

# A comparison of burden of care in caregivers of patients with schizophrenia and obsessive-compulsive disorder



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Submission: 06-04-2022

Revision: 27-07-2022

Publication: 01-09-2022

## ABSTRACT

**Background:** Schizophrenia and obsessive-compulsive disorder (OCD) are two common and chronic psychiatric illnesses known to be associated with a considerable burden of caregiving. Various sociodemographic and clinical variables can influence the caregiving experience of the caregivers of these patients. **Aim and Objectives:** The present study aims to assess the burden of care, with the help of a well-standardized tool, and its relationship with different factors related to the caregivers. **Materials and Methods:** After obtaining the ethical approval from the Institutional Ethical Committee, a total of 50 adult caregivers with their patients with OCD as well as 50 caregivers with their patients with schizophrenia were enrolled on the study. The burden assessment schedule (BAS) was the principal tool to assess the burden of care in the caregivers of both patient groups. **Results:** The majority of the caregivers were male in both study groups. Both the study groups were comparable in terms of all sociodemographic variables except education and occupation. An education level of high school and above was found in a significantly higher number of the caregivers of patients with the OCD than those with schizophrenia (76% vs. 34%;  $\chi^2 = 25.76$ ;  $P < 0.001$ ). A significantly higher number (70% vs. 42%,  $\chi^2 = 8.227$ ,  $P < 0.05$ ) of caregivers of patients with schizophrenia were unemployed. Both groups were comparable in terms of the overall burden of care (i.e., total BAS score), but the caregivers of patients with schizophrenia had a significantly higher mean score of the burden in the domain "caregiver's routine" ( $8.92 \pm 1.82$  vs.  $8.08 \pm 1.85$ ;  $t = 2.291$ ;  $P < 0.05$ ) and in the domain "taking responsibility" ( $11.0 \pm 0.50$  vs.  $10.08 \pm 0.94$ ;  $t = 6.103$ ;  $P < 0.001$ ) than the caregivers of patients with OCD. **Conclusion:** The burden of care in the caregivers of patients with the OCD was not less than that in patients with schizophrenia in almost all of its domains except the burden of caregiver's routines and taking responsibilities which were higher than the caregivers of patients with schizophrenia. There is a need for the development of educational inputs and support programs for these caregivers based on their local needs.

**Key words:** Caregiving; Burden; Schizophrenia; Obsessive-compulsive disorder

## INTRODUCTION

Psychiatric disorders are important public health problems not only for the individuals suffering from them but also for their caregivers.<sup>1</sup> Worldwide, psychiatric disorders are prevalent in around 13% of the population.<sup>2</sup> The family members of patients with psychiatric disorders play a key

role in the overall treatment and rehabilitation of these patients.<sup>3</sup> These family caregivers face different challenges in terms of physical, mental, and social pressure in the course of care and control of the sick members of the family.<sup>4</sup>

Schizophrenia and obsessive-compulsive disorder (OCD) are two common and chronic psychiatric illnesses that

### Access this article online

**Website:**

<http://nepjol.info/index.php/AJMS>

**DOI:** 10.3126/ajms.v13i9.44317

**E-ISSN:** 2091-0576

**P-ISSN:** 2467-9100

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are known to carry a huge burden of care on their caregivers.<sup>5-8</sup> Schizophrenia is an incapacitating, long-lasting psychotic disorder characterized by incoherent or bizarre thoughts, abnormal speech and behavior, and delusions or hallucinations. Its chronic course and characteristic symptoms cause a considerable cost to the patient in terms of individual suffering and the caregiver due to the shift of the burden of care from the hospital to families. OCD is another chronic psychiatric disorder characterized by ego-dystonic repetitive thoughts (obsessions) and/or behaviors (compulsions) with the urge to repeat them over and over again. Family members are often drawn into the ritualistic behavior of these patients. Family members often have to modify the family functioning and routines to accommodate their relative's rituals and this family adjustment is frequently linked with global family dysfunction and distress. The significance of caring is high in the life of a family member who bears maximum responsibility.<sup>9</sup>

Taking care of such chronic psychiatric patients is not an easy task and it affects the physical and psychological well-being of the caregivers so much so that they are often termed "invisible patients".<sup>10</sup> The term "Caregiver-burden" has been used to define the multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience.<sup>11,12</sup> This caregiver burden is often the outcome of a stressful and negatively perceived experience of providing care.<sup>13</sup> A proper address of the burden of care is desirable given its ultimate poor impact on the overall caregiving of patients with chronic mental illnesses. In India, caregiving is a responsibility to take care of family members when they fall sick. Family members inevitably take the role of caregiver and unite to provide the best possible care. A transient caregiving assignment may not have any significant impact on the health of caregivers, but chronic and long-lasting caregiving charges may have adverse impacts on the health of caregivers who take the sole responsibility for caring for such patients.<sup>14</sup>

Caregivers of schizophrenia and OCD too face emotionally challenging experiences and have an increased chance of psychological ill-being in comparison to the general population. Earlier research works from both India<sup>5-7,9</sup> and abroad<sup>8</sup> have compared the burden of care and its determinants in patients with schizophrenia and OCD. However, the outcomes of these studies have been inconclusive due to methodological differences in terms of varied sample sizes, measuring tools, and different psychosocial factors.

This study was designed to assess the burden of care and its relationship to different psychosocial and clinical variables in patients with schizophrenia and OCD in a

tertiary care center in North India. The burden of care was assessed with the help of the burden assessment schedule (BAS),<sup>15</sup> a well-known tool specially designed for the Indian population.

### Aims and objectives

This study was designed to assess the burden of care and its relationship to different psychosocial and clinical variables in patients with schizophrenia and OCD in a tertiary care center in North India.

## MATERIALS AND METHODS

This study was carried out on the patients and their caregivers presenting to the psychiatry out-patient department and in-patient department of a tertiary care center in North India. After obtaining the ethical approval from the Institutional Ethical Committee, a total of 50 adult caregivers with their patients with OCD as well as 50 caregivers with their patients with schizophrenia were enrolled on the study. Obtaining written and informed consent from the patients or their respective caregivers (if the patients were not in the condition to give the consent) was a must before including them in the study. The patients were diagnosed as per ICD-10 diagnostic criteria for research (DCR).

The patients and caregivers were in the age range of 18–65 years and of both genders. The duration of caregiving for both the groups was decided to be 1 year or more for their inclusion in the study. The caregivers of both the groups with comorbid chronic physical or other psychiatric illnesses as well as those having another family member with a psychiatric and/or chronic physical illness were excluded from the study. The caregivers having intellectual disability or any disease that could affect their cognitive or mental functioning were also excluded from the study. Out of many caregivers of a particular patient, only one caregiver who had the primary responsibility of the patient was included in the study. The Pollak and Perlick (1991)<sup>16</sup> method of identifying a primary caregiver was used: "Primary caregiver is one who satisfies 3 or more of the 5 criteria: (1) Parent, spouse, or spouse equivalent; (2) Most persistent contact with patients; (3) Supports patient financially; (4) Most persistent collateral participant in patient's treatment; and (5) He/she is the person contacted in case of emergency. Diagnoses of schizophrenia and OCD were made according to ICD-10 DCR. The confirmation of psychiatric diagnoses was done with the help of a consultant psychiatrist of the department.

The sociodemographic details of both caregivers and their patients were collected on a self-prepared datasheet using a semi-structured interview. Clinical details of the

patients with schizophrenia and OCD were collected on a self-prepared data clinical datasheet. The BAS<sup>15</sup> was the principal tool to assess the burden of care in the caregivers of both patient groups. BAS is a 40-item instrument that assesses the burden of care on nine domains, namely, spouse related (five items), physical and mental health (six items), external support (five items), caregiver's routine (four items), support of patient (three items), taking responsibility (four items), other relations (three items), patient's behavior (four items), and caregiver's strategy (four items). Each item of the tool is scored on a three-point Likert scale with scores ranging from 1 ("not at all") to 3 ("very much") showing the degree of caregiving burden. The total burden of care is assessed by the sum of scores obtained on all 40 items and it ranges from 40 to 120 with a higher total score representing a higher burden of care in the individual.

The collected data were entered and analyzed using the IBM SPSS-23 software. Preliminary analyses were performed to check the fulfillment of assumptions of normality. Descriptive statistics such as means and standard deviations for continuous variables and frequency (n%) for categorical variables were calculated for the study participants. Independent-sample "t"-test and Chi-square test were used to find significant differences and associations.  $P < 0.05$  was considered to be statistically significant.

## RESULTS

Table 1 shows the comparison of sociodemographic characteristics of the caregivers of patients with schizophrenia (n=50) and those of patients with OCD (n=50). The majority of the caregivers were males in both study groups (schizophrenia group – 70% vs. OCD group 52%). Both the study groups were comparable in terms of these variables except education and occupation. The majority (76%) of the caregivers of patients with OCD and only one-third (34%) of the caregivers of patients with schizophrenia had an education of high school and above. Only a minority (20% vs. 10%) of the caregivers of both study groups were illiterate. A significantly higher number (70% vs. 42%,  $P < 0.05$ ) of caregivers of patients with schizophrenia were unemployed.

Table 2 shows a comparison of the clinical details of patients with schizophrenia and OCD. The mean duration of schizophrenia was 6.42 ( $\pm 5.35$ ) years while that of OCD was 5.94 ( $\pm 4.51$ ) years. Only a minority of the patients of both groups (38% vs. 22%) had a history of hospitalizations. The given clinical parameters of the duration of illness, age of onset, and history of hospitalizations of the two groups of patients were comparable.

Table 3 shows a comparison of the burden of care among the caregivers of the two patient groups. Both groups were comparable in terms of the overall burden of care (i.e., total BAS score) and all domains except the burden in the caregiver's routine and caregiver's taking responsibility. The caregivers of patients with schizophrenia had a significantly higher mean score of the burden in the domain "caregiver's routine" ( $8.92 \pm 1.82$  vs.  $8.08 \pm 1.85$ ;  $t = 2.291$ ;  $P < 0.05$ ) and in the domain "taking responsibility" ( $11.0 \pm 0.50$  vs.  $10.08 \pm 0.94$ ;  $t = 6.103$ ;  $P < 0.001$ ) than the caregivers of patients with OCD.

Table 4 shows a comparison of the burden of care (BAS total score) of the caregivers of both patient groups in terms of their different relationships with their respective patients. Around half of the caregivers of patients with schizophrenia (48%) and OCD (52%) were the parents of the patients. The burden of care (i.e., mean BAS score) was comparable in the parents of the patients with schizophrenia and those of the patients with OCD. For patients with schizophrenia, 20% of the caregivers were their spouses, while the same figure was 24% for patients with the obsessive-compulsive disorder. The burden of care (i.e., mean BAS score) was also comparable in the spouses of both patient groups. In the remaining category, other relatives included the patients' siblings and other close relatives for both study groups. In this category too, the mean BAS scores were comparable across the two study groups.

## DISCUSSION

The present study was conducted to assess the burden of care in the caregivers of patients with two common and chronic psychiatric illnesses – schizophrenia and OCD. While schizophrenia is recognized as a psychotic illness characterized by poor insight and loss of judgment in the majority of the patients, OCD is a neurotic disorder that does not have such amplified loss of insight and judgment and it is considered to cause a lesser level of disability as compared to schizophrenia.<sup>17,18</sup>

In our study, both the study groups were comparable in terms of their different sociodemographic characteristics except for education level and employment. The majority (76%) of the caregivers of the patients with the OCD had a significantly higher educational level (high school and above) than those of patients with schizophrenia. The majority of the caregivers of the patients with schizophrenia were more unemployed than those of the patients with OCD. A better educational level and employment in the caregivers of the patients with OCD might have influenced their caregiving to the patients positively.

**Table 1: Comparison of sociodemographic variables of the caregivers of patients with schizophrenia and those of patients with OCD**

Variables	Caregivers of patients with schizophrenia (N=50)	Caregivers of patients with OCD (N=50)	t	P
	Mean±SD	Mean±SD		
Age (in years)	31.32±11.04	31.94±9.82	0.297	0.767
	n (%)	n (%)	$\chi^2$	
Sex				
Male	35 (70%)	26 (52%)	3.405	0.065
Female	15 (30%)	24 (48%)		
Religion				
Hindu	29 (58%)	32 (64%)	0.378	0.539
Muslim	21 (42%)	18 (36%)		
Education				
Illiterate	10 (20%)	5 (10%)	25.76	<0.001
Primary to middle	23 (46%)	7 (14%)		
High school and above	17 (34%)	38 (76%)		
Occupation				
Unemployed	35 (70%)	21 (42%)	8.227	<0.05
Unskilled employment	12 (24%)	21 (42%)		
Skilled employment	3 (6%)	8 (16%)		
Marital status				
Single	20 (40%)	25 (50%)	2.479	0.290
Married	21 (42%)	21 (42%)		
Separated	9 (18%)	4 (8%)		
Socio-economic status				
Lower	31 (62%)	21 (42%)	5.849	0.119
Upper lower	13 (26%)	14 (28%)		
Lower middle	5 (10%)	13 (26%)		
Upper middle	1 (2%)	2 (4%)		
Family type				
Nuclear	30 (60%)	31 (62%)	0.042	0.838
Extended	20 (40%)	19 (38%)		

OCD: Obsessive-compulsive disorder

**Table 2: Comparison of clinical variables of patients with schizophrenia and those with OCD**

Variables	Patients with Schizophrenia (N=50)	Patients with OCD (N=50)	t	P
	Mean±SD	Mean±SD		
Duration of illness range (in years)	6.42±5.35 (2–24)	5.94±4.51 (1–22)	0.485	0.629
Age of onset range (in years)	24.76±10.34 (12–50)	25.26±7.89 (12–50)	0.272	0.500
	n (%)	n (%)	$\chi^2$	
History of hospitalizations (present)	19 (38%)	11 (22%)	3.048	0.081

OCD: Obsessive-compulsive disorder

Both the groups were comparable in terms of the overall burden of care and its different domains except for two domains namely “caregiver’s routines” and “taking responsibility” which were significantly higher in the caregivers of patients with schizophrenia than those in the patients with OCD. The domain “caregiver’s routines” incorporates issues such as caregivers’ time to look after their health, their sleep disturbances, their ability to relax, and their concern that the patient is looking after himself. The domain “taking responsibility” means the caregivers’ concerns about all needs of their patients including financial needs as well as their sharing problems with others. A higher burden on these two

domains of the burden in care in the caregivers of patients with schizophrenia can be understood by a poor educational level and unemployment in these caregivers in comparison, as discussed above. Further, the nature of the illness of the patients might have also influenced the burden of care on their caregivers. Schizophrenia is a psychotic condition, in which a patient’s reality testing is compromised, resulting in significant social and professional difficulties.<sup>19,20</sup> OCD, on the other hand, is a neurotic disorder, in which the patient maintains a normal sense of reality.<sup>20</sup> In the present study, only a minority of the caregivers of the patients of both groups (schizophrenia-20% vs. OCD-24%) were the spouses of the patients. We did not

**Table 3: Comparison of burden of care (total BAS score) and its domains between the caregivers of patients with schizophrenia and those of patients with OCD**

Burden of care	Caregivers of patients with schizophrenia (N=50)	Caregivers of patients with OCD (N=50)	t	P
	Mean±SD	Mean±SD		
Total BAS score (range: 52–100)	80.12±12.55	79.24±10.89	0.375	0.709
Domains of burden of care				
Spouse related	10.70±1.25 <sup>#</sup>	10.08±1.51 <sup>@</sup>	1.031	0.315
Physical and mental health	14.24±2.66	13.78±2.55	0.882	0.380
External support	9.58±2.30	9.70±2.03	0.276	0.783
Caregiver's routine	8.92±1.82	8.08±1.85	2.291	<0.05
Support of patient	7.38±1.11	7.68±1.04	1.399	0.165
Taking responsibility	11.0±0.50	10.08±0.94	6.103	<0.001
Other relations	7.20±1.23	7.22±1.06	0.087	0.931
Patient's behavior	9.44±2.17	9.78±1.71	0.871	0.386
Caregiver's strategy	10.22±1.33	10.50±1.30	1.066	0.289

<sup>#</sup>n=10; <sup>@</sup>n=12. OCD: Obsessive-compulsive disorder, BAS: Burden assessment schedule, SD: Standard deviation

**Table 4: Comparison of BAS total score of the caregivers in terms of different relationships with their patients**

Relationship with patient	Caregivers of patients with schizophrenia		Caregivers of patients with OCD		t	P
	n (%)	BAS score	n (%)	BAS score		
		Mean±SD		Mean±SD		
Parents	24 (48%)	77.77±14.19	26 (52%)	75.5±10.25	0.223	0.824
Spouse	10 (20%)	90.13±4.43	12 (24%)	89.92±10.25	0.028	0.978
Others	16 (32%)	76.12±3.75	12 (24%)	76.89±3.73	0.074	0.946

OCD: Obsessive-compulsive disorder, BAS: Burden assessment schedule, SD: Standard deviation

find a statistically significant group difference in the spouse-related domain of the burden of care.

Similar to our study, a comparison of the caregiving burden of patients with schizophrenia and OCD has been sought by other researchers<sup>5-9</sup> from India and abroad and they too failed to find a statistically significant group difference in the overall burden of care, though on using different tools to measure the same. Similar to our study, an Indian study by Oza et al.,<sup>6</sup> too found no significant difference between the two groups for total burden score, but the burden caused by component disruption of routine family activities was significantly higher in the caregivers of patients with schizophrenia than the caregivers of patients with OCD. However, Negm et al.,<sup>8</sup> and Das et al.,<sup>21</sup> did not find a significant difference between the caregiving burden for the schizophrenia and OCD patients for both the total score as well as component level scores.

Assessment of the caregiving burden of patients with psychiatric illnesses or other chronic medical conditions is one of the highly researched topics in the literature. The answer to any difference in the burden of care in these conditions is not straightforward. The burden of care can be influenced by not only the caregiver's different sociodemographic characteristics or different clinical characteristics of their patients but also by the caregivers' coping abilities and psychological

wellbeing. Further studies should seek these aspects in detail in predicting the burden of care in these individuals.

#### Limitations of the study

There are certain limitations of this study which should be taken care of while conducting similar future studies. We conducted the study on smaller sample size and selected the sample from a single tertiary care center using the cross-sectional design, all of which restrict the ability of this study to generalize the findings. We could not go for different multivariate analyses in delineating the impact of different sociodemographic and clinical variables on the burden of care, due to the smaller sample size.

#### CONCLUSION

Our study found that the caregivers of patients with OCD were comparable to that with schizophrenia in terms of the overall burden of care but the burden on the routines and the responsibilities of the caregivers of patients with schizophrenia were higher. Overall, the sociodemographic characteristics of both groups were almost comparable. This study, further, highlights the issue of better involvement of caregivers in the overall management of chronic psychiatric conditions such as schizophrenia and OCD. The family members suffer a lot, while taking care of their patients

and they need to be supported. There is a need for the development of educational inputs and support programs for these caregivers based on their local needs. As for other psychiatric illnesses, the caregivers of patients with the OCD should also be targeted the effect of various professional and non-professional support interventions on them needs to be addressed in future research.

## ACKNOWLEDGEMENT

None.

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ES, SS, NS, SP- Concept and design of the study, prepared first draft of manuscript; SK, AJ- Interpreted the results; reviewed the literature and manuscript preparation; RA- Concept, coordination, statistical analysis and interpretation, preparation of manuscript and revision of the manuscript.

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Source of Support: Nil, Conflicts of Interest: None declared.