

# A Comparative Study On The Burden Of Caregivers Of Schizophrenia And Substance Use Disorder In Nuclear And Joint Family

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## Abstract:

**Background:** Caregiver's burden became a topic of interest since mid-twentieth century and most of the earlier studies were concerning schizophrenia. Caregiver's burden in SUD has not been closely studied as in schizophrenia. The present study is an attempt to assess and compare the burden in caregivers of schizophrenia and SUD. With the changing beliefs, cultures and priorities of life, it would be pertinent to study different domains of caregiver's burden in schizophrenia and SUD in joint and nuclear family.

**Materials and Methods:** A cross-sectional hospital-based study was done with primary caregivers of the patients with schizophrenia and SUD as per ICD-10. The caregivers belong to age group of 18 to 60 years. A total of 60 participants including 30 caregivers of patients with schizophrenia and 30 caregivers of patients with SUD were taken from a tertiary care hospital. Subjects were assessed using socio-demographic profile and Burden Assessment Schedule (BAS).

**Results:** Caregivers of both groups had moderate to severe degrees of burden. The mean difference in total burden was not significant when caregivers of schizophrenia were compared with caregivers of SUD. But the total burden was significantly higher in caregivers belong to nuclear family compared to caregivers belong to joint family ( $p > 0.05$ ).

**Conclusion:** The presence of moderate to severe degree of burden among the caregivers need further study in this area. The caregivers also require comprehensive interventions in order to reduce the level of stress among the caregivers of severe mental illnesses.

**Key Word:** Caregiver burden; Schizophrenia; Substance Use Disorder; Joint family; Nuclear family.

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## I. Introduction

In India, due to deficit of trained staff and infrastructure, family takes the major role in supporting the person with mental disorder. Caregiver is a person who has the responsibility for meeting physical and psychological needs of the dependent. Commonly, caregiver is a member of family. Family consists of group of individuals who actively participate in crucial phases of their lives together. Most of the families are traditional joint family type in India. Joint family is a group with several family subunits living in separate rooms of the same house<sup>1</sup>. It is well recognized that the maximum impact of a psychiatric disorder is borne by the family and often leads to a disruption in its functioning. Most of the studies in this area during the past five 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<sup>2,3,4,5,6,7,8,9,10</sup>. As per the global burden of diseases, injuries and risk factors study 2016, schizophrenia is one of the top 15 leading causes of disability worldwide<sup>11</sup>. There are studies on family caregivers of diagnosed substance dependence subjects and the result showed moderate and severe family burden<sup>12,13,14</sup>. Sethi et al., (1978) showed that the joint family system is more helpful in coping with stress, whereas nuclear families are more vulnerable to stress<sup>15</sup>. On the contrary there are studies which showed that the caregivers belonging to nuclear families coped better than those of joint families<sup>16</sup> and larger families experience high level of burden<sup>17</sup>. Mandal, et al.,<sup>18</sup> in AIIMS, New Delhi have failed to find out significant difference in burden between different traditional joint family and nuclear family. In the study by Matto et al.,<sup>19</sup> it was shown that burden was not associated with family size. Similar result was also shown by Sharma et al.,<sup>14</sup>.

## **II. Material And Methods**

This was a hospital-based, cross sectional and comparative study conducted at Kalinga Institute of Medical Science, Department of Psychiatry, Bhubaneswar. A total of 60 caregivers (both male and females) were selected by purposive sampling and being caregivers of schizophrenia patient and SUD patient from the outpatients visiting the department of psychiatry of the hospital. The “caregiver” includes any primary caregiver, who is 18 years above of age, committed to look after the patient.

**Study Design:** Cross-sectional and comparative study

**Study Location:** This was a hospital-based study done in Kalinga Institute of Medical Science, Department of Psychiatry, Bhubaneswar, Odisha.

**Study Duration:** April 2017 to June 2017

**Sample size:** 60 caregivers

**Sample size calculation:**

The sample was selected by purposive sampling and being caregivers of schizophrenia patient and SUD patient from the outpatients visiting the department of psychiatry of the hospital. A total of 100 participants are included in the initial round, but 60 (30 from caregivers of schizophrenia and 30 from caregivers of SUD) are retained for the study after eliminating on the basis of inclusion-exclusion criteria.

### **Inclusion criteria:**

1. The “caregiver” includes any primary caregiver
2. Either sex
3. Aged  $\geq 18$  years,

### **Exclusion criteria:**

1. Patients having concomitant mental retardation
2. Patients with any other medical or psychiatric comorbidity
3. Caregiver having a history of mental illness
4. Caregiver under treatment for medical illness
5. Caregiver taking care of more than one patient with mental or medical illness is not considered as sample for this study.

### **Procedure methodology**

The study protocol was approved by hospital ethics committee and all participants gave written informed consent to participate. A fully informed consent was taken from all participants in the study prior to data collection. Participation or nonparticipation of the participants did not cause any benefit or loss to them. Participation is voluntary; the participant may withdraw from the study or may take a break at any point of time during the course of study. This study is of a research nature. The confidentiality of the participant is maintained and answers will only be used by researcher and committee. Data was collected over a period of 2 months. Relevant demographic and clinical data for the caregivers and patients were collected from the patients and the caregivers suggesting their age, gender, education, socioeconomic status, marital status, employment status, family type, onset of illness, duration of treatment. Caregiver burden was assessed using Burden Assessment Schedule (BAS) by Thara et al.<sup>20</sup>. It is a semi-quantitative instrument with 40 items measuring 9 different areas of subjective and objective caregiver burden. 4 items are specially pertaining to spouse. Each item is rated on a 3-point scale with 1 not at all, 2 to some extent and 3 very much. Total score ranges from 40 to 120. Face-to-face interview was arranged for data collection. Caregivers were interviewed separated from patients and other members, to facilitate free expression of their feelings. It took between 20 to 30 minutes to complete each interview.

### **Statistical analysis**

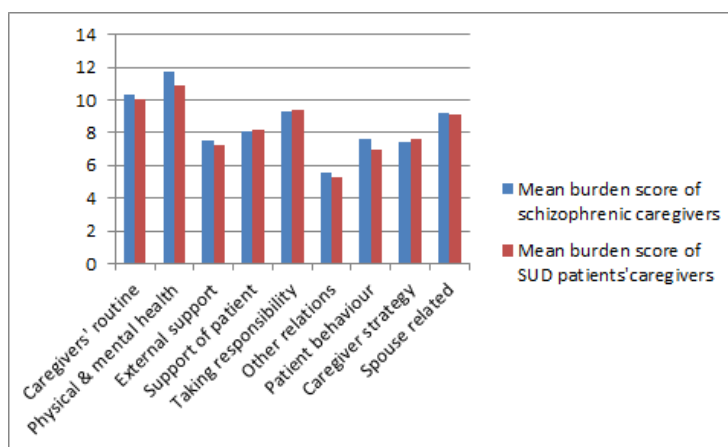
Data was analysed using SPSS version 17. Appropriate quantitative statistical analysis and Student's *t*-test was used to compare the significance of differences between level of burden among different groups. The level  $P < 0.05$  was considered as the cut-off value or significance.

## **III. Result**

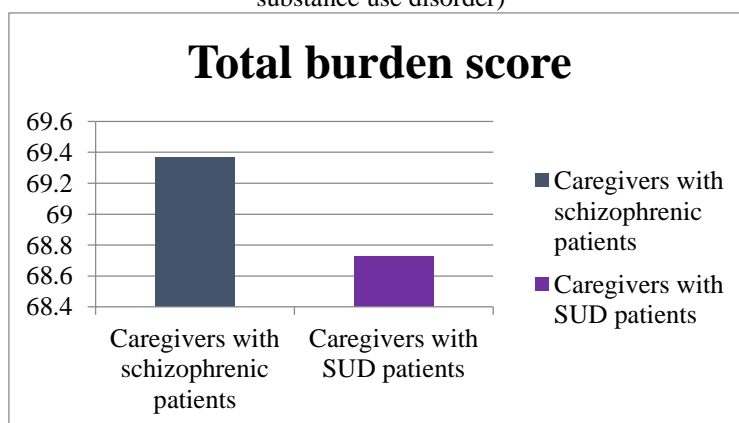
Table no.1 shows comparison of caregiver burden in the two groups as reflected in Burden Assessment Schedule scores. Independent t-test was applied to compare the mean scores in the two groups. The difference in total burden was non-significant when caregivers of schizophrenia were compared with caregivers of SUD. Caregivers of patients with schizophrenia has the mean value of 69.37 (SD=11.76) and caregivers of SUD patients has the mean value of 68.73 (SD=11.674). Similarly, t-test was applied to compare means of each of the nine factors of Burden Assessment Schedule. All the nine domains are non-significant when compared with the caregivers of schizophrenia and SUD groups.

**Table no 1:** Distribution of burden scores in two groups (among the caregivers of schizophrenia and substance use disorder-SUD)

Areas of burden	Type of disorder	N	Mean	Std. D	t value	Df	f	Sig. (2-tailed)
Caregivers' routine	Schizophrenia	30	10.37	2.205	0.554	58	0.413	0.581
	SUD	30	10.07	1.982	0.554	57.351		0.582
Physical & mental health	Schizophrenia	30	11.70	2.973	0.975	58	0.054	0.334
	SUD	30	10.93	3.118	0.975	57.869		0.334
External support	Schizophrenia	30	7.57	1.775	0.609	58	0.356	0.545
	SUD	30	7.27	2.033	0.609	56.963		0.545
Support of patient	Schizophrenia	30	8.10	1.954	-0.149	58	1.754	0.882
	SUD	30	8.17	1.487	-0.149	54.164		0.882
Taking responsibility	Schizophrenia	30	9.30	1.557	-0.255	58	0.022	0.799
	SUD	30	9.40	1.476	-0.255	57.836		0.799
Other relations	Schizophrenia	30	5.60	1.850	0.701	58	3.520	0.486
	SUD	30	5.30	1.442	0.701	54.744		0.486
Patient behavior	Schizophrenia	30	7.60	1.940	1.195	58	0.136	0.237
	SUD	30	6.97	2.157	1.195	57.361		0.237
Caregiver strategy	Schizophrenia	30	7.43	1.695	-0.409	58	0.612	0.684
	SUD	30	7.60	1.453	-0.409	56.668		0.684
Spouse related	Schizophrenia	5	9.20	0.837	0.148	13	0.526	0.884
	SUD	10	9.10	1.370	0.175	12.84		0.884
Total scores	Schizophrenia	30	69.37	11.760	0.209	58	0.072	0.835



(Distribution of mean burden scores in nine domains among caregivers of patient with schizophrenia and substance use disorder)

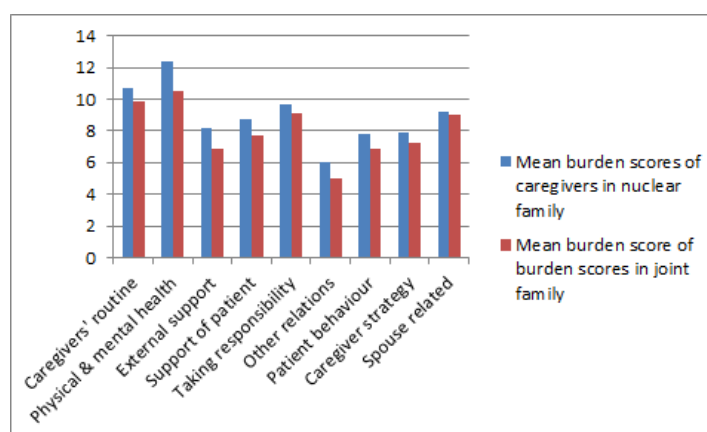


(Distribution of total mean scores of burden among caregivers of patient with schizophrenia and substance use disorder)

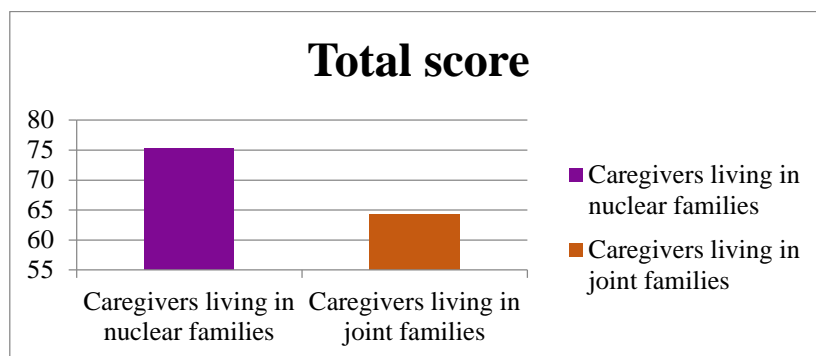
Table no. 2 indicates comparison of caregiver burden in the two-family types (nuclear or joint). Independent t-test was applied to compare the mean scores in the two groups. There was a significantly higher total burden with mean value of 75.23 (SD=10.390) in caregivers belong to nuclear family compared to caregivers belong to joint family with mean value of 64.32 (SD=10.340) ( $p < 0.05$ ). The nine domains of burden assessment schedule were compared between nuclear and joint family. Significantly higher burden was noted in caregivers belong to nuclear family on four domains, like ‘physical and mental health’ with a mean of 12.35 ( $t=2.38$ ) and a mean score of 10.53 ( $t=2.37$ ) in joint family; ‘external support’ with a mean of 8.15 ( $t=2.78$ ) and a mean score of 6.85 ( $t=2.78$ ) in joint family; ‘support of patient’ with a mean of 8.73 ( $t=2.45$ ) and a mean score of 7.68 ( $t=2.47$ ) in joint family; ‘other relations’ with a mean of 6.00 ( $t=2.34$ ) and a mean score of 5.03 ( $t=2.28$ ) in joint family. There were no significant differences when compared with two different family types (nuclear or joint).

**Table no 2:** Distribution of burden scores in two family types (nuclear or joint)

Areas of burden	Family type	N	Mean	S D	t value	Df	F	Sig. (2-tailed)
Caregivers’ routine	Nuclear	26	10.73	2.219	1.698	58	0.475	0.095
	Joint	34	9.82	1.914	1.664	49.425		0.102
Physical & mental health	Nuclear	26	12.35	2.966	2.379	58	0.012	0.021
	Joint	34	10.53	2.905	2.372	53.375		0.021
External Support	Nuclear	26	8.15	1.782	2.776	58	0.002	0.007
	Joint	34	6.85	1.811	2.782	54.389		0.007
Support of patient	Nuclear	26	8.73	1.564	2.448	58	0.175	0.017
	Joint	34	7.68	1.718	2.479	56.193		0.016
Taking responsibility	Nuclear	26	9.69	1.408	1.559	58	0.181	0.124
	Joint	34	9.09	1.545	1.579	56.162		0.120
Other relations	Nuclear	26	6.00	1.766	2.340	58	1.670	0.023
	Joint	34	5.03	1.446	2.278	47.692		0.027
Patient behavior	Nuclear	26	7.81	1.960	1.755	58	0.137	0.085
	Joint	34	6.88	2.071	1.768	55.347		0.083
Caregiver strategy	Nuclear	26	7.88	1.558	1.611	58	0.496	0.113
	Joint	34	7.24	1.539	1.609	53.613		0.114
Spouse related	Nuclear	11	9.18	1.328	0.253	13	1.180	0.804
	Joint	4	9.00	.816	0.318	9.039		0.758
Total scores	Nuclear	26	75.23	10.390	4.044	58	0.287	0.0008
	Joint	34	64.32	10.324	4.041	53.779		0.0005



(Distribution of mean burden scores in nine domains among caregivers living in nuclear family and in joint family)



(Distribution of total mean burden scores among caregivers living in nuclear families and in joint families)

#### IV. Discussion

The result of the study indicates that the level of subjective and objective burden among caregivers of schizophrenia and SUD patients are moderate to severe and this is consistent with the findings of other studies<sup>12,16,18,21</sup>. It also shows that feeling of burden by caregivers remains moderate to severe regardless of the fact that schizophrenia and SUD are two different types of disorder. In the present study, no significant difference was found between the burden perceived by the caregivers of schizophrenia patients with mean score of 69.37 (SD=11.760) and mean score of 68.73 (SD=11.674) among caregivers of SUD patients. This finding contradicts the study conducted by Hyder et al., in Kerala which concluded that caregivers of alcohol dependence syndrome feel higher level of burden<sup>22</sup>. In our study, analysis of the areas of burden among these two groups further revealed that burden scores are not significantly different in any of the nine domains of burden assessment schedule. Family members of patients with schizophrenia may be hesitant to be identified as relatives of mentally ill person due to social stigma and some may be unable to share their problems with others due to the same reason. Similar stigma is experienced by substance users who are seen people who are morally flawed and of weak character.

It is found that both types of families experience moderate degree of burden, however, the burden perceived by caregivers living in nuclear families was significantly more than that in joint family. The burden reported by caregivers living in nuclear families was high with mean 75.23 (SD=10.39) on Burden Assessment Schedule which suggests moderate burden and burden reported by caregivers living in joint families was also moderate but was comparatively lower with a mean of 64.32 (SD=10.33). There are other studies which reported similar findings<sup>15</sup> whereas contradict to some other studies<sup>16</sup>. Much research has not been done on this, as most of the studies are from developed nations where the concept of joint family is not prevalent. A joint family consists of a number of small families of married couple and their children who live together in the same household. In a nuclear family, when a member in the family suffers from any mental disorder, the caregiver has to do multiple tasks like looking after the entire the domestic household chores, child care, managing finances, dealing with the related problems and at the same time takes care of the patient. However, in a joint family structure each member has been assigned different roles and responsibilities. During crisis situation the burden is shared by all the members. As there is more than one member to take care of the patient, the whole responsibility does not fall on the principal caregiver and others are there to take care of the household chores, childrearing, finance, etc. These factors could be the reason of experiencing lower burden by the caregivers in a joint family as compared to the caregivers in a nuclear family.

Further analysis of the areas of burden revealed that five domains of caregiver burden that are not significantly different when the two different family types were compared. However, in four domains, namely, “physical and mental health”, “external support”, “support of patient” and “other relations”, there was significantly more burden in caregivers living in nuclear families as compared to caregivers in joint families. The reason behind this may be due to the availability of more social support in joint family. Also, as there are many persons in a joint family the responsibilities are not carried by only one person as in a nuclear family.

Hours spent in care giving per day and use of emotional, functional and physical support is associated with mental health of the caregivers. Mental health and burden are significantly associated with caregivers’ health problems simultaneously. Significantly higher burden was noted in caregivers belonging to nuclear family on “physical and mental health” with mean 12.35 but mean score of 10.53 in joint family indicating that nuclear family have more problems in their physical and mental health compared to joint family.

The “external support” indicates the amount of help or support one gets from the family members and friends. The help may be physical, mental, emotional or economical help. The nuclear family obtained mean score of 8.15 on “external support” domain but mean score of 6.85 in joint family. As it indicates the joint family system is more helpful in coping with stress as they have more external support. On the contrary, the nuclear family has less external support, so they are more vulnerable to stress.

“Support of patient” include the problems arise due to the illness of the patient. It includes all the negative symptoms and the problematic behaviours. Due to these problematic behaviours, the family members suffer a lot. When “support of patient” domain is measured, it showed the mean score of 8.73 in nuclear family and mean score of 7.68 in joint family. The caregiver of a nuclear family suffers more due to the problematic behaviour of the patient compared to joint family.

The “other relations” refers to the relationship between family members and friends. As the consequence of the patient’s illness family members often develop misunderstanding. They blame each other by saying, “It’s your fault” or “It’s your responsibility”. The nuclear family obtained mean score of 6.00 in “other relations” domain whereas mean score of 5.03 in joint family.

## V. Conclusion

The presence of moderate to severe burden among the caregivers need further study in this area. The caregivers also require comprehensive interventions in order to reduce the level of stress among the care givers of severe mental illness.

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