47.39 (SD: 12.03) years in the schizophrenia and bipolar groups, respectively. The duration of caregiving was higher in bipolar group, though the difference was not statistically significant ($P > 0.05$).

Both the groups were comparable in terms of gender, education years, marital status, employment, family type, and background.

Comparison of caregiver burden

The caregivers of schizophrenia group had significantly higher total burden score as compared with caregivers of bipolar disorder ($P < 0.05$), with small effect size (Cohen’s $d = 0.428$). There were significantly higher burden in caregivers of schizophrenia patients in domains of external support ($P < 0.05$, Cohen’s $d = 0.479$) and caregivers routine ($P < 0.01$, Cohen’s $d = 0.539$), and a trend toward higher score in other relations ($P < 0.05$, Cohen’s $d = 0.380$). In rest of the domains, both the groups had comparable scores. The comparisons of burden are summarized in Table 2.

DISCUSSION

The result of the study shows that the families of both schizophrenia and bipolar disorder experience considerable burden. The extent of burden in relatives of schizophrenia was, however, significantly higher than that in bipolar disorder consistent with the earlier studies,^[17,18] though the overall effect size was small. Ohaeri et al.,^[26] reported that the relatives of patients with psychotic

Table 1: Sample characteristics

	Schizophrenia group (n=52)	Bipolar disorder group (n=51)	t/ χ^2	P
Patient variables				
Age, mean (SD)	34.50 (8.65)	37.59 (11.42)	-1.55	0.125
Education years, mean (SD)	13.27 (4.00)	12.84 (3.56)	0.57	0.570
Age of onset of illness, mean (SD)	26.98 (7.79)	27.68 (10.10)	-0.39	0.692
Duration of illness (years), mean (SD), median (IQR)	7.44 (3.90) 6.50 (5.00)	9.82 (5.47) 8.00 (7.00)	972 [§] (-2.35)*	0.019
Duration of treatment (years), mean (SD), median (IQR)	5.23 (3.68) 4.50 (4.00)	7.07 (5.09) 6.00 (7.00)	1034.5 [§] (-1.94)	0.053
Duration of untreated illness (months), mean (SD), median (IQR)	14.88 (21.19) 6.50 (15.25)	2.09 (3.18) 1.00 (1.50)	342.5 [§] (-6.53)***	<0.001
Number of hospitalizations, mean (SD), median (IQR)	0.78 (1.33) 0 (1)	0.92 (1.24) 1 (2)	1157 [§] (-1.23)	0.219
GAF, mean (SD)	55.69 (11.15)	62.45 (8.14)	-3.51**	0.001
Male gender, n (%)	30 (57.7)	30 (58.8)	0.01	0.907
Unemployed, n (%)	22 (42.3)	18 (35.3)	0.43	0.465
Married, n (%)	21 (40.4)	30 (58.8)	3.50	0.061
Caregiver variables				
Age, mean (SD)	48.32 (11.65)	47.39 (12.03)	0.40	0.690
Education years, mean (SD)	12.61 (4.56)	11.51 (4.37)	1.25	0.213
Duration of caregiving, mean (SD), median (IQR)	7.13 (3.91) 6 (5.75)	8.67 (4.95) 7 (5)	1075 [§] (-1.66)	0.096
Male gender, n (%)	32 (61.5)	28 (54.9)	0.46	0.495
Married, n (%)	49 (94.2)	47 (92.2)	0.17	0.676
Unemployed, n (%)	0	1 (2)	1.03	0.310
Lower socioeconomic status, n (%)	1 (1.9)	1 (2)	0	0.989
Nuclear family, n (%)	43 (82.7)	44 (86.3)	0.25	0.616
Urban background, n (%)	46 (88.5)	44 (86.3)	0.11	0.738

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$ (two-tailed); [§]Mann-Whitney U (Z) values reported. GAF – Global assessment of functioning; IQR – Inter quartile range; SD – Standard deviation

Table 2: Comparison of burden between caregivers of schizophrenia and bipolar disorder patients

	Schizophrenia caregivers (n=52) mean (SD)	Bipolar disorder caregivers (n=51) mean (SD)	t (df=101)	P	Effect size (Cohen's d)
BAS total score [§]	68.75 (10.16)	64.45 (10.14)	2.15*	0.034	0.428
Spouse-related	4.76 (4.54)	5.66 (4.44)	-1.01	0.313	-
Physical and mental health	13.53 (2.86)	12.60 (2.93)	1.63	0.107	-
External support	8.94 (1.92)	8.05 (1.79)	2.41*	0.018	0.479
Caregivers routine	8.05 (1.97)	7.07 (1.68)	2.71**	0.008	0.539
Support of the patient	5.78 (1.30)	5.86 (1.29)	-0.29	0.772	-
Taking responsibility	9.13 (1.57)	8.80 (1.80)	0.99	0.323	-
Other relations	6.07 (1.73)	5.39 (1.89)	1.91	0.059	0.380
Patient behavior	9.11 (1.97)	8.68 (1.93)	1.11	0.268	-
Caregivers strategy	8.09 (1.64)	7.96 (1.52)	0.43	0.666	-

* $P < 0.05$, ** $P < 0.01$, (two-tailed); [§]Total score calculated excluding spouse-related items. BAS – Burden assessment schedule; SD – Standard deviation

symptoms bear a greater burden. This difference cannot be attributed to sociodemographic factors as both groups were comparable. Though the bipolar disorder patients had longer duration of illness and treatment, the difference of burden was more in caregivers of schizophrenia. One of the possible reasons for the difference could be due to the fact that most of the bipolar patients were in remission, whereas schizophrenia patients were having some residual symptoms. Also, it could be due to the lower level of functioning in schizophrenia patients as compared to bipolar disorder. The longer duration of illness is likely to increase the objective burden.^[27] Chronic course of schizophrenia has a greater burden.^[28] Giel *et al.*,^[29] reported that families of patients with chronic illness with severe loss of insight experience higher burden. Fadden *et al.*,^[12] reported that the spouses of affective disorder, especially bipolar disorder cope with the situation better possibly due to: The episodic nature of the illness, the ability of the spouse to identify the forthcoming episode early, and the expectations of near normal functioning between episodes. In schizophrenia, even when the more florid symptoms of illness have been controlled, caregivers continue to be concerned about the patient's ability to achieve the normal gratification of social life, work life, and leisure activities.^[30]

Despite the difference in global burden, the pattern of burden in various domains in both the study groups was almost similar. The two study groups differ slightly in burden with regard to the external support, caregiver routine, and other relation which was high in schizophrenia caregivers as compared to the bipolar disorder.

The external support indicates the amount of support he/she gets from the family members or friends. Family members will be hesitant to be identified as relatives of mentally ill person due to social stigma and some relatives express inability to share the problem with others as they are worried about stigma regarding the illness in the society. Rapid urbanization is leading

to the emergence of more nuclear families, especially in urban areas which leads to less support from other family members and friends. The joint family system is more helpful in coping with stress; whereas, nuclear families are more vulnerable to stress.^[31]

Disturbance in the caregivers' daily activities was another significant aspect of burden. Schizophrenia being a chronic illness needs long-term follow-up and caregivers have to accompany the patient every time for consultation. As a consequence, caregivers do not get time to look after their health and activities. Their behavior caused disruption of family interaction and activities and was very distressing for the caregivers of schizophrenia.^[6]

Burden factor, the "other relation" refers to the relationship between family members and friends. As a consequence of the patient's illness, family members often develop misunderstanding among themselves in caring for the patient. The high-expressed emotion and maladaptive way of functioning were seen to be more in families, where the associated burden was high. There is often difficulty in maintaining cordial relations with friends due to constant involvement with the patient. The psychopathology of the patient like persecutory/referential ideas may cause breaks in relationship with family or friends. Similar findings were reported in previous studies.^[17,32,33]

Our sample was largely restricted to the urban population, thus limiting generalization to rural population. Also, the cross-sectional nature of our study does not allow causal inferences. Longitudinal data might give further insight into the extent of burden among caregivers of schizophrenia and bipolar disorder. Furthermore, the caregivers' beliefs about the patients' illness may influence the level of burden, which has not been specifically addressed in our study. Additional factors may account for variation in caregivers' experience of burden such as satisfaction with other aspects of life, personality profile of caregivers, and supporting systems

of the family. We did not study the emotional climate within the family and support from other members of the family and society. Future studies should focus on longitudinal relationship between the burden, mood, and also coping strategies among the caregivers.

CONCLUSION

The extent of burden among families of schizophrenic patients is more than that of bipolar disorder. The families of patients with bipolar disorder also do experience considerable burden. The pattern of burden among families of schizophrenia and bipolar disorder is almost identical in most of the domains except in external support, caregivers routine, and other relations.

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