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Research Paper

Family caregiver Burden in Bipolar I Disorder and Schizophrenia: A Comparative Study

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ABSTRACT

Objectives: To compare the extent and pattern of caregiver burden in families of bipolar I disorder and Schizophrenia. ***Materials and methods:*** Study design: Cross sectional study with internal comparison. Study setting: The study was conducted in the psychiatry outpatient department, Government Medical College Trivandrum, India. Study period: 6 months Study population: Primary care givers, accompanying patients diagnosed as having schizophrenia and bipolar I disorder. Inclusion criteria Cases-Diagnosis of schizophrenia as per DSM IV TR criteria, Diagnosis of bipolar 1 disorder as per DSM-IV TR criteria which includes mania, depression, mixed with/without psychotic features. Patients with their minimum duration of illness 2yrs only were recruited. Only patients who on regular follow up & on maintenance medication were included. Caregiver-Living with the patient in the same environment for at least 12 months & directly involved in giving care to patient.64 caregivers of patients diagnosed with bipolar I disorder and schizophrenia was assessed using Burden Assessment Scale. ***Results:*** The study showed that the extent and pattern of burden among caregivers of schizophrenic patients were more than that among bipolar I disorder. The burden was felt more in the areas of physical health, caregiver routine, support of patient, patient behavior, caregiver strategy. ***Conclusion:*** The determinant factors that were found to influence caregiver burden in both groups were increased severity of illness, more time spent per day in caregiving.

Keywords: *caregiver burden, bipolar disorder, schizophrenia, family, mania, depression*

In India family play a major role in management of psychiatric patients. Living with a schizophrenia patient can put considerable burdens and restrictions on the rest of the family. The patient‘s relatives experience feeling of loss and grief. They are confronted with

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uncertainty and emotions of shame, guilt and anger. Like the patient, they feel stigmatized and socially isolated. Their lives may be disrupted by providing more care than would be normal for someone of the patient‘s age. In cases where the reciprocity between family members is out of balance, normal care changes to caregiving. Addition of the caregiving role to the already existing family role may become stressful, both psychologically and economically. The term caregiver burden is now more widely used to describe the physical, psychological, or emotional, social and financial problem that are experienced by family members caring for a chronically ill, or impaired family member.

Schizophrenia is a severe mental illness characterized by delusional thinking, thought disorders and hallucinations. Although these symptoms may be controlled by medication, the course of the illness is often marked by relapses or exacerbations of these psychotic phenomena and approximately one third of sufferers continue to have persistent positive symptoms despite optimum medication. There are also long-term impairments in functioning known as negative symptoms. Due to the wide-ranging problems, the illness makes considerable emotional, practical and financial demands on those close to the sufferer-typically the parents or the spouse or partner.

Under these circumstances, the coping resources of family members may be severely challenged and hence it is unsurprising that the impact of the illness results in negative outcomes in terms of personal distress and burden for many carers. Burden among these caregivers have been identified including physical problems, restrictions in social life, tense relationships in the family, changes in household routines, diminished opportunities for leisure, deteriorating finances, emotional problems, and disturbance in their work performance. Notably, research studies over the past several decades have provided consistent evidence that caregivers of patients with schizophrenia and other psychotic disorder experience high levels of burden and these caregivers reported significant psychological distress as well as financial demands.

Bipolar disorder is characterized by recurrent manic and depressive or mixed episodes, is another burdensome illnesses occurring in the early productive years of life. Bipolar disorder follows a chronic course and is associated with significant distress, disability, marital problems and premature mortality. During the acute phase of the illness great demand may be placed on family members to be involved in care giving. Such demands may persist even during remission, where residual symptoms may still be present demanding family care giving. Despite the extent of the impact of bipolar disorder, very little work has been done to define more precisely the caregiver burden associated with the bipolar illness compared with the relatively extensive literature on schizophrenia, dementia and unipolar depressive disorder. It could be argued that differences in disease characteristics make it difficult to extrapolate caregiver burden in patients with schizophrenia or dementia to bipolar disorder basedon the available literature. Bipolar disorder is episodic and cyclic in nature; hence the caregiver burden over time may vary more than that seen in either schizophrenia or dementia.

However, the average age of onset of bipolar disorder is lower than that of schizophrenia or dementia and likely affects the extent and degree of caregiver burden.

Despite overwhelming evidences of the problems which people face when living with the psychiatrically ill, research data pertaining to family burden is rather limited, more so in the case of bipolar disorders .There is a lack of studies which have actually compared family burden among different groups of psychiatric patients in India.

Aim and Objectives: To compare the extent and pattern of burden in families of bipolar I disorder and schizophrenia.

MATERIALS AND METHODS

*Study design***:** Cross sectional study with internal comparison.

*Study setting***:** The study was conducted in the psychiatry outpatient department, Government Medical College Trivandrum, India. It is a tertiary care teaching centre where cases come from southern parts of Kerala and Tamilnadu.

Study period: 6 months
Study population: Primary care givers, accompanying patients diagnosed as having schizophrenia and bipolar I disorder.

Inclusion criteria

1. ***Cases*****:** Diagnosis of schizophrenia as per DSM IV TR criteria, Diagnosis of bipolar 1 disorder as per DSM-IV TR criteria which includes mania, depression, mixed with/without psychotic features. Patients with their minimum duration of illness 2yrs only were recruited. Only patients who on regular follow up & on maintenance medication were included.
2. ***Caregiver*****:** Living with the patient in the same environment for at least 12 months & directly involved in giving care to patient.

Exclusion criteria: We excluded patients with any Axis II diagnosis, chronic physical illness, organic syndromes or substance related disorder except nicotine /caffeine, Families with another family member (other than the patient) with a psychiatric or chronic physical illness, staying with them.

Sample Size: Sample size is calculated using the formula Assuming α= 5%, β=20%, the S.D (σ) =5 and difference between 2 means (Δ)=3 from previous study.[13]

Sample size (n) = $2(Z_\alpha+Z_\beta)^2 * \sigma^2/\Delta^2$ =64.
Thus 64 cases in each comparison group.

Sampling: Consecutive cases of bipolar I disorder and schizophrenia patients attending Psychiatry OPD, Government Medical College, Trivandrum who satisfied the inclusion criteria were taken.

Study procedure: All patients diagnosed with bipolar I disorder and schizophrenia as per the criteria defined in DSM IV TR by a qualified psychiatrist were screened by a semi-structured questionnaire which includes the Patients and Caregivers Socio-demographic Data. A written consent of the patient & the caregiver for participation in the study was obtained. Assessment of the patient was done by the investigator and the caregiver assessment was done by another postgraduate/house surgeon of Psychiatry department who was blind to the diagnosis.

*Tools used***:** The extent and pattern of burden in caregiver was assessed using Burden Assessment Scale (BAS). The severity of patient's illness was assessed using the Brief Psychiatric Rating Scale (BPRS).Translated/ back-translated versions of all instruments were used.

Data analysis: The data collected was analysed using SPSS version 16 and the results were interpreted accordingly using Chi Square Test was and Student's t tests.

RESULTS

Table 1.Socio-demographic details of caregivers

	Bipolar Disorder CG N(%)	**Schizophrenia CG N(%)**	**p value**
Type of family			
Nuclear	**42(65.6)**	**46(71.9)**	p =0.98
Extended	**13(20.3)**	**13(20.3)**	
Joint	**9(14.1)**	**5(7.8)**	
Caregiver's Gender			
Male	**30(46.9)**	**29(45.3)**	p =0.85
Female	**34(53.1)**	**35(54.7)**	
Caregivers Age(yrs)			
<20 yrs	**2(3.1)**	**1(1.6)**	
20-30	**5(7.8)**	**4(6.3)**	p =0.57
30-40	**10(15.6)**	**12(18.8)**	
40-50	**20(31.3)**	**13(20.3)**	
>50 yrs	**27(42.2)**	**34(53.1)**	
Caregiver's education			
Primary	**20(31.3)**	**11(17.3)**	p =0.28
SSLC /+2	**39(61.0)**	**46(71.9)**	
Graduates/Professional	**5(7.8)**	**7(10.9)**	
Caregiver's Occupation			
Unemployed	**26(40.6)**	**20(31.3)**	p =0.21
Unskilled	**18(28.1)**	**18(28.1)**	
Skilled labourer	**14(21.9)**	**13(20.3)**	
Clerical job	**4(6.3)**	**2(3.1)**	
Administrative job	**0 (0)**	**1(1.6)**	

	Bipolar Disorder CG N(%)	Schizophrenia CG N(%)	p value
Businessman	**0(0)**	**3(4.7)**	
Professional	**2 (3.1)**	**7(10.9)**	
Caregiver's Marital status	**7(10.9)**	**5(7.8)**	p =0.28
Unmarried	**50(78.1)**	**48(75.0)**	
Married	**3 (4.7)**	**7(10.9)**	
Widow/Widower	**2 (3.1)**	**0(0)**	
Separated	**2(3.1)**	**4(6.3)**	
Divorced			
Caregiver's Relation			
Parents	**26 (40.6)**	**31(48.4)**	p =0.84
Spouse	**18 (28.1)**	**16(25.0)**	
Sibling	**4 (6.3)**	**3(4.7)**	
Others	**16 (25.0)**	**14(21.9)**	
Caregiver's Income			
<5000Rs	**38(59.4)**	**37(57.8)**	p =0.98
5000-10000 Rs	**24(37.5)**	**25(39.1)**	
>10000 Rs	**2(3.1)**	**2(3.1)**	

The two groups were comparable with respect to caregiver age, gender, education, occupation, income, marital status and caregiver relations.

Table 2. Burden scores of bipolar & schizophrenia caregivers

Total Burden Score	Bipolar Disorder CG N(%)	Schizophrenia CG N(%)	p value
Severe	11(17.2)	25 (39.1)	
Moderate	34 (53.1)	23 (35.9)	p =0.02
Mild	19(29.7)	16 (25.0)	

39.1% of caregivers of schizophrenia patients suffered from severe burden compared to 17.2% in bipolar patients. 53.1 % of caregivers of bipolar patients suffered from moderate burden compared to 35.9% of caregiver in schizophrenia patients. The observed difference was statistically significant with p value 0.02.

Table 3.Domain scores of burden scale in bipolar & schizophrenia caregivers(CG)

Domain	Group	N	Median	Mann-Whitney U	Significance p
Spouse related	Schizophrenia CG	64	7	0.17	0.86
	Bipolar Disorder CG	64	6		
Physical health	SchizophreniaCG	64	13	2.34	0.01
	Bipolar Disorder	64	12		

Domain	Group	N	Median	Mann-Whitney U	Significance p
External Support	SchizophreniaCG	64	9	0.34	0.73
	Bipolar DisorderCG	64	9		
Caregiver Routine	SchizophreniaCG	64	10	1.43	0.03
	Bipolar DisorderCG	64	10		
Support of patient	SchizophreniaCG	64	9	2.24	0.03
	Bipolar DisorderCG	64	8		
Taking Responsibility	SchizophreniaCG	64	7.5	1.21	0.22
	Bipolar DisorderCG	64	7		
Other Relations	SchizophreniaCG	64	7	1.73	0.08
	Bipolar DisorderCG	64	8		
Patient Behaviour	SchizophreniaCG	64	10	2.24	0.02
	Bipolar DisorderCG	64	8		
Caregiver Strategy	Schizophrenia	64	10	3.86	0.00
	Bipolar Disorder	64	9		

The burden assessment scale is composed of 9 domains of which the observed difference between bipolar and schizophrenia caregivers was found to be significant in areas of physical health, caregiver routine, support of patient, patient behaviour, caregiver strategy. Median scores were significantly higher in the schizophrenia group when compared to bipolar group in these 5 domains.

Table 4.Mean BPRS and clinical factors score of bipolar & schizophrenia patients

	Group	N	Mean	SD	t	p
BPRS score	Bipolar	64	41.47	14.32	-2.66	0.00
	Schizophrenia	64	49.23	18.41		
Age at onset of Illness(yrs)	Bipolar	64	29.39	12.82	.50	0.61
	Schizophrenia	64	28.27	12.20		
Duration of Illness (yrs)	Bipolar	64	9.63	7.28	-.68	0.49
	Schizophrenia	64	10.50	7.16		
Duration of Active illness (Months)	Bipolar	64	32.56	29.62	-2.57	0.01
	Schizophrenia	64	51.34	50.30		
Duration of Treatment (months)	Bipolar	64	94.58	86.76	-.84	0.39
	Schizophrenia	64	106.97	78.24		
No of Hospitalization	Bipolar	64	2.50	3.33	1.67	0.09
	Schizophrenia	64	1.61	2.64		

The mean BPRS scores were found to be significantly higher in the schizophrenia group when compared to bipolar group of the various clinical parameters which were included the mean scores were found to be significantly higher in schizophrenic group for duration of active illness. Although mean score of number of hospitalization was found to be more for bipolar disorder it was not significant. The mean scores for age of onset of illness & duration of illness and duration of treatment were comparable in both groups.

Table 5. Mean scores of duration of care giving of bipolar & schizophrenia patients

	Group	N	Mean	sd	t	p
Duration of Care giving (yrs)	Bipolar	64	7.34	5.44	.33	0.73
	Schizophrenia	64	7.06	3.97		
Time of Care giving Hours/day	Bipolar	64	2.48	1.58	-2.26	0.02
	Schizophrenia	64	3.34	2.49		

The mean scores were significantly higher in schizophrenia group in account of amount of time spent for care giving per day. The mean scores of the duration of years of care giving were comparable in both groups.

Table 6.Corelation between Clinical Variables and Total Burden Scores

			TOTAL BURDEN SCORE
Bipolar	Age at onset of Illness	Correlation Coefficient Sig. (2-tailed)	0.15 p=0.21
Schizophrenia		Correlation Coefficient Sig. (2-tailed)	0.29 p=0.02
Bipolar	Total duration Of active Illness	Correlation Coefficient Sig. (2-tailed)	0.21 p=0.08
Schizophrenia		Correlation Coefficient Sig. (2-tailed)	.221 p=0.08
Bipolar	Duration of Care giving	Correlation Coefficient Sig. (2-tailed)	.178 p=0.16
Schizophrenia		Correlation Coefficient Sig. (2-tailed)	.327 p=0.008
Bipolar	Time of care Giving Hours/day	Correlation Coefficient Sig. (2-tailed)	.431 p=0.00
Schizophrenia		Correlation Coefficient Sig. (2-tailed)	.573 p=0.00
Bipolar	No of Hospitalization	Correlation Coefficient Sig. (2-tailed)	.106 p=0.40
Schizophrenia		Correlation Coefficient Sig. (2-tailed)	.111 p=0.38
Bipolar	Total duration Of illness	Correlation Coefficient Sig. (2-tailed)	.142 p=0.26
Schizophrenia		Correlation Coefficient Sig. (2-tailed)	.251 p=0.04

Here the total burden score was positively correlated with age at onset of illness, total duration of illness, duration of caregiving in schizophrenia group only.The total burden score was positively correlated to time of caregiving per day in both schizophrenia and bipolar group.

DISCUSSION

Caregivers were comparable with respect to their gender. In bipolar group 42.2% of caregivers and in schizophrenia group 53.1% belonged to age group above 50.The two groups were comparable in respect to the educational status. 40.6% of caregivers in bipolar group were unemployed compared to 31.3% in schizophrenia group. Parents formed the major proportion of caregivers who looked after the patient with 40.6% belonging to bipolar group & 48.4% belonging to schizophrenia group.

As mentioned earlier, studies of family burden have been mainly conducted with schizophrenic subjects, other psychiatric conditions like bipolar disorders have been neglected because of the notion that they do not entail chronicity or impairment. The present study arouse from the concern that such notions may be false and families with bipolar disorder patients also face considerable burden. Our results show that the families of patients with bipolar disorder as well as schizophrenia experience considerable burden.39.1% of caregivers of schizophrenics suffered from severe burden compared to 17.2% in bipolar patients. 53.1 % of caregivers of bipolar patients suffered from moderate burden compared to 35.9% of caregiver in schizophrenia. So in our study the extent of burden in families with schizophrenia was significantly more than in families with bipolar patients. This finding were found by Chaudhari et al who found burden to be higher in caregivers of schizophrenics than bipolar disorder. This could be attributed to increased severity of symptoms in schizophrenia patients in our study. Also the total duration of active illness in schizophrenia patients was significantly more in our study. This difference in the extent of burden thus reflects differences in both study groups i.e. chronic nature of schizophrenia in contrast to discrete episodic nature of bipolar disorder.

Similar to extent of burden, the pattern of burden also differed in the two study groups. Of the 9 domains which were compared, significant differences were seen in domains of physical health, patient behavior, caregiver routine, support of patient and care giver strategy .In this five domains median domain scores were significantly higher in schizophrenia group than bipolar group. The physical health of caregiver was an area which was affected .Caregivers of schizophrenia patient felt more tired, more depressed and anxious than bipolar group. Also the patient‘s behavior in form of disturbance at home, unpredictability caused more burden in schizophrenia group. The caregivers daily routine were also more affected in schizophrenia group in that their efficiency at work, the time they spent for their needs and for relaxation & for their sleep were impaired. The support for the caregivers was also more affected in schizophrenic group. The patient illness had reduced the support they received from their family members and most of them were forced to work to meet the financial cost as a result of patient‘s illness. Also strategies the caregivers used to compensate for the shortcoming of the patient were more used by caregivers of schizophrenia patients than caregivers of bipolar group.

The BPRS is mainly used to assess the severity of psychopathology. The mean scores were found to be significantly more in the schizophrenia group (49.23) when compared to bipolar

group (41.47) with p value 0.009.This can be explained by the fact that schizophrenia is characterized by a chronic and relapsing course with exacerbations of psychotic phenomena despite optimum medication. Also the duration of active illness was found to be significantly more in schizophrenia group in our study which could be another reason.

The mean duration of illness in bipolar group was 9.63 yrs(SD 7.28) and in schizophrenia group was 10.50 yrs (SD 7.16) but the difference was not statistically significant. However comparison based on the mean scores of active illness was found to be statistically significant (p=.01) in schizophrenia patients (51.34 months)than bipolar patients (32.56 months).This could be due to the fact that schizophrenia is a continuous mental illness in contrast to episodic nature of bipolar disorder with inter episode period of recovery and normal functioning.

The mean number of hospitalization was more in bipolar group (2.50) when compared to schizophrenia group (1.61) but the observed difference was not statistically significant. Other clinical variable which was studied was the mean duration of caregiving by caregivers which was comparable in both bipolar (7.34 yrs) and schizophrenia group(7.06 yrs).However the mean hours spent per day by caregivers for the patients was statistically significant (p=.022) which was more in schizophrenia caregivers (3.34 hrs) than bipolar caregivers (2.48 hrs).This finding was similar to finding studied by Chii et al & Lambert et al who found positive correlation between hours of care per day and caregiver burden in schizophrenia patients.

The total burden score was positively correlated with age at onset of illness and total duration of illness in schizophrenia group but not in the bipolar group. These findings were consistent with study by Juvang et al who found there was a positive correlation between age of onset of illness and burden in schizophrenia and Trivedi et al who found a positive correlation of family burden and duration of illness in schizophrenia patients. The total burden score was also positively correlated with duration of caregiving in schizophrenia group only. This finding was replicated in the CrossEuropean study (EPSILON) who found correlation between caregiver burden and duration of caregiving. The total burden score was positively and significantly correlated to time of caregiving per day in both schizophrenia and bipolar group. Higher the number of hours spent on providing care per day, more will be the burden felt by the caregiver. These finding was consistent with studies by Chii et al, Juvanget al.

CONCLUSIONS

The conclusion of this study was that the extent and pattern of burden among caregivers of schizophrenic patients were more than that among bipolar I disorder. The caregiver burden was felt more in the areas of physical health, caregiver routine, support of patient, patient behavior, caregiver strategy. Schizophrenia group showed significant positive correlation between caregiver burden and age at onset of illness, total duration of illness, total duration of caregiving. In our study the determinant factors that were found to influence caregiver burden in both groups were increased severity of illness and more time spent in caregiving.

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Conflict of Interest

The authors colorfully declare this paper to bear not conflict of interests

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