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Family Burden in Caregivers of Chronic Schizophrenia and Bipolar Affective Disorder – A Comparative Study

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Abstract
Introduction: *Due to paucity of organised care, families have been part of mental health care all throughout the history of India. The primary objectives of the present study were to assess burden of Caregiver of Chronic Schizophrenia, to assess burden of Caregiver of Bipolar Affective Disorder, make a comparison between these two and to assess the relationship of burden of the caregiver with the global assessment of functioning of patients of Chronic Schizophrenia and Bipolar Affective Disorder.*
Materials and Methods: *It was a hospital based cross sectional and comparative study, conducted in the Department of Psychiatry, Assam MedicaI College and Hospital with a sample size of 30 primary caregivers of equal number of patients of Chronic Schizophrenia and 30 Primary caregivers of equal number of Bipolar Affective Disorder patients. Appropriate statistical tests were used for analysis of obtained data setting significance threshold at p <0.05.*
Results: *Caregivers of Chronic Schizophrenia experienced significantly higher burden than the caregivers of BPAD. A strong positive correlation was seen between caregiver's burden and level of impairment in functioning of patients of Chronic Schizophrenia whereas in the Bipolar Affective Disorder group although the correlation was positive it was weak in comparison to the Schizophrenia group.*
Conclusion: *The chronic nature of Schizophrenia puts more burden on the family. A stronger positive correlation between caregiver's burden and level of impairment in functioning is seen in case of Chronic Schizophrenia compared to BPAD.*
Keywords: *Family, Schizophrenia, Bipolar Affective Disorder, Burden.*

Introduction

Schizophrenia is the paradigmatic illness of psychiatry. The policy of de-institutionalization has highlighted the role of family members as the primary source of care giving for relatives with schizophrenia. A noteworthy finding by Weidman et al [1] was that despite the apparent downfall of traditional family structure, over 60% of patients with long term schizophrenia live with atleast one 'significant other' i.e. Primary Caregiver.

Bipolar Affective disorder, previously known as manic-depressive illness, is a mood disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day

tasks. It is characterized by repeated (i.e. atleast two) episodes in which the patient's mood and activity levels are significantly disturbed, this disturbance consisting on some occasions of an elevation of mood and increased energy and activity (mania or hypomania), and on others of a lowering of mood and decreased energy and activity (depression). [2] At least half of all cases start before the age of 25 years. Some people have their first symptoms during childhood, while others may develop symptoms late in life. The frequency of episodes and the pattern of remissions and relapses are both very variable, though remissions tend to get shorter as time goes on and depressions to become commoner and longer lasting after middle age. [3]

In India, families are always recognised as an integral part of the care system for persons with chronic mental illness. The demands of being involved in the care of a seriously mentally ill relative have both an emotional as well as practical impact on the caregiver. [4, 5]

The costs that families incur in terms of economic hardships, social isolation and psychological strain, are referred to as family burden[6-8] .The fact that the illness leaves a varying degree of disability in the patient and leads to disturbing behaviour means that its management is associated with a significant burden of care. As a result of the paucity of organised care, families have been part of mental health care all throughout the history of India. In addition there is also evidence to suggest that family involvement in patient-care continues to be of preference to families and thus family members serve as the main source of support for individuals with chronic mental illness. All the relatives do not necessarily behave in the same manner and the nature of the burden placed on them may possibly lead some to resort to ineffective coping strategies. It has been observed that for a given amount of burden, the individual level of distress show considerable variations [9], because it varies according to their ways of coping. Folkman and Lazarus [10, 11] have defined coping as a person's constantly changing cognitive and behavioural efforts to manage an encounter appraised as stressful.

Pai and Kapur [12] observed that in view of the economic and cultural conditions of a developing country being vastly different from those of the western world, the areas of burden and the pattern of accepting or rejecting patients in India may be entirely different. Several patient and caregiver variables have been found to contribute to family burden. Greater burden is associated with patient who are male [13, 14], younger in age [15, 16] and who have poorer levels of functioning [17, 18]. Caregiver characteristics associated with burden have received comparatively less attention. Women take on a large part of care giving responsibilities [19] and caregivers who are younger and more educated experience greater burden [20]. The relationship of the primary caregiver to the patient may also mediate the experience of burden.

Burden refers to the presence of problems, difficulties or adverse events which affects the lives of individuals who are primary carers of persons with mental health problems. Numerous definitions of burden exist in literature and these share a common underlying frame of reference, namely the effect of the patient on the family [21]; impact of living with a psychiatric patient on the way of life and health of family members or the difficulties felt by the family of a psychiatric patient [12] . Platt (1985) [9] defined burden as "the presence of problems, difficulties or adverse events that affect the lives of psychiatric patients". Hoeing and Hamilton in the late 1960s were the firsts to make a clear distinction between subjective and objective aspects of burden. 'Objective burden' is used to identify anything that occurs as a disrupting factor in family life owing to the patient's illness. 'Subjective burden' refers to the feeling that the burden is being carried in a subjective sense or the extent to which relatives felt they carried a burden. Of the family members, the consequences of caring is high in the life of a family member who bears maximum responsibility. [22]

In 1955, Clausen and Yarrow [23] led a group of social scientists of the United States to carry out the first study on the demands of the families of the mental patients. In Indian context, Pai and Kapur in 1981[7] described six areas of burden: financial burden, effect on family routine, effect on family leisure, effect on family interaction, effects on physical health of other family members and effect on mental health of other family members.

Thara in 1998 [24] developed a burden assessment schedule, which is a 40 item scale measuring different areas similar to as mentioned by Pai and Kapur. In addition, it contains items that tap areas of emotional burden specific to spouses, such as the effect of the illness on the patient's ability to share responsibilities, sexual relations and the overall quality of the marital relationship. Singh et al. 2012 [25] in his study 'Burden of schizophrenia on caregivers in Nepal' reported that most burden was in the area of finance and family dynamics and overall burden was moderate. Gupta et al. 2014 [26] found that 80% of the caregivers have experienced moderate levels of burden. Older caregivers experienced higher burden whereas gender and educational status exerted no significant effect on burden. The burden was significantly higher among spouses followed by parents, and the level of burden was positively correlated to the duration of care. Maji et al. 2011 found that more than 90% of family members of bipolar affective disorder reported severe subjective burden and objective burden at admission; none of them was free from burden. [27] According to Vasudeva et al. 2013 caregivers of Schizophrenia had significantly higher total burden as compared to caregivers of Bipolar Disorder. Caregivers of Schizophrenia experienced significantly higher burden in area of external support, caregiver's routine and other relations. [28] The primary objectives of the present study were as follows:

1. To assess burden of Caregiver of Chronic Schizophrenia.
2. To assess burden of Caregiver of Bipolar Affective Disorder.
3. To compare the burden of Caregiver of Chronic Schizophrenia with the burden of Caregiver of Bipolar Affective Disorder
4. To assess the relationship of burden of the caregiver with the global assessment of functioning of patients of Chronic Schizophrenia and Bipolar Affective Disorder.

Materials and Methods

Study sample: Sample was randomly selected from the Caregivers of Chronic Schizophrenic and Bipolar Affective Disorder in-patients and out-patients of Department of Psychiatry, Assam Medical College and Hospital, Dibrugarh.

Sample size: Primary Caregiver of 30 Chronic Schizophrenic patients and 30 Bipolar Affective Disorder Patients.

Study design: Hospital Based Cross sectional and comparative study.

Duration of study: One year

Definition of Primary Caregiver – A person who is currently shouldering maximum responsibility and care of the patient in terms of social, physical, emotional and financial support for a considerable period of two years or more.

Inclusion criteria

- For the patient –
  - Age 18 years and above (either sex)
  - Diagnosed case of Schizophrenia and Bipolar Affective Disorder according to ICD-10 without any co-morbid psychiatric disorder
  - Duration of illness, two years and above at the time of examination
- For the caregiver –
  - Healthy adult family members staying currently with the patient and for previous two years of illness

Exclusion criteria:

- For the patient –
  - Those with co-morbid major physical illness like diabetes, hypertension, carcinoma etc.

- Mental Retardation.
- Substance dependence.
- Absent from home for a period of 6 months or more.

❖ For the caregiver –

- Those with psychiatric illness were excluded.

Tools

Burden Assessment Schedule (Thara, 1998) [24]: The Burden Assessment Schedule (BAS, 98) developed by Thara et al, at the Schizophrenia Research Foundation is based on the principle of 'stepwise ethnographic exploration' described by Sell and Nagpal in 1992. This is a semi-quantitative, 40 items scale measuring 9 different areas of subjective and objective caregiver burden. In BAS the minimum score is 40 and the maximum score is 120.

Global Assessment of Functioning Scale (GAF) [29] – the GAF scale is a measure of rating the overall psychological, social and occupational functioning of the patient, first included in DSM – III-R as Axis V of the multi axial diagnostic system. It is a modified version of "The Global Assessment Scale" developed by Endicott et al in 1976. The scale has 10 ranges of functioning where each range has two components covering symptom severity and patient functioning.

The ICD-10 classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines for diagnosing Schizophrenia and Bipolar Affective Disorder.

Proforma for Socio demographic details of the caregivers, designed to collect the following details in addition to the age, sex, education, socio-economic status, family type and domiciliary status – the type of diagnosis and duration of illness of the patients. The proforma also includes caregiver details, mentioning the relationship to the patient and the duration of care.

Procedure: Study subjects were thoroughly evaluated on the basis of history and mental status examination. Diagnosis of Schizophrenia and Bipolar Affective Disorder were made as per guidelines listed in ICD-10. Patients and their primary caregiver who fulfil the inclusion criteria and did not meet the exclusion criteria were selected. Written Informed consent was taken from each of the Caregivers before including them in the study. Proforma for socio demographic data was filled up for socio-demographic details of the patient's primary caregiver. Global assessment of functioning was applied to all patients. Burden Assessment Schedule was applied to all primary caregivers and scoring done. Appropriate statistical tests in MS Excel were applied to analyze the obtained data setting the significance threshold at $p<0.05$.

Results

Table 1: Distribution of caregivers according to socio-demographic characteristics

Caregiver variable	Sub-variable	Schizophrenia		BPAD	
		no	(%)	no	(%)
Age	18-30	7	23.33	13	43.33
	31-43	10	33.33	6	20.00
	44-56	5	16.67	7	23.33
	>56	8	26.67	4	13.33
Sex	Male	14	46.67	18	60.00
	Female	16	53.33	12	40.00
Marital status	Unmarried	8	26.67	12	40.00
	Married	22	73.33	18	60.00
Employment	Unemployed	4	13.33	1	3.33
	Full time employed	4	13.33	5	16.67
	Part time employed	1	3.33	6	20.00
	Self employed	8	26.67	10	33.33
	Student	0	0.00	1	3.33
	Housewife	12	40.00	6	20.00

	Others	1	3.33	1	3.33
Education	Illiterate	5	16.67	5	16.67
	Literate	2	6.67	4	13.33
	Primary education	5	16.67	2	6.67
	Middle education	8	26.67	11	36.67
	Matriculation/H.S	7	23.33	6	20.00
	Graduate	3	10.00	2	6.67
Family income	<2,040	13	43.33	7	23.33
	2,041-6,100	13	43.33	19	63.33
	6,101-10,160	4	13.33	2	6.67
	10,161-15,280	0	0.00	0	0.00
	15,281-20,360	0	0.00	2	6.67
Relationship to patient	Spouse	5	16.67	5	16.67
	Parent	13	43.33	8	26.67
	Sibling	8	26.67	10	33.33
	Children	2	6.67	5	16.67
	Others	2	6.67	2	6.67

From Table 1 it is seen that majority of caregivers of Chronic Schizophrenia were in the age range of 31-43 years followed by >56 year age group. Mean age of caregivers was 44.03±15.56. Majority were female (53.3%), married (73.33%), housewives (40%), educated upto middle education level and belonged to poorer families. Parents constituted the predominant population among the caregivers followed by siblings and spouses. On the other hand Majority of caregivers of BPAD were in the age range of 18-30 years (43.33%) followed by those in the age group of 44-56 years. Mean age of caregivers was 38.87±13.91. Majority were males (60%), married (60%), self employed (33.33%), siblings (33.33%), educated upto middle education level and belonged to poorer families. Siblings constituted the predominant population among the caregivers of BPAD followed by parents and spouses.

Table 2: Distribution of caregivers according to duration of care

Duration of Care (in years)	Schizophrenia		BPAD	
	No	(%)	No	(%)
2-5	14	46.67	14	46.67
6-9	8	26.67	8	26.67
Equal to or more than 10	8	26.67	8	26.67

Table 2 shows that in both the groups of patients in terms of duration of care caregivers were equally distributed. Table 3 shows that majority of patients in both the groups had a GAF score between 31-40 (15 in case of Chronic Schizophrenia and 13 in case of BPAD).

Table 3: Distribution according to Global Assessment of functioning (GAF) score of patients

GAF Score	Schizophrenia		BPAD	
	No	%	No	%
21-30	2	6.67	2	6.67
31-40	15	50.00	13	43.33
41-50	11	36.67	6	20
51-60	2	6.67	6	20
61-70	0	0	2	6.67
71-80	0	0	1	3.33

Table 4: Distribution of caregivers according to total burden assessment schedule (BAS) score

Total BAS score	Schizophrenia		BPAD		P-Value
	No	(%)	No	(%)	0.03*
<80	6	20.00	8	26.67	
>80	24	80.00	22	73.33	
Mean BAS ±SD	102.86±27.04		88.80±22.31		

*p value significant at <0.05

Table 4 shows the mean BAS score in the both the groups. It was seen that the mean BAS score for Chronic Schizophrenia group was 102.86 ± 27.04 whereas the mean BAS score for the BPAD group was 88.80 ± 22.31. On applying unpaired sample t test a p-value of 0.03 was obtained which denoted that that Caregivers of Chronic Schizophrenia experienced significantly higher burden than the caregivers of Bipolar Affective Disorder.

Table 5: Comparison of Family Burden as per age distribution of Caregivers

Age of Caregiver	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
18-30	89.57	23.07	90.92	24.11	0.90
31-43	99.20	29.52	96.33	25.67	0.84
44-56	85.80	20.29	81.71	19.21	0.72
>56	115.95	35.28	80.46	20.25	0.04*

*p value significant at <0.05

Table 5 shows that Caregivers of Chronic Schizophrenia in the age group of more than 56 years experienced significantly higher burden (p value = 0.04) than the caregivers of BPAD in the age group of more than 56 years. In the other groups however, there was no significant difference in Burden experienced.

Table 6: Comparison of Family Burden according to Gender of Caregivers

Sex of Caregiver	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
Male	91.28	24.60	87.17	20.89	0.62
Female	114.96	31.97	89.56	22.36	0.02*

*p value significant at <0.05

Table 6 shows that Burden was significantly higher among the female caregivers of Chronic Schizophrenia compared to the female caregivers of BPAD (p value = 0.02). However no such significant difference in burden was seen between the male caregivers of both the groups of patients. Table 7 shows that burden was significantly higher among the married caregivers of Chronic Schizophrenia when compared to the burden experienced by the married caregivers of BPAD (p value 0.03). From Table 8 it is seen that Burden was significantly higher among the literate caregivers of Chronic Schizophrenia when compared to the Burden experienced by the literate caregivers of BPAD (p value=0.04)

Table 7: Comparison of Family Burden according to Marital Status of Caregivers

Marital status of Caregiver	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
Unmarried	91.25	26.87	90.66	24.70	0.96
Married	106.45	29.66	87.40	22.31	0.03*

*p value significant at <0.05

Table 8: Comparison of Family Burden according to Educational Status of Caregivers

Education of Caregiver	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
Illiterate	92.60	24.89	87.20	23.90	0.73
Literate	115.00	21.13	70.00	17.65	0.04*
Primary School	97.50	29.80	97.22	27.72	0.99
Middle School	96.75	30.74	85.00	26.78	0.38
Matriculate/HS	88.42	26.51	87.50	20.83	0.94
Graduate	100.33	23.83	70.00	21.13	0.24

*p value significant at <0.05

Table 9: Comparison of Family Burden as per family income in both the groups

Family income (Rs/month)	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
≤2040	87.46	32.26	80.14	20.98	0.59
2041-6100	109.00	18.70	90.47	22.85	0.02*
6101-10160	93.00	23.85	86.50	23.62	0.76
10161-15280	0	0	0	0	
15281-20360	0	0	78.00	20.09	

*p value significant at <0.05

Table 9 shows that in caregivers of Chronic Schizophrenia with a family income of between Rupees 2041-6100, Burden was significantly higher than caregivers of BPAD with the same family income. Table 10 shows that spouses of Chronic Schizophrenia patients experienced significantly higher burden than the spouses of BPAD patients. Although siblings of BPAD patients experienced more burden than siblings of Chronic Schizophrenia Patients it was not statistically significant. Table 11 shows that caregivers of Chronic Schizophrenia with duration of care more than or equal to 10 years experienced significantly higher burden than caregivers of BPAD with the same duration of care.

Table 10: Comparison of Family Burden of both the disease group as per relationship of caregiver to the patient

Relationship to patient	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
Spouse	115.20	20.90	83.90	21.91	0.04*
Parent	94.76	26.67	82.25	22.26	0.28
Sibling	90.25	30.91	93.66	25.07	0.79
Children	96.50	22.60	88.80	24.63	0.71
Others	88.00	28.80	74.00	22.96	0.62

*p value significant at <0.05

Table 11: Comparison of Family Burden with duration of care

Duration of Care (in years)	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
2-5	91.21	28.89	92.07	23.34	.93
6-9	95.63	26.60	85.00	22.45	.77
≥10	116.25	29.64	86.54	22.54	.04*

*p value significant at <0.05

Table 12: Comparison between Global Assessment of Functioning of patients with burden of caregiver

Total GAF score	Schizophrenia		BPAD		P-Value
	Mean BAS	SD	Mean BAS	SD	
21-30	109.50	28.89	98.50	20.90	.70
31-40	110.26	25.72	84.67	23.56	.01*
41-50	93.18	29.67	82.83	22.71	.98
51-60	91.00	24.45	81.83	24.79	.66
61-70	0.0	0	80.00	23.93	
71-80	0.0	0	70.00	0	

*p value significant at <0.05

Table 12 shows that burden experienced by caregivers of Chronic Schizophrenia with functioning score between 31 and 40 was significantly higher than the caregivers of BPAD with the same range of functioning score. Table 13 shows an "r" value of 0.8921, which is closer to 1.00, indicating high positive correlation between caregiver's burden and level of impairment in functioning of Chronic Schizophrenia patients. Similarly Table 14 shows an "r" value of 0.1137, which is less close to 1.00, indicating a weak positive correlation between caregiver's burden and level of impairment in functioning of patients of Bipolar Affective Disorder.

Table 13: Correlation between Global Assessment of Functioning (GAF) of patients with burden of caregiver in Chronic Schizophrenia

TOTAL GAF SCORE	Caregiver of Schizophrenia		"r" Value (correlation coefficient)
	Mean BAS score	SD	
21-30	109.50	28.89	r = 0.8921
31-40	110.26	25.72	
41-50	93.18	29.67	
51-60	91.00	24.45	
61-70	0.00	0	
71-80	0.00	0	

Table 14: Correlation between Global Assessment of Functioning (GAF) of patients with burden of caregiver in BPAD

TOTAL GAF SCORE	Caregiver of BPAD		"r" value (correlation coefficient)
	Mean BAS score	SD	
21-30	98.50	20.90	r = 0.1137
31-40	84.67	23.56	
41-50	82.83	22.71	
51-60	81.83	24.79	
61-70	80.00	23.93	
71-80	70.00	0	

Discussion

The present study explored caregiver's burden caused by two major psychiatric illness – Schizophrenia and Bipolar Affective Disorder. It was seen from this study that caregivers of Chronic Schizophrenia experienced significantly higher burden than the caregivers of BPAD. Our findings were in line with the findings of Gautam and Nijhawan 1984 [13] and Roy Choudhury et al. 1995 [16]. Higher burden among caregivers of Chronic Schizophrenia could be due the chronic nature of the illness. Giel et al. 1983 [30] had mentioned that a chronic illness with severe loss of insight would significantly increase the extent of burden. Mean age of caregivers of Chronic Schizophrenia was 44.03 whereas mean age of caregivers of BPAD was 38.87 years. It was seen from this study that caregivers of Chronic Schizophrenia in the age group of more than 56 years experienced significantly higher burden than caregivers of BPAD in the same age group. Females Caregivers of both groups of patients had higher mean BAS scores. From our study it was also seen that female caregivers of Chronic Schizophrenia experienced significantly higher burden than their female counterparts in BPAD. Our finding was consistent with the finding of Jenkins and Schumacher 1999 [19], who found that women take on a large part of care giving responsibility. In this study majority of caregivers in both the groups were married. Family burden was also found to be significantly higher among the married caregivers of Chronic Schizophrenic patients than the married caregivers of the BPAD

group. This could be because married caregivers have to balance multiple roles, raising children and withstanding financial burden, particularly when the illness strikes the primary bread earner. Majority of caregivers in both the groups were educated upto middle school. On statistical analysis it was seen that literate caregivers of Chronic Schizophrenia experienced significantly higher burden than the literate caregivers of BPAD. Our finding corresponds with the findings of Gopinath and Chaturvedi 1992[20], who also found that caregivers who were educated experienced more burden. Majority of caregivers in both the groups belonged to poor families. It was seen on statistical analysis that caregivers of Chronic Schizophrenia who belonged to families with income between 2041-6100 rupees experienced significantly higher burden than caregivers of BPAD with the same family income. In our study parents constituted the predominant caregiver population in Schizophrenia in contrast to Bipolar Affective Disorder where siblings constituted the largest group. As most of the Schizophrenics were unmarried parents took over their care giving responsibility. On statistical analysis it was seen that spouses of Chronic Schizophrenic patients experienced significantly higher burden than spouses of the BPAD group. It is in keeping with the finding of Rammohan and Rao 2002 [31]. From the present study it was also seen that caregivers of Chronic Schizophrenia with duration of care equal to more than 10 years suffer significantly higher burden than caregivers of BPAD with the same duration of care. This finding was in line with the findings of Saiyad et al. 2005 [32] and Neog et al. 1998 [33]. Using the Burden Assessment Schedule, the total burden scores were calculated and compared with global assessment of functioning in both the disease groups. We found that caregivers of patients with lower level of functioning in both the groups had higher burden. On statistical analysis it was seen that caregivers of Chronic Schizophrenia with a functioning score between 31 and 40 experienced significantly higher burden than caregivers of BPAD with the same range of functioning score. Our finding was in line with the findings of Gautam and Nijhawan 1984 [13], Roy Choudhury et al. 1995 [16] and Creado et al. 2006 [34]. Our study revealed a strong positive correlation between caregiver's burden and level of impairment in functioning of patients of Chronic Schizophrenia whereas in the Bipolar Affective Disorder group although the correlation was positive it was weak in comparison to the Schizophrenia group.

Conclusion

Burden was significantly higher among the caregivers of Chronic Schizophrenia than the caregivers of Bipolar Affective Disorder probably due to the chronic nature of the illness. Spouses of Schizophrenic patients experienced significantly higher burden than their counterparts in the BPAD. Burden also seemed to increase with the duration of illness in both the groups. A strong positive correlation between caregiver's burden and level of impairment in functioning of patients of Chronic Schizophrenia was seen whereas in the Bipolar Affective Disorder group although the correlation was positive it was weak in comparison to the Schizophrenia group. Limitations of the study included its modest sample size, cross sectional design and since it was a hospital based study the results may not be generalised to the larger group who do not seek hospital based services.

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