

**Burden of care among caregivers of patients with schizophrenia and bipolar disorder****Vivek Srivastava<sup>1</sup>, Ashish Kumar Malik<sup>2</sup>, Priyanka Tatarwal<sup>3</sup>, Rajiv Gupta<sup>4</sup>, Priti Singh<sup>5</sup>, Piyush Verma<sup>6\*</sup>**<sup>1</sup>Senior Resident, Department of Psychiatry, Pt. BD Sharma PGIMS, Haryana, India<sup>2</sup>Assistant Professor, Department of Psychiatry, NC Medical College, Haryana, India<sup>3</sup>Senior Resident, Department of Anesthesia, NC Medical College, Haryana, India<sup>4</sup>Senior Professor & Head, Department of Psychiatry, Pt. BD Sharma PGIMS, Haryana, India<sup>5</sup>Professor, Department of Psychiatry, Pt. BD Sharma PGIMS, Haryana, India<sup>6</sup>Senior Resident, Department of Psychiatry, Pt. BD Sharma PGIMS, Haryana, India

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**Abstract**

**Introduction:** Caregivers of patients with severe psychiatric illnesses suffer significant impairment in their socio-occupational, interpersonal as well as emotional functioning, amounting to enormous burden. **Aim:** To compare the burden of care among the caregivers of patients with schizophrenia and bipolar affective disorder. **Methodology:** It was a cross-sectional study, conducted at a tertiary care hospital, and involved 30 caregivers each of patients with schizophrenia and bipolar disorder. Burden Assessment Schedule (BAS) was used for assessing the burden experienced by the caregivers, along with a specially designed proforma was used to gather socio-demographic information about the patients and their caregivers. **Result:** Most subjects were males, were spouses in case of bipolar affective disorder patient (43.30%) and parents (46.70%) among schizophrenia patients. In terms of socio-demographic profile, no significant difference was found between the groups. 17 (12 of schizophrenia and 5 of bipolar group) of the total 60 subjects were found to experience severe burden of care. Total burden score was  $64.4 \pm 13.88$  for the subjects of bipolar disorder group and  $75.03 \pm 13.7$  among the subjects of schizophrenia group and, the difference was statistically significant. **Conclusion:** Severe burden of care worsens the quality of life and poses substantial subsyndromal psychiatric morbidity among the caregivers of patients with chronic psychiatric morbidities. Support programme should be planned to help the caregivers, acknowledging the uniqueness of each caregiving situation, monitoring the individual care process and taking into consideration the phase in the caregiving process.

**Keywords:** burden, schizophrenia, bipolar disorder, caregivers.

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**Introduction**

Persons with long-standing psychiatric disorders exhibit greater vulnerability to stress, have higher levels of social dysfunction and tend to be more dependent. They suffer significant impairment in their socio-occupational, interpersonal as well as emotional functioning[1]. As such, the burden associated with psychiatric disorders is enormous and grossly under-reported in public health statistics, which focus more on mortality than morbidity or dysfunction[2].

Among the wide array of mental illnesses, schizophrenia and bipolar affective disorder are considered to be the most debilitating ones. Schizophrenia is a severe chronic brain disorder with a reported median incidence of 15.2 per 100,000 persons and a pooled lifetime prevalence of 0.40 %, affecting general health and well-being, functioning, autonomy as well as life-satisfaction of those who suffer from it[3]. On the other part, bipolar affective disorder is a clinically severe, episodic, lifelong mood disorder with a prevalence ranging from 1 to 2% and is responsible for cognitive impairment, along with interpersonal, social and occupational dysfunction, often persisting in remission also[4].

Occurrence of a severe mental illnesses such as schizophrenia and bipolar affective disorder in a close relative serves to be very devastating for the family, both at the onset and afterwards. Caregiving a person with chronic psychiatric morbidity is highly challenging as it drains the caregivers emotionally, physically,

financially as well as disturbs the normal rhythm of their own life owing to increased family conflicts[5]. As such, schizophrenia and bipolar affective disorder, both being mental illnesses of serious nature results in a huge burden of care which is highlighted by a number of studies[6,7,8].

Ganguly et al[6] studied burden of caregiving among 100 caregivers, each having relatives with schizophrenia and bipolar affective disorder, using qualitative method. The study reported that caregivers of persons suffering from schizophrenia and bipolar affective disorder suffer similar levels of burden, particularly in the areas of family functioning, social isolation, financial issues, and physical well-being. Chakrabarti et al[7] conducted his study on two different patient groups, namely, affective disorders and schizophrenia, and concluded that both the objective as well as subjective burden is more in relatives of schizophrenia patients as compared to caregivers of former group.

Study by Chadda et al[8] was conducted to assess relationship between burden and coping in caregivers of clinically stable patients with schizophrenia and bipolar affective disorder. It was noted that the two patient groups exert similar pattern of burden upon their caregivers and the caregivers, in turn, use similar coping strategies to deal with it.

Providing care to a family members afflicted with chronic psychiatric morbidity results in a persistent strenuous experience for the caregivers that can diminish their quality of life, and is directly related to the subjective and objective burden of the illness[9,10]. The continuous burden upon the caregivers in terms of financial functioning, family routine and family interaction, over the time leads to poor physical and emotional consequences[11,12,13]. Studies in the past have come up with contrasting results of burden among the caregivers associated with these two disorders[6,7,8]. However, there

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is a dearth of recent studies assessing burden among the caregivers of schizophrenia and bipolar affective disorder patients during the stable phase of the illness. Evaluating the burden, its severity and patterns and working out these outcomes in tandem, might be helpful in charting out better psychosocial interventions for the patients. Keeping this in view, this study was done to compare the burden of care among the caregivers of patients with schizophrenia and bipolar affective disorder.

#### Materials and method

The study was done at the Department of Psychiatry, Pt. B.D. Sharma PGIMS, Rohtak, a tertiary care hospital. It had a cross-sectional design and involved 30 caregivers each of patients with schizophrenia and bipolar affective disorder. The sample size was estimated after reviewing the last years' trend of patients diagnosed with schizophrenia and bipolar affective disorder visiting the Department of Psychiatry, Pt. B.D. Sharma PGIMS, Rohtak. Caregivers of the patients whose treatment had not been significantly changed and were not deteriorated to be admitted during past two years of treatment were included. First registered patients, coming for follow up in the psychiatry OPD with their caregiver, who fulfilled inclusion and exclusion criteria were selected and included considering the sample size and the number of OPD days of unit 1 in one week after obtaining the written consent.

Caregivers who were 18 years old or more, living with the patient for more than one year prior to inclusion in the study, looking after patient's daily needs, supervising the treatment, accompanying the patient to the hospital, liaising with the treating team were chosen for obtaining a written consent. The caregivers suffering from any chronic physical and psychiatric disorder including substance use disorder were excluded. Hospitalized patients were not included in the study as it would have resulted in over-reporting of the burden

and also decreased the generalizability of the results to the general population.

#### Tools

1. **Proforma for Socio-demographic variables:** A specially designed proforma was used to gather socio-demographic information about the patients and their caregivers.
2. **Burden Assessment Schedule (BAS)[14]:** It is a 40-item structured instrument assessing objective as well as subjective burden experienced by the caregivers of chronically ill psychiatric patients. Total burden is assessed by obtaining sum of the individual scores on each item. Higher score means higher burden of care with highest score in each domain being 3 and highest possible total score is 120.

#### Statistics

Burden Assessment Schedule (BAS) scores was considered as the primary outcome variable. Study group, bipolar disorder Vs schizophrenia (N=30) was considered as primary explanatory variable. Various socio-demographic parameters were considered as other interested variables.

All Quantitative variables were checked for normal distribution by using the normality Q-Q plots. For various domains of Burden Assessment Schedule (BAS), Median and Interquartile range (IQR) were compared between study groups using Mann Whitney U-test (2 groups). P-value < 0.05 was considered statistically significant. Statistical Package for Social Sciences (SPSS) version 22.0<sup>[15]</sup> was used for statistical analysis.

#### Ethics

Appropriate clearance was obtained from the Institute Ethical Committee for the study.

#### Results & observations

**Table 1: Demographic profile of caregivers of patients with bipolar disorder (N= 30) and schizophrenia (N=30).**

Demographic parameters	Bipolar Disorder (N=30)	Schizophrenia (N=30)	P value
<b>Age group</b>			
Young age (18 to 29)	7 (23.30%)	4 (13.30%)	0.191
Middle age (30 to 49)	12 (40.00%)	8 (26.70%)	
Old age (50 to 60)	11 (36.70%)	18 (60.00%)	
<b>Gender</b>			
Male	20 (66.70%)	21 (70.00%)	0.781
Female	10 (33.30%)	9 (30.00%)	
<b>Education</b>			
Illiterate	8 (26.70%)	7 (23.30%)	0.081
Primary	8 (26.70%)	12 (40.00%)	
Matriculate	2 (6.70%)	7 (23.30%)	
Higher secondary	9 (30.00%)	2 (6.70%)	
Graduate	3 (10.0%)	2 (6.70%)	
<b>Occupation</b>			
Employed	13 (43.30%)	18 (60.0%)	0.214
Unemployed	8 (26.70%)	3 (10.0%)	
Housewife	9 (30.0%)	9 (30.0%)	
<b>Marital status</b>			
Single	12 (40.00%)	4 (13.30%)	0.061
Married	16 (53.30%)	24 (80.00%)	
Widow	2 (6.70%)	2 (6.70%)	

\*P value < 0.05 (statistically significant)

**Table 2: Proportion of caregivers in patients with bipolar disorder (N= 30) and schizophrenia (N=30).**

Caregiver	Study group		Chi square	P value
	Bipolar Disorder (N=30)	Schizophrenia (N=30)		
Parents	9 (30.0%)	14 (46.70%)	2.148	0.542
Spouse	13 (43.3%)	9 (30%)		
Children	6 (20.0%)	6 (20%)		
Sibling	2 (6.70%)	1 (3.3%)		

\*P value < 0.05 (statistically significant)

**Table 3: Burden score classification of care givers of patients with bipolar disorder (N= 30) and schizophrenia (N=30).**

Burden score classification	Study group		P value	Inference
	Bipolar Disorder (N=30)	Schizophrenia (N=30)		
Moderate burden	25 (83.30%)	18 (60.00%)	0.045*	Significant
Severe burden	5 (16.70%)	12 (40.00%)		
<b>Total Burden Score</b>	64.4 ± 13.88	75.03 ± 13.7	0.004*	Significant

\*P value < 0.05 (statistically significant)

**Table 4: Comparison of mean score for each domain of BAS scale among care givers of patients with bipolar disorder (N= 30) and schizophrenia (N=30).**

Domains of burden scale	Study group		P value (Mann Whitney U test)	Inference
	Bipolar Disorder Median (IQR)	Schizophrenia Median (IQR)		
Spouse related	4.5 (3, 7)	6 (4, 8)	0.089	Insignificant
Physical and mental health score	10 (7, 11.25)	12 (8.75, 14.5)	0.030*	Significant
External support score	7 (5.75, 8)	8 (6, 10)	0.063	Insignificant
Care-Giver routine	5.5 (5, 7)	7.5 (7, 8)	0.003*	Significant
Support of patient	5.5 (5, 6.25)	5 (5, 7)	1.000	Insignificant
Taking responsibility	10 (8.75, 12.25)	13 (12, 14)	<0.001*	Significant
Other Relations	5 (3, 6)	6 (5, 7)	0.008*	Significant
Patient behaviours	8 (6, 9)	9 (6.75, 10.25)	0.070*	Insignificant
Care-givers strategy	7 (6, 9)	8 (8, 9)	0.010*	Significant

\*P value < 0.05 (statistically significant)

The socio-demographic details of the caregiver population are shown in Table 1. Majority in the bipolar disorder group (43.3%) were spouses while with schizophrenia patients, most of the caregivers (46.7%) were parents. (Table 2) Among the caregivers in bipolar disorder group, 25 (83.30%) participants had moderate burden and 5 (16.70%) participants had severe burden. While 18 (60.00%) caregivers of schizophrenia patients had moderate burden and 12 (40.00%) had severe burden. The difference in the total burden score between the groups was statistically significant (P Value 0.004). (Table 3) The score obtained in the individual domains of the BAS scale for the two study groups is shown in Table 4. Statistically significant difference was found between the study groups, specifically in the domains of- 1) physical and mental health score, 2) care-giver routine, 3) taking responsibility, 4) other relations and 5) care-giver strategy.

## Discussion

The present study is based upon the clinical concern that in the cases of severe mental disorders like schizophrenia and bipolar affective disorder, the caregivers experience a considerable amount of burden which, in turn, affects their well-being. This is not just detrimental to the course and treatment of the disorder a person is implicated with, but also further increases the burden on the caregivers as a part of a vicious cycle. In view of the recent advances in psychiatry, in terms of better accessibility, infrastructure, human resources and treatment options, the dynamics of relationship between the disease, patient and the caregiver has evolved significantly, and needs to be studied and understood.

The socio-demographic characteristics were comparable between the two study groups. Most subjects were males, were spouses followed by parents in case of bipolar affective disorder patient (43.30% and 30% respectively) and parents followed by spouses (46.70% and 30% respectively) among schizophrenia patients. However, in context of this relationship, the difference was not statistically significant between the groups. Past studies have depicted similar findings and corroborate the current study[16]. In terms of age, gender, education, background, occupation and marital status, no significant difference was found between the groups. The socio-demographic profile, thus did not seem to be a major confounding factor in the study.

Out of the total study population (n=60), 17 subjects (28.3%) were found to experience severe burden of care while 43 subjects (71.7%) felt moderate burden of care. When the two study groups are considered separately, it is revealed that out of the 17 subjects who experienced severe burden of care, 12 belonged to the schizophrenia

group while only 5 were from bipolar disorder group. While out of the 43 subjects experiencing moderate burden, most were from bipolar affective disorder group when compared to schizophrenia group (25 in comparison to 18). This difference between the experienced burden of care by the two study groups was statistically significant.

When the comparison was made between various domains of burden, there was a statistically significant difference between the study groups, specifically in the domains of- 1) physical and mental health score, 2) care-giver routine, 3) taking responsibility, 4) other relations and 5) care-giver strategy. Total burden score was 64.4 ± 13.88 for the subjects of bipolar disorder group and 75.03 ± 13.7 among the subjects of schizophrenia group. The burden was experienced more in the subjects of schizophrenia group and the difference in the burden between the groups was statistically significant.

Episodic nature of the affective disorders might bring a feeling of respite among the caregivers in the inter-episodic phase of the illness and, hence, appear to experience lesser burden than their schizophrenia counterparts, which are usually identified with a chronic continuous course[16,17]. While Martyns-Yellowe[18], Salleh[19], Roychaudhuri et al[17] and Jungbauer et al[20] and others[21,22,23,24,25], have pointed out significant burden of caregiving in schizophrenia patients in their studies, in our study too, 40% of the caregivers in the schizophrenia group (against 16.70% of bipolar disorder group) reported severe burden and, in the rest, moderate burden was found. As it implies, the subjects in schizophrenia group were found to experience more burden than the bipolar group in our study, a finding which is supported in the study conducted by Vasudeva et al[26]. A study by Mandal et al[27] has also indicated 40% caregivers of schizophrenia patients to perceive severe burden while the rest experienced moderate burden. However, a few studies have happened to conclude oppositely. Chadda et al[8] and Ohaeri[28] have reported no difference in burden indices among the caregivers of the two patient groups.

It is evident from our study that among the schizophrenia patients, 18 (60.00%) participants had moderate burden and 12 (40.00%) participants had severe burden. It can be implied that in an illness like schizophrenia, characterized by repeated exacerbations and remissions, not all caregivers perceive the same amount of burden[29]. This finding is in line with the studies suggesting that experienced burden is contingent to caregivers' estimation of patient's condition rather than the real deficits and symptom profile[30,31].

In this study, the burden score was higher in all the domains among the caregivers of schizophrenia patients, except in the domain of

patient's support, where burden score was higher among the caregivers of bipolar disorder patients. However, when compared statistically, more burden was found in the schizophrenia group only in the domains of physical and mental health score, care-giver routine, taking responsibility, other relations and care-giver strategy, while in none of the domains the burden was higher for bipolar group. Roychaudhuri et al[17], reported similar findings, as he found the burden to be higher in the caregivers of young male schizophrenic patients with low family income. These findings are partially in line with the findings by Kumar and Mohanty[32], who have reported significant burden only in the domains of external support, support of patient and patient's behavior apart from caregiver-routine and caregiver strategy. Sharma et al[33] in their study found that the burden for schizophrenic caregivers is more as compared to the caregivers of bipolar disorder, although in the domain of taking responsibility and caregivers' strategy the burden was more in the bipolar group. Chadda et al[8], on the other hand, has reported high scores specifically in two domains only: physical and mental health, and taking responsibility.

The current study has certain limitations being hospital-based, and employing convenience sampling, hence the findings are not generalizable. The coping strategies known to mediate the perception of the burden have not been assessed in the study as was the assessment of patient's functioning. The cross-sectional design of the study provides limited information about the dynamic influence of various social as well as clinical factors on the burden.

#### Conclusion

Severe burden of care worsens the quality of life and poses substantial subsyndromal psychiatric morbidity among the caregivers of patients with chronic psychiatric morbidities. Mental health professionals need to be sensitive towards various issues of the caregiving and must evaluate as well as provide appropriate interventions for reducing their burden, thereby improving their quality of life. Support programme should be planned to help the caregivers, acknowledging the uniqueness of each caregiving situation, monitoring the individual care process and taking into consideration the phase in the caregiving process.

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#### Conflict of interest

Nil

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