

# Comparison Of Burden Between Family Caregivers Of Patients Having Schizophrenia And Epilepsy

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## Abstract

This cross sectional study was undertaken to assess the burden between family caregivers of patients having Schizophrenia and Epilepsy. Data was collected on sixty. Findings revealed that the 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 groups of caregivers and also no significant difference was found in total burden score between male and female caregivers of both the groups. The study highlights the need for family interventional programs in follow up clinics to address the specific concern, related to burden of caregivers.

## BACKGROUND

Chronic illness refers to an altered health state that will not be cured by a simple surgical procedure or a short course of medical therapy. A person with a chronic illness experiences unpredictable dilemmas that promote powerlessness causing symptom exacerbation, failure of therapy, physical deterioration despite adherence to the prescribed regimen, the side effects of drugs, iatrogenic alterations, and breakdown in the client's psychological stamina. Of late the trend towards caring for chronically ill patients by family members at home is a common phenomenon because of the high costs of institutional care, dissatisfaction with the lack of personalized care in long term settings and the institutions's rejection of some clients as unsuitable due to the nature of their illness or the behaviors that result from the illnesses. The trend of deinstitutionalization places considerable burden for family caregivers who takes the sole responsibility in taking care of chronically ill patients especially in India.

Family burden has been extensively explored for illnesses like Schizophrenia, Dementia and Cancer by researchers. The cost families incur in terms of economic hardships, social isolation and psychological strain are referred to as family burden. Review of literature available suggest that family burden in mental and neurological diseases have some common characteristics such as the fact that several cognitive and behavioural symptoms may occur both in

brain disorders and schizophrenia and these have been found to be strong predictors of anxiety and depression in patient's relatives because of the inability of the relatives' difficulty in understanding the meaning of some psychiatric and neurological symptoms. Relatives of patients with neurological or mental disorders tend to overestimate a patient's capacity to control symptoms and disabilities. In India there are limited number of studies in the field of burden whereas it has been reported extensively in studies done abroad. Even among western studies, very few studies have compared the burden status between family caregivers of persons having chronic mental illness and a chronic physical illness requiring long term management. Owing to diversity and difference in economical, social, cultural and family dynamics compared to western countries, researcher felt the need to explore the burden of caregivers of long-term illness from the perspective of Indian families.

This study examines the differences in the experience of burden between family caregivers of patients having schizophrenia and epilepsy. The aim is to compare the burden on families of schizophrenia and compare the same with patients having physical disease requiring long term management. Epilepsy is the most common serious brain disorder and a global problem affecting all ages, races, social classes and countries. It imposes enormous physical, psychological, social, and economic burdens on individuals, families, and countries especially because of misunderstanding, fear, and stigma of epilepsy. Family

caregivers also face multiple psychosocial and economic problems. Schizophrenia is a chronic mental disorder associated with health, social and financial burden for a long duration, affecting not only for patients but also for families, other caregivers, and the wider society. Caring for a family member who is having schizophrenia is an enduring stressor and causes considerable amount of burden.

Analysis of burden and coping of family provide for a real world clinical decision, application of research finding, and generation of nursing strategies, all geared to promote holistic caring. The ultimate goal of nursing care is to maintain and enhance client and family quality of life irrespective of nature of illness.

### METHOD

Sixty family caregivers of patients having Schizophrenia and Epilepsy and taking consultation from All India Institute of Medical Sciences (AIIMS), Newdelhi. Thirty caregivers of patients diagnosed, as Schizophrenia according to ICD 10 criteria were selected from department of Psychiatry, AIIMS. And thirty caregivers of patients diagnosed as "Intractable epilepsy" were selected from department of Neurology, AIIMS. Only family caregivers (spouse, parent, child, or siblings of the patient), who are above 18 years and living with the patient for one year were included in the study. Duration of illness in both the groups was more than two years. Caregivers having chronic physical illness, past/current psychiatric illness, taking care of more than one chronically ill person in the family, unwilling to participate in the study and those who were illiterate were excluded from the study. Caregivers of patients having co-morbidity were also excluded from the study. Detail profile of caregivers and patient are given in table no.1 and table no.2 respectively.

Tools consisted of a data sheet for recording demographic and select variables of patient and caregiver, and Burden Assessment Schedule. Burden assessment tool is a standardized 40 item scale, which measures different areas of burden like financial burden of caregivers, occupation, patient behavior, social relations, caregiver's health, family relations and emotional burden. Each item is rated on a three point scale (not at all, to some extent and very much). The scores range from 40 to 120, with higher scores indicating greater burden. Criteria validity was computed against the interview schedule of Pai and Kapur (1981). Correlation of the items ranged from 0.71-0.82. Internal consistency, as measured by the alpha co-efficient, for the full scale is 0.81.

All the tools were translated to Hindi and tried out on a similar population before use. Ethical clearance was obtained from competent authority. A pilot study was done on 10 subjects to ascertain the feasibility of actual study. Descriptive statistics (Mean, Standard deviation) and inferential statistics (Unpaired t test, Chi square) were used for the analysis.

### RESULTS

There are an equal number of male and female caregivers in both the groups. Majority (44 out of 60) of the caregivers are married. Majority (17 out of 30) of the caregivers of patients having schizophrenia were taking care of patients for 0-5 years and majority (24 out of 30) of caregivers of patients having epilepsy were taking care of patients for 10 years or more.

As shown in Table No. 1 that, majority (57 out of 60) of the caregivers are educated upto high school or more. Equal number of caregivers are employed and unemployed in both the groups. Majority (52 out of 60) of the caregivers are Hindus, 31 out of 60 are having income less than Rs.5000 per month. Majority (32 out of 60) of the caregivers are parents.

There was no significant difference between the caregivers of patients having Schizophrenia and Epilepsy in their characteristics except in duration of caregiving and the type of relation with the patient. The duration of caregiving is longer for caregivers of patients having Epilepsy compared to that of Schizophrenia. Most (21 out of 30) of caregivers of the patients with epilepsy are parents.

As shown in Table No.2 that, majority (39 out of 60) of the patients were unmarried, (48 out of 60) studied upto high school and more, and majority (45 out of 60) of them were not having any employment. Patients having epilepsy were younger and had longer duration of illness as compared to the patients having schizophrenia. There is no significant difference between the two groups in their demographic characteristics except in duration of illness and age.

Majority (38 out of 60) of the caregivers reported 'Moderate burden' and 22 out of 60 reported 'Severe burden. None reported 'no burden'. The burden was predominantly felt in areas of patient care, finance, physical and emotional burden, family relations and occupation respectively. There was no significant difference in burden between the male and female caregivers of patients having schizophrenia. ( $t=0.765$   $p>0.05$ ,  $df\ 28$ )

Figure 1

Table 1: Characteristics of Caregivers

Variables	Caregivers of patient having		T value
	Schizophrenia n = 30	Epilepsy n = 30	
Gender			
• Male	15	15	
• Female	15	15	
Mean age(SD)	38.33(18.6)	41.13(11.9)	
Duration of caregiving			
• 0-5yr	17	4	$\chi^2 = 16.1^*$
• 6-10yr	9	8	
• 11-15yr	4	9	
• >16yr	0	9	
Mean duration	5.5(3.8)	12.18(6.27)	
Marital status			
• Unmarried	0	1	$\chi^2 = 1.018$
• Married	21	23	
• Divorcee	7	5	
• Widow/widower	2	1	
Educational status			
• Primary	1	4	$\chi^2 = 5.53$
• High School	9	12	
• Higher Secondary	8	4	
• Graduation	6	7	
• Post graduation	4	3	
• Others	2	0	
• Relationship with the patient			$\chi^2 = 8.63^*$
• Spouse	7	3	
• Parent	11	21	
• Sibling	8	5	
• Daughter	4	0	
• Aunt/uncle	0	1	

\*p<0.05

Figure 2

Table 2: Demographic Characteristics of Patients

Variables	Patients having		T value
	Schizophrenia n = 30	Epilepsy n = 30	
Gender			
• Male	15	20	$\chi^2 = 1.7$
• Female	15	10	
Mean age(SD)	30.46(7.2)	23.16(9.9)	
Duration of illness			
• 0-5yr	17	3	$\chi^2 = 16.1^*$
• 6-10yr	9	9	
• 11-15yr	2	8	
• >16yr	2	10	
Marital status			
• Unmarried	17	22	$\chi^2 = 11.3$
• Married	13	8	
• Divorcee	0	0	
• Widow/widower	0	0	
Educational status			
• Illiterate	0	3	$\chi^2 = 8.15$
• Primary	4	5	
• Highschool	15	12	
• Higher secondary	5	3	
• Graduation	2	5	
• Postgraduation	3	2	
• Others	1	0	
Occupation			
• Present	6	9	$\chi^2 = 0.80$
• Absent	24	21	

\*p<0.05

Figure 3

Table 3: Frequency Distribution of Caregivers According to the Status of Burden

Status of caregiver's burden	Caregivers of patients having	
	Schizophrenia n=30	Epilepsy n=30
No burden	0	0
Moderate burden	19	19
Severe burden	11	11

Figure 4

Table 4: Comparison of the Burden between Family Caregivers of Patients Having Schizophrenia and Epilepsy

N=60					
Areas of Burden	Caregivers of Patients having				t-value
	Schizophrenia n=30		Epilepsy n=30		
	Mean	SD	Mean	SD	
Financial burden	8.86	1.65	9.33	1.90	1.016
Occupation	5.53	1.83	5.86	2.01	0.738
Patient care	6.87	1.22	6.66	1.56	0.552
Family	11.33	2.53	11.23	3.32	0.08
Marital relations	2.5	3.71	3	4.78	0.452
Physical illness	22.53	4.76	22.66	4.61	0.110
Social support	17.3	3	17.46	3.02	0.214
Total burden	74.4	11.95	74.86	13.18	0.144

p < .05, df 58

## DISCUSSION

In the present study, thirty-eight out of sixty caregivers have reported 'Moderate burden' and 22 out of 60 have reported 'Severe burden'. Caregivers of both groups have burden predominantly in same areas; i.e. patient care, finance, physical and emotional burden, family relations and occupation respectively. The results of the current study show that the caregivers of patients having Schizophrenia and Epilepsy experience significant amount of burden just like most of the studies reported in literature. Sanjeev Thomas (nbm,nm,) reported that parents of children with epilepsy suffer many psychosocial problems, which are largely neglected.<sup>37</sup> Caring for such children on regular basis takes away their time for personal care, leisure and other commitments besides eroding their physical and mental health.

Majority of studies on burden of caregivers of patients having schizophrenia conducted so far report significant burden of caregivers with over 90% of families, experiencing moderate to severe burden.<sup>34,10,11,28</sup> The

burden of carers of schizophrenia is large and multifaceted. Headmost, there are the direct costs of providing care for individuals with schizophrenia. The indirect costs encompass the loss of productivity through impairments, disability as well as some legal problems including violence. The burden was present in areas like finance, routine activities, family leisure and interaction. The result of the current study are also consistent with these findings. The behaviour of the person with mental disorders requires that the caretaker places their own needs and wishes after those of the client. The burden on families' ranges from emotional reaction to the illness, the stress of coping with disturbed behaviour, the disruption of household routine, the stigma they are confronted with and the restriction of social activities to economic difficulties. Lauber reported that threats, nuisances, time spent with the affected one, restricted social life and leisure activities are also predictors of burden.<sup>17</sup> Data on such issues are essential in organizing services for the primary caregivers and mobilizing financial assistance.

The five principal areas of burden in both the groups were similar i.e. disruption in family relations, finance, caregiver's occupation, patient care, physical and mental health of caregivers. A similar pattern has been reported by other researchers also. Creer et al have also reported that the most common problems faced by the relatives while caring for the patient was putting up with his/her socially embarrassing and difficult behaviour.

It is generally believed that patients of Schizophrenia are disruptive and dysfunctional, and caregivers have more burden but the present study reveals otherwise that is, equal burden status of both the groups of caregivers is equal. This finding is not surprising as in a study conducted by L. Magliano et al in 2005, objective burden was found to be more substantial in neurological disorders compared to Schizophrenia.<sup>10</sup> It is likely that the degree of dysfunction of patient is one of the significant predictor of carers' burden, which is similar among carers of patients having Schizophrenia or Epilepsy. In the present study majority (45 out of 60) of the patients were not having any employment. Patients of Schizophrenia have disruption in work due to negative symptoms whereas patients of epilepsy are devoid of job because of uncertainty and subsequent fear of seizure activity which means both are in same state in relation to employment. Taking the disability component of burden alone, the global burden of disease (WHO, 2000) estimates that mental illness and neurological conditions accounts for

30.8% of all years lived with disability. This report also focused on a few common disorders that place a heavy burden on communities, which includes Schizophrenia and epilepsy.<sup>49</sup>

Studies of caregivers of chronic patients have found levels of burden to be associated with greater severity of illness symptoms and longer duration of illness.<sup>13, 20, 32</sup> In the current study, the mean duration of illness of schizophrenia is 6 years whereas that of epilepsy is 12 years. This difference is significant and it can be attributed to the time of onset of disease, which is early for epilepsy and late for schizophrenia comparatively. The longer duration of illness of Epilepsy might have contributed to the increased burden of the caregivers. Moreover, epilepsy is a disease which is still having significant stigma attached to it like mental disorders. In a WHO multicentric study (1983), Giel et al reported that certain socio-cultural factors contribute to a pattern of burden unique to the Indian milieu. Another possible reason for the equal burden could be the fact that most of the patients having Schizophrenia were not having active positive symptoms, and since the assessment is made on cross sectional basis, the influence of the current state of the patients could have influenced the burden scores. It may be possible that the extent of burden experienced by caregivers of patients having Schizophrenia is higher than that is expressed in the documented results of the present study.

Male patients having epilepsy outnumber female patients as female patients are registered in lesser number in the selected setting. This may be due to gender bias whereas intractability occurs in equal frequency in both the sexes. The family members are hesitant to bring female patients for treatment may be because of the stigma attached to seeking treatment, anticipating social consequences in future. About 60% of intractable epilepsy constitute focal seizures, which may not be so frequent, and it could be hidden. Whereas in schizophrenia the symptoms are obvious, the caregivers cannot afford not to bring the patients for treatment.

The burden of male and female caregivers is also compared in the present study. There was no significant difference in burden between the male and female caregivers of patients having Schizophrenia and Epilepsy. This is in contrast to the findings of Sartorius et al, Nippon et al (2004) who reported that there are significant gender differences regarding the mode of caregiving and experience of caregiver's distress. Studies indicated that women caregivers typically report more negative feelings, more physical symptoms, and higher

levels of burden, greater strain and poorer morale than male caregivers. This study demonstrated equal amount of burden reported by both male and female caregivers. The reason may be unlike traditional system where females perform the larger part of caretaking responsibility of ill persons in the family, males are also sharing the responsibility nowadays. However, further studies that address underlying mechanism of gender difference and focus on similar caregiving situations and context deserve attention.

The present study has implications for practice, administration, education and research. The analysis of burden of family caregivers provide basic data required for making decisions, future research and generation of interventional strategies, all geared to promote holistic caring. Family interventional programs should be planned on the basis of a careful assessment of the burden experienced, coping strategies, interpersonal skills and social resources of each relative.

Schizophrenia and epilepsy has a larger impact not only on the individual, but also on families and communities. Individuals not only suffer from the symptoms of the illness, but they are unable to participate in work and leisure activities often not only as a result of disability, but also because of the stigma and discrimination. In spite of modern medicine and emphasis on public health education, the attitude towards epilepsy or mental disorder is still coloured by traditional beliefs. Those programmes which address the questions of public are needed which may help patients of schizophrenia or epilepsy to reintegrate into normal life and more practical support from social network is needed for this. The lion share of this responsibility lies with the health professionals as resource persons in giving right information to the caretakers as well as public. There is a need to modify the current structure of organisation of current service delivery where specialist mental health nurse has limited role and responsibility of psycho- educational intervention. New positions have to be created for mental health specialist nurses, who is at present does not exist in the system at various levels of hospital and community settings.

Psychosocial rehabilitation of patients is an important aspect of intervention, that is, to involve patients in purposeful activities in view of their dysfunction. Various socio-therapeutic activities of rehabilitation improve patients' levels of psychosocial functioning, and alleviate the serious psychosocial and emotional problems of caregivers caused by their relatives' chronic and severe illness. Organizations which are in the forefront of psychiatric rehabilitation

include Schizophrenia Research Foundation (SCARF) (Chennai), Sanjivini Society for Mental Health (New Delhi), Saarthak (New Delhi), and Richmond Fellowship International. Health professionals should identify such centres in their locality and refer patients to those centres for counseling so to alleviate the burden of carers. The well being of carers can be enhanced through strategies, which lead to a reduced perception of burden with respite services providing tangible relief from burden. Unfortunately there is very little documentation in the literature concerning the neuropsychological rehabilitation of patients having intractable epilepsy and to-date there have been no randomised studies documenting any benefits from such an intervention.

The concepts of burden are to be incorporated in to the undergraduate curriculum of health professionals training program, to sensitize future professionals in this area. Administrators of mental health services should be aware of the needs of the carers of patients having long term illness and formulate policies which enforces mental health professionals to include psychosocial interventions in their day to-day interventional activities with the patients and caregivers.

### **CONCLUSION**

In summary, the present study has shown that there is a significant amount of burden experienced by caregivers of patients having long-term physical illness and mental illness. However the study has limitations of small sample size, patients' variables are not comparable in terms of duration of illness in two groups, unequal distribution of patients according to gender in both groups and lack of intervention following the study. Future studies should be replicated on a larger sample and longitudinal studies are needed to find out the pattern of burden over time.

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