

## RESEARCH

# A comparative study of care burden and social support among caregivers of persons with schizophrenia and epilepsy

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## Abstract

**Background:** The caregivers of persons with epilepsy and schizophrenia undergo severe emotional, physical, financial burden due to the nature, chronicity, disability, and stigma attached to the illness.

**Aim:** To assess the burden and social support among caregivers of persons with schizophrenia and epilepsy.

**Method:** The study was conducted at the Out Patient Department of LokopriyaGopinathBordoloi Regional Institute of Mental Health, Tezpur. It was a comparative study. Purposive sampling technique was used for selection of the sample. The sample for the current study comprised of caregivers of 30 persons with schizophrenia and 30 persons suffering from epilepsy. A semi-structured socio-demographic data sheet, the Burden Assessment Schedule (BAS), the Social Support Questionnaire, and the General Health Questionnaire were administered to the caregivers.

**Results:** There was no significant difference reported by the caregivers in the two groups with the entire domains of BAS and perceived social support. Physical and mental health, and caregivers' strategy domains of BAS had significant negative correlation at 0.05 levels with perceived social support. External support, support of patient, taking responsibility, and other relation domains of BAS had significant negative correlation at the 0.01 level with perceived social support.

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Epilepsy affects approximately 50 million people worldwide, with 80% of these individuals are residing in developing regions. Epilepsy accounts for about one per cent of the global burden of disease.[1,2] Epilepsy has significant economic implications in terms of health-care needs, premature death, and lost work productivity. An Indian study calculated that the total cost per epilepsy case was US\$ 344 per year (or 88% of the average income per capita). The total cost for an estimated five million cases in India was equivalent to 0.5% of gross national product.[3] Similarly, schizophrenia imposes very considerable clinical, social, and economic consequences on societies throughout the world, resulting in it being a leading contributor to global and regional levels of disability and the overall disease burden.[4] Burden of care is defined as "the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patients' significant others (e.g. members of the household and/or the family)".[5] Caring for patients with psychiatric disorders is associated with significant

physical, psychological, social, and financial burden. Studies have shown that caregivers of patients with epilepsy and schizophrenia have high levels of stress, strains, experience moderately high levels of burden, fears that the illness may cause physical injury or death as well as concern about the patient's future.[6-10]

Sreejaet *al.*[11] found that caregivers of both long term physical illness like intractable epilepsy and mental illness like schizophrenia experience high level of burden in the areas of patient care, finance, physical and emotional burden, family relations, and occupation. No significant difference was found in both the groups of caregivers and also no significant difference was found in total burden score between male and female caregivers of both the groups. Anjumet *al.*[12] found that burden of care and mental health problems are high in caregivers of patients with schizophrenia and epilepsy.

Various researchers have independently looked into care giving burden in schizophrenia and epilepsy, but as

such, efforts to look into the caregivers' experience of burden in schizophrenia and epilepsy, and compare the groups have been minimal. In the present research, schizophrenia and epilepsy were chosen because, like schizophrenia, epilepsy is also a chronic condition having high burden and its management is often related to presence of social support. Studies indicate that like schizophrenia, epilepsy causes high levels of psychosocial difficulties for all family members, perceived stigmatisation, and discrimination. There is no evidence available of any study being conducted in North East Region of India in regard to care burden and perceived social support in chronic diseases like schizophrenia and epilepsy.

Therefore, this study was conducted to assess burden and social support among the caregivers of persons with schizophrenia and epilepsy towards enhancing psychosocial family based interventions. Based on this study, intervention can be planned for the future. Moreover, while undertaking psychosocial interventions, mental health professionals not only deal with patient but also with family members. So, it is mandatory for the therapists/clinicians to know about the problems faced by the relatives while giving care to the patients.

**Aim:** To assess the burden and social support among caregivers of persons with schizophrenia and epilepsy.

**Objectives:** (1) To assess the burden among caregivers of persons with schizophrenia and epilepsy; (2) To assess the social support among caregivers of persons with schizophrenia and epilepsy; (3) To see the relationship between burden and social support among caregivers of persons with schizophrenia and epilepsy; (4) To see the correlation between burden and social support among caregivers of persons with schizophrenia and epilepsy.

### **Methodology**

The study was conducted at the Out Patient Department (OPD) of LokopriyaGopinathBordoloi Regional Institute of Mental Health (LGBRIMH), Tezpur. A comparative and descriptive research design was used for the study. The caregivers were selected using purposive sampling technique based on inclusion and exclusion criteria set for the study. The sample for the current study comprised of caregivers of 30 persons with schizophrenia and 30 persons suffering from epilepsy. Patients of both genders, between age group of 18-50 years with duration of illness more than one year were included. For caregivers between age group of 18-50 years, primarily educated, with duration of care giving for more than two years were included. All the cases were diagnosed by the psychiatrists as per the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) criteria[13] in OPD of LGBRIMH. Patients with mental retardation, comorbidity,

and substance abuse (excluding tobacco) were excluded. The period of data collection was from June to October 2009. The study was approved by the Scientific and Ethical Committee of the Institute.

### **Tools of data collection**

The following scales were used for data collection -

**1. Socio-demographic datasheet:** A semi-structured socio-demographic datasheet was prepared by the researchers to gather personal data of the respondents as well as other details. The sheet includes information such as age, sex, marital status, religion, education, and occupation about the caregivers and patients.

**2. Burden Assessment Schedule:[14]** This scale measures the burden of care among family members/caregivers. This scale is composed of nine factors or subscales: spouse related burden, physical and mental health burden, burden related to external support, burden on caregivers' routine, burden to support patient, burden related to taking responsibility, burden on other relations, burden due to persons' behaviour, and caregivers' strategy due to burden of care. The subscales of spouse related, caregivers' routine, taking responsibility, patients' behaviour, and caregivers' strategy related burden have constituted of four items each. The physical and mental health burdens, burden related to external support subscales comprised of six items each, burden to support patient subarea has five items, and burden on other relations subscale comprised three items. A total 40 items are there in the scale. On each item of the scale, the minimum possible score is one and maximum of three. The responses could be very much, scored as three; to some extent, scored as two; and not at all, scored as one. Fifteen items of the scale, i.e. item no. 1, 8, 11, 13, 15, 17, 18, 24, 25, 29, 34, 35, 36, 39 and for item no. 40, the scoring is reversed, as one for very much, to some extent as it is, and not at all measured as three. The scale was translated to local language according to prescribed translation procedures.

**3. Social Support Questionnaire:[15]** This scale measures perceived social support, i.e. social support as perceived by the subject. It has a total of 18 items, and four possible responses are: four=extremely, three=quite a bit, two=a little, one=not at all. Six items are positively worded and scoring remains same as four, three, two, one, as in the scale, and 11 are negatively worded, so the scoring is reversed for these items, i.e. one, two, three, four. Score indicates the amount of perceived social support. Higher score indicates more perceived social support and vice versa. It is a reliable and valid questionnaire. Test retest reliability after two weeks' interval on 50 subjects was found to be 0.59, significant at .01 levels. This scale is an Indian adaptation of the Social Support Questionnaire by Pollock and Harris.[16] The

scale was translated to local language as per prescribed translation procedures.

**4. General Health Questionnaire-12:**[17] The questionnaire was constructed by David P Goldberg in 1972 as a screening instrument in community surveys to identify ‘potential cases’ of neurosis leaving the task of identifying ‘actual cases’ to psychiatric interview. The General Health Questionnaire (GHQ) was administered to the caregivers to rule out the presence of any psychiatric disorders in them.

**Table 1: Age of caregivers and patients (N=60)**

Variables	Groups		df	t
	Schizophrenia (n=30)	Epilepsy (n=30)		
	Mean±SD	Mean±SD		
Age of caregivers (years)	40.4±9.85	39.60±9.37	58	.322
Age of patients (years)	32.53±7.48	28.96±8.72		1.699

*N=number, df=degree of freedom, SD=standard deviation*

**Statistical analysis**

Analysis of data was done using descriptive and inferential statistics. To compare the significant differences between means of two groups, an independent sample t test had been used. Pearson correlation was used to find out the relationship between burden and social support among caregivers of persons with schizophrenia and epilepsy.

**Result**

Thirty patients in both schizophrenia and epilepsy groups were included in the study. The socio-demographic profile of the sample is shown in tables 1, 2, and 3. There was no significant variance in age of caregivers and patients between the groups of schizophrenia and epilepsy (Table 1).

In socio-demographic profile, majority of the caregivers were male, Hindu by religion, educated up to high school. In occupation, majority of the female caregivers were housewives and male caregivers were engaged in agriculture activities or having their own businesses. Majority of the caregivers were married in both the groups. After applying chi-square test, no significant variance was found between the two groups in socio-demographic profile of the caregivers (Table 2).

Table 3 shows socio-demographic profile of the patients; majority were male, Hindu by religion. Majority of the patients in schizophrenia group were unemployed, while in epilepsy group, majority of the respondents were engaged in agricultural activities. Majority of the patients were educated up to high school and married in both the groups. Majority of the patients were living in joint family setup in schizophrenia group, while majority of patients were living in nuclear family setup in epilepsy group. After applying chi-square test, no significant variance was found between the two groups in socio-demographic profile of the patients (Table 3).

**Table 2: Socio-demographic profile of caregivers (N=60)**

Variables		Groups		χ <sup>2</sup>	df
		Schizophrenia (n=30)	Epilepsy (n=30)		
Gender of caregiver	Male	16 (53.3%)	17 (56.6%)	.067	1
	Female	14 (46.6%)	13 (43.3%)		
Religion	Hinduism	24 (80%)	25 (83.3%)	.111	1
	Islam	6 (20%)	5 (16.6%)		
Education	Primary	8 (26.6%)	9 (29.9%)	3.31	6
	Middle	10 (33.3%)	6 (20%)		
	High school	7 (23.3%)	9 (23.3%)		
	Higher secondary	3 (10%)	3 (10%)		
	Graduate	1 (3.3%)	3 (10%)		
	Postgraduate	1 (3.3%)	0		
Occupation	Business	6 (20%)	6 (20%)	1.96	3
	Agriculture	10 (33.3%)	9 (29.9%)		
	Housewife	10 (33.3%)	12 (40%)		
	Unemployed	4 (13.3%)	3 (10%)		
Marital status	Married	29 (96.6%)	29 (96.6%)	.000	1
	Unmarried	1 (3.3%)	1 (3.3%)		

*N, n=number; df=degree of freedom*

**Table 3: Socio-demographic profile of persons with schizophrenia and epilepsy (N=60)**

Variables		Group		χ <sup>2</sup>	df
		Schizophrenia (n=30)	Epilepsy (n=30)		
Gender	Male	21 (70%)	20 (66.6%)	.077	1
	Female	9 (30%)	10 (33.3%)		
Religion	Hinduism	24 (80%)	25 (83.3%)	.111	1
	Islam	6 (20%)	5 (16.6%)		
Occupation	Unemployed	10 (33.3%)	2 (6.6%)	11.213	3
	Business	4 (13.3%)	7 (23.3%)		
	Agriculture	8 (26.6%)	14 (46.6%)		
	House wife	8 (26.6%)	7 (23.3%)		
Education	Primary	4 (13.3%)	4 (13.3%)	5.834	4
	Middle school	10 (33.3%)	10 (33.3%)		
	High school	15 (50%)	14 (46.6%)		
	Higher secondary	1 (3.3%)	1 (3.3%)		
	Graduate	0	1 (3.3%)		
Marital status	Married	16 (53%)	16 (53.3%)	.067	1
	Unmarried	14 (50%)	14 (46.6%)		
Family type	Nuclear	14 (46.6%)	20 (66.6%)	2.443	1
	Joint	16 (53.3%)	10 (33.3%)		

*N, n=number; df=degree of freedom*

Table 4 shows the comparison of burden among caregivers of persons with schizophrenia and epilepsy.

Independent t test has been applied to find out the difference between these groups. There was no significant difference reported by the caregivers in the two groups with all the domains of BAS.

Table 5 shows the comparison of perceived social support among caregivers of persons with schizophrenia and epilepsy. Independent t test was applied to find out the difference between these groups. There was no significant variance reported by the caregivers in the two groups in perceived social support.

Table 6 shows the correlation (Pearson) of domains of BAS with perceived social support. Physical and mental health and caregivers' strategy domain of BAS has significant negative correlation at 0.05 levels with perceived social support. External support, taking responsibility, other relations, and support of patient domains of BAS has significant negative correlation at the 0.01 level with perceived social support.

## Discussion

Results of the study indicate that there was no significant difference reported by the caregivers in the two groups with all the domains of BAS and this is consistent with the findings of other studies.[11,12,18-20]. Similar finding was found in a study conducted in India,[11] and it was found that the caregivers had high levels of burden of care, regardless of the fact that schizophrenia and epilepsy are different disorders in nature. Chronic mental disorders generally affect the overall functioning and well-being of caregivers and bring negative consequences on their mental health.[21,22]. Numerous studies have explored the existence of burden among primary caregivers and family members of persons with schizophrenia.[23-27]. In perceived social support, significant difference was not found between the groups in the present study. Thus, it can be said that schizophrenia and epilepsy are chronic and distressing disorders, and caring a person with schizophrenia and epilepsy requires adequate support from the society, family, and friends in both the disorders. Social support can buffer the negative impact of stressful events and chronic health conditions. Social support plays a very important role in the life of patients, especially those having serious mental conditions.[28] Caring for patients with chronic medical and psychiatric disorders is associated with significant burden. Caregivers of patients with epilepsy experience significant burden while caring for their relatives.[20] Barman and Chakravorty[29] observed that certain levels of stress are found in all the family members of mentally ill clients; in order to reduce the stress, they are in need of support.

**Table 4: Comparison of burden among caregivers of persons with schizophrenia and epilepsy**

Variables	Group		df	t	Level of significance
	Schizophrenia	Epilepsy			
	Mean±SD	Mean±SD			
Spouse related	5.06±5.31	4.66±4.57	58	.312	NS
Physical & mental health	15.63±3.21	14.43±2.97	58	1.501	NS
External support	14.66±3.81	11.93±2.42	58	3.32	NS
Caregivers' routine	9.80±2.48	9.16±2.08	58	1.070	NS
Support of patient	12.96±2.22	11.36±2.31	58	2.734	NS
Taking responsibility	10.06±2.19	8.10±1.84	58	3.756	NS
Other relation	8.00±1.59	6.80±1.51	58	2.983	NS
Patients' behaviour	10.50±1.83	9.83±2.305	58	1.240	NS
Caregivers' strategy	10.00±2.31	9.10±1.64	58	1.733	NS

*SD=standard deviation, df=degree of freedom, NS=not significant*

**Table 5: Comparison of perceived social among caregivers of persons with schizophrenia and epilepsy**

Variables	Group		df	t
	Schizophrenia (n=30)	Epilepsy (n=30)		
	Mean±SD	Mean±SD		
Perceived social support	34.40±3.792	35.33±2.951	58	.856

*n=number, SD=standard deviation, df=degree of freedom*

The correlation of the domains of BAS was done with perceived social support. Physical and mental health and external support, support of patient, caregivers' taking responsibility, other relation, and caregivers' strategy domains of BAS has a significant negative correlation with perceived social support. The presence of social support is beneficial for parental well-being, adjustment, and care giving. Social support on different dimensions of parenting and care giving affects the various domains of caregivers' burden. Nevertheless, it has been demonstrated that social support directly affects burden to the caregivers. Social support serves as a resource that reduces parenting stress and burden; subsequently, exerts beneficial effects on care giving. It is evident that social support was poor for the families who had been studied. External services are lacking and social support from families and external setups is poor in the society. The burden experienced by caregivers may be the cumulative effect of the disease over the years. Frequent relapses and repeated seizure attacks challenge the coping and problem-solving ability of the caregiver. This also

**Table 6: Correlation (Pearson product-moment correlation) of perceived social support and Burden Assessment Schedule**

Domain of burden assessment	Total score Perceived social support
Physical and mental health	-.284*
External support	-.415**
Caregivers' routine	-.203
Support of patient	-.409**
Taking responsibility	-.509**
Other relations	-.421**
Patients' behaviour	-.253
Caregivers' strategy	-.285*

*\*P<0.05, \*\*P<0.01*

involves frequent hospital visits, using high doses of psychotropic drugs which are expensive, close monitoring of persons at home. Thus, prolonged attacks and relapses, and stigmatisation - all add to caregiver burden, and inadequate inputs in social services and facilities are an indication for social support. The main limitation of the study was the size of the sample; the other variables like family home environment, family coping and problem-solving skill should be taken for study in order to understand the true burden of caregivers. In fact, Kumar *et al.*[30] studied the subjective well-being and coping among people with schizophrenia and epilepsy.

### Conclusion

The implications from this study are that it will help us to understand the burden of illness and perceived social support, existent in caregivers of patients with a chronic mental illness such as schizophrenia and epilepsy in a North Eastern society. There is often a perception that the burden of care and social support, existent in a traditional society like in Assam, may be different from other parts of the country. It is also known that social support services are inadequate, and stigma associated with treatment of chronic illnesses is seen to be more in traditional and developing societies. Knowledge about burden perception and enhancement of social support services goes a long way in improving the quality of life of patients and their families, and also towards management of chronic illnesses like schizophrenia and epilepsy. Various inputs in the psychosocial area can be planned based on knowledge gained.

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### References

1. Reynolds EH. The ILAE/IBE/WHO Global Campaign against Epilepsy: Bringing Epilepsy "Out of the Shadows" *Epilepsy Behav.* 2000;1(4):S3-S8.
2. Epigraph WHO. The newsletter of the International League against Epilepsy. Geneva. 1999;1:5-6.
3. World Health Organization Fact sheet N°999. Epilepsy [Internet]. 2012 Oct [cited 2015 Apr 11]. Available from: <http://www.who.int/mediacentre/factsheets/fs999/en/>
4. World Health Organization. The world health report 2001. Mental health: new understanding, new hope. Geneva: World Health Organization; 2001.
5. Avasthi A. Preserve and strengthen family to promote mental health. *Indian J Psychiatry.* 2010;52:113-26.
6. Anderson E, Barton R. Epilepsy: a family burden? *ClinPsychol Forum.* 1990;25:3-5.
7. Thompson PJ, Upton D. The impact of chronic epilepsy on the family. *Seizure.* 1992;1:43-8.
8. Budd RJ, Oles G, Hughes IC. The relationship between coping style and burden in the carers of relatives with schizophrenia. *ActaPsychiatr Scand.* 1998;98:304-9.
9. Pakenham KI, Dadds MR. Family care and schizophrenia: the effects of a supportive educational program on relatives' personal and social adjustment. *Aust N Z J Psychiatry.* 1987;21:580-90.
10. Koujalgi SR, Patil SR. Family burden in patient with schizophrenia and depressive disorder: a comparative study. *Indian J Psychol Med.* 2013;35:251-5.
11. Sreeja I, Sandhya G, Rakesh L, Singh M. Comparison of burden between family caregivers of patients having schizophrenia and epilepsy. *The Internet Journal of Epidemiology [serial online].* 2008 [cited 2015 Apr 12]; 6:2. Available from: <https://ispub.com/IJE/6/2/9378>
12. Anjum W, Chaudhry HR, Irfan M. Burden of care in caregivers of patients with schizophrenia and epilepsy. *J Pak Psychiatr Soc [serial online].* 2010 Jul-Dec [cited 2015 Apr 12];7(2):79. Available from: [http://www.jpps.com.pk/display\\_articles.asp?d=258&p=art](http://www.jpps.com.pk/display_articles.asp?d=258&p=art)
13. World Health Organization. The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. Geneva: World Health Organization; 1992.
14. Thara R, Padmavati R, Kumar S, Srinivasan L. Instrument to assess burden on caregivers of chronic mentally ill. *Indian J Psychiatry.* 1998;40:21-9.
15. Nehra R, Kulhara P, Verma SK. Adaptation of social support questionnaire in Hindi. *Indian J Clin Psychol.* 1996;23:33-9.
16. Pollack L, Harris R. Measurement of social support. *Psychol Rep.* 1983;53:446-9.
17. Goldberg D. The detection of psychiatric illness by questionnaire: a technique for the identification and assessment of non-psychotic psychiatric illness. London: Oxford University Press; 1972.
18. Platt S. Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychol Med.* 1985;15:383-93.
19. Rose LE, Mallinson RK, Gerson LD. Mastery, burden, and areas of concern among family caregivers of mentally ill persons. *Arch Psychiatr Nurs.* 2006;20:41-51.
20. TajudeenNuhu F, Jika Yusuf A, Akinbiyi A, OluyinkaFawole J, Joseph Babalola O, TitilopeSulaiman Z, *et al.* The burden experienced by family caregivers of patients with epilepsy attending the government psychiatric hospital, Kaduna, Nigeria. *Pan Afr Med J.* 2010;5:16.
21. Laidlaw TM, Coverdale JH, Falloon IR, Kydd RR. Caregivers' stresses when living together or apart from patients with chronic schizophrenia. *Community Ment Health J.* 2002;38:303-10.
22. Jenkins JH, Schumacher JG. Family burden of schizophrenia and depressive illness. Specifying the effects of ethnicity, gender and social ecology. *Br J Psychiatry.* 1999;174:31-8.
23. Mors O, Sørensen LV, Therkildsen ML. Distress in the relatives of psychiatric patients admitted for the first time. *ActaPsychiatr Scand.* 1992;85:337-44.
24. Chakrabarti S, Kulhara P, Verma SK. Extent and determinants of burden among families of patients with affective disorders. *ActaPsychiatr Scand.* 1992;86:247-52.

25. Sen SK, Nath K. A clinical study of family burden in chronic schizophrenia. *Dysphrenia*. 2012;3:153-7.
26. Koujalgi SR, Patil SR. Family burden in patient with schizophrenia and depressive disorder: a comparative study. *Indian J Psychol Med*. 2013;35:251-5.
27. Lasebikan VO, Ayinde OO. Family burden in caregivers of schizophrenia patients: prevalence and socio-demographic correlates. *Indian J Psychol Med*. 2013;35:60-6.
28. Khalid A, Aslam N. Psychological distress among patients with epilepsy. *Indian J Psychol Med*. 2011;33:45-8.
29. Barman N, Chakravorty P. A descriptive study to assess the level of stress among family members of selected mentally ill clients attending psychiatry OPD of a tertiary care teaching hospital. *Dysphrenia*. 2012;3:65-73.
30. Kumar P, Nehra DK, Verma AN. Subjective well-being and coping among people with schizophrenia and epilepsy. *Dysphrenia*. 2013;4:25-30.

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