

Family Burden and Coping in Caregivers of Bipolar Affective Disorder – A Hospital Based Study

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Abstract: 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. Care giving is a chronic stressor and different coping methods are used to handle such a situation. To assess burden of Caregiver of patients of Bipolar Affective Disorder. To assess coping strategies adopted by the Caregivers of patients of Bipolar Affective Disorder. To study the relationship of burden and coping strategies in Caregivers of Bipolar Affective Disorder. To assess the relationship of burden of the caregiver with the global assessment of functioning of patients of Bipolar Affective Disorder. The study was conducted in the Department of Psychiatry, Assam Medical College and Hospital, in Dibrugarh (Assam) with a sample size of 30 primary caregivers of equal number of patients of Bipolar Affective Disorder (BPAD). Diagnosis of BPAD was made as per guidelines listed in ICD-10. The study was of cross sectional, exploratory research design conducted with the use of scales and questionnaire. Caregivers with lower burden in BPAD had resorted to coping strategies like Positive cognitive, Problem solving and Religious coping strategies significantly more than the caregivers with higher burden. On the other hand those with higher burden used coping strategies like negative coping, external attribution and avoidance significantly more than those with lower burden. A positive correlation was found between caregiver's burden and level of impairment in functioning of patients of BPAD. Coping mechanisms like cognitive coping, problem solving and religious coping can decrease the burden of illness. Therefore they must be analyzed before clinical interventions, to improve the coping skill of the caregiver.

Keywords: Bipolar Affective Disorder, Caregiver, Burden, Coping, Problem Solving, External Attribution, Avoidance

INTRODUCTION

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)[1]. During a mixed state, symptoms often include agitation, trouble sleeping, major changes in appetite, and suicidal thinking. People in a mixed state may feel very sad or hopeless while feeling extremely energized. Sometimes, a person with severe episodes of mania or depression has psychotic

symptoms too, such as hallucinations or delusions. The psychotic symptoms tend to reflect the person's extreme mood. People with bipolar disorder may also have behavioural problems. They may abuse alcohol or substances, have relationship problems, or perform poorly in school or at work. 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 tend to become commoner and longer lasting after middle age[2].

In India, families are always recognised as an integral part of the care system for persons with 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[3].

The costs that families incur in terms of economic hardships, social isolation and psychological strain, are referred to as family burden [4-6]. 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 preference of families and thus family members serve as the main source of support for individuals with 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[7], because it varies according to their ways of coping. Folkman and Lazarus[8,9] have defined coping as a person's constantly changing cognitive and behavioural efforts to manage an encounter appraised as stressful.

The relationship between coping styles and perceived burden of care is complex because caregivers subjectively report 'burden'. This subjectivity in turn is a product of the coping styles used by the caregivers. Pai and Kapur[10] 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. The relationship of the primary caregiver to the patient may also mediate the experience of burden. According to Bauer *et al.* 2011 patients' noncompliance as well as the helplessness of the caregivers in interaction with the (changing) depressive and manic symptoms of the patients emerged as serious burdens on the caregivers. Whereas female caregivers suffered more from problems regarding quality of relationship with the patient, male caregivers experience more constraints on their own autonomy, uncertainty concerning their judgement of and uncertainty because of the changing symptoms of illness[11]. According to Rao *et al.* 2015 females, illiterates, low socioeconomic status, rural background, advancing age of the caregivers, married caregivers and those with longer duration of care and treatment were significantly associated with higher burden scores. Fewer burdens are noted in caregivers with patients who were regularly adherent to medication, and those with higher education. Major impact of the burden was found in the form of physical and mental health problems in caregivers followed by

factors related to external support and taking responsibility[12].

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[13]; 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[5]. Platt [7] 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[14].

In 1955, Clausen and Yarrow[15] 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 [5] 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[16] 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.

Pearlin and Schooler[17] defined coping as the cognitive and behavioural effort made to master, tolerate or reduce demands that tax or exceed a person's resources. Freud [18] and Haan [19] viewed coping and defence through psychoanalytic conception or largely unconscious responses to internal conflicts. Coping has been conceptualized in terms of approach vs. avoidance [20] and in terms of appraisal; problem focus and emotion focus[21]. According to Chakrabarti *et al.* caregivers of bipolar patients used a wide variety of coping strategies, both problem and emotion focussed. Problem focussed coping strategies were however most commonly used. In bipolar disorder, demographic

parameters, illness duration, levels of dysfunction, burden and social support, and appraisal by caregivers demonstrated significant associations with coping style of caregivers[26]. Another study by Chadda et al. in 2007 found that caregivers of bipolar patients use problem focused coping strategies more often than seek social support and avoidance strategies[27].

Care giving is a chronic stressor and different coping methods are used to handle such a situation. The use of coping strategies such as avoidance, denial and resignation is linked to greater burden[22,23] whereas utilization of social support and a sense of mastery over the situation are associated with lower level of burden and distress[24].

In 1994, the consensus reported by Troop[25] states that emotion based coping is associated with an unsatisfactory outcome whereas problem focused coping is associated with a more satisfactory outcome. The study highlights the fact that family intervention programs need to address the specific concerns of caregivers. The present study is an attempt to assess these areas of burden and coping in families of patients of bipolar affective disorder. The objectives of the study were as follows -

- To assess burden of Caregiver of patients of Bipolar Affective Disorder.
- To assess coping strategies adopted by the Caregivers of patients of Bipolar Affective Disorder.
- To study the relationship of burden and coping strategies in Caregivers of Bipolar Affective Disorder.
- To assess the relationship of burden of the caregiver with the global assessment of functioning of patients of Bipolar Affective Disorder.

MATERIAL AND METHODS

Study sample

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

Sample size

Primary Caregiver of 30 patients of Bipolar Affective Disorder.

Study design

Hospital Based Cross sectional 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 and exclusion criteria

Inclusion criteria

- ❖ For the patient –
 - Age 18 years and above (either sex)
 - Diagnosed case of Bipolar Affective Disorder according to ICD-10 without any co-morbid psychiatric disorder
- ❖ 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 [28]: 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.
- Coping checklist[29]: This scale comprises of 70 items describing a broad range of behavioural, emotional and cognitive responses that may be used to handle stress. Items are scored as Yes or No. This scale is reported to be useful in both clinical and research settings especially within the stress coping social support framework on the basis of the type of questions.
- Global Assessment of Functioning Scale (GAF)[33] – 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 Bipolar Affective Disorder.
- Socio demographic details of both the patients and caregivers were recorded on a proforma 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 Bipolar Affective Disorder was done 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 patients and their primary

caregivers. Global assessment of functioning was applied to all patients. Burden Assessment Schedule and Coping Checklist were 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 AND DISCUSSION

In the present study 30 patients of Bipolar Affective Disorder participated out of whom 36.67% were in the age range of 18-30 years, 26.67% in the range of 31-43 years and another 26.67% in the age range of 44-56 years with the mean age being 38.20 ± 12.36 years. Prevalence was more among male with male to female ratio being 1.7:1. The prevalence of the disease was significantly higher in the rural areas. Majority of the patients were Hindus (93.33%), married (70%), belonged to joint families (53.33%), unemployed (36.67%), educated upto middle education level (33.33%) and belonged to poorer families with family income between 2,041-6,100 Rs/month (63.3%). Majority had duration of illness between 2-5 years (43.33%) followed by patients with duration 10 or more than 10 years (30.0%).

Table-1: Socio-Demographic Characteristics of Patients

Patient Variable	Variable subgroup	BPAD	
		No	(%)
Age (years)	18-30	11	36.67
	31-43	8	26.67
	44-56	8	26.67
	>56	3	10.00
Sex	Male	19	63.33
	Female	11	36.67
Religion	Hindu	28	93.33
	Muslim	2	6.67
Locality	Urban	8	26.67
	Rural	22	73.33
Marital status	Unmarried	9	30.00
	Married	21	70.00
Family type	Nuclear	14	46.67
	Joint	16	53.33
Employment status	Unemployed	11	36.67
	Full time employed	6	20.00
	Part time employed	0	0.00
	Self employed	7	23.33
	Student	1	3.33
	Housewife	5	16.67
Family income	<2,040	7	23.33
	2,041-6,100	19	63.33
	6,101-10,160	2	6.67
	10,161-15,280	0	0.00
	15,281-20,360	2	6.67
Education	Illiterate	4	13.33
	Literate	0	0.00
	Primary education	4	13.33
	Middle education	10	33.33
	Matriculation/H.S	9	30.00
	Graduate	3	10.00

Table-2: Distribution according to duration of illness

Duration of illness (in years)	BPAD	
	No	(%)
2-5	13	43.33
6-9	8	26.67
Equal to or more than 10	9	30.00

Table 3 shows that 43.33% of the patients of Bipolar Affective Disorder had functioning score between 31-40 followed by 20% of patients with

functioning score of 41-50 and another 20% with functioning score between 51-60.

Table-3: Distribution according to global assessment of functioning (GAF) score of patients

GAF score	BPAD	
	No	%
21-30	2	6.66
31-40	13	43.33
41-50	6	20.00
51-60	6	20.00
61-70	2	6.66
71-80	1	3.33

Table 4: Distribution of caregivers according to socio-demographic characteristics

Caregiver variable	Sub-variable	no	(%)
Age	18-30	13	43.33
	31-43	6	20.00
	44-56	7	23.33
	>56	4	13.33
Sex	Male	18	60.00
	Female	12	40.00
Marital status	Unmarried	12	40.00
	Married	18	60.00
Employment	Unemployed	1	3.33
	Full time employed	5	16.67
	Part time employed	6	20.00
	Self employed	10	33.33
	Student	1	3.33
	Housewife	6	20.00
	Others	1	3.33
Education	Illiterate	5	16.67
	Literate	4	13.33
	Primary education	1	3.33
	Middle education	11	36.67
	Matriculation/H.S	8	26.67
	Graduate	1	3.33
Family income	<2,040	7	23.33
	2,041-6,100	19	63.33
	6,101-10,160	2	6.67
	10,161-15,280	0	0.00
	15,281-20,360	2	6.67
Relationship to patient	Spouse	6	20.00
	Parent	8	26.67
	Sibling	10	33.33
	Children	5	16.67
	Others	1	3.33

Majority of caregivers 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 followed by parents

and spouses. 46.67% of caregivers had duration of care between 2 and 5 years.

Table-5: Distribution of caregivers according to duration of care

Duration of Care (in years)	BPAD		Mean BAS
	No	(%)	
2-5	14	46.67	90.07
6-9	8	26.67	85.00
Equal to or more than 10	8	26.67	92.00

Table-6: Distribution of caregivers according to total burden assessment schedule (BAS) score

Total BAS score	BPAD	
	No	(%)
<80	8	26.67
>80	22	73.33

Among the caregivers, 8 had a BAS score of less than 80 whereas 22 had a BAS score of more than 80. Caregivers in the age group of 31-43 tended to have more family burden with mean score 96.33 ± 25.67 . Mean Burden Assessment Schedule Score (BAS) were more for female caregivers than males and more among

those who were unmarried, literate, spouses and siblings and those who belonged to poorer families. Again as per duration of care, those with duration of 10 or more than 10 years experienced the highest burden with a mean BAS of 92.00.

Table-7: Distribution of caregivers of BPAD according to their mean Burden Assessment Score

Caregiver variable	Sub-variable	Mean BAS
Age	18-30	90.92
	31-43	96.33
	44-56	81.71
	>56	86.25
Sex	Male	87.17
	Female	92.33
Marital status	Unmarried	90.66
	Married	88.27
Education	Illiterate	87.20
	Literate	96.25
	Primary education	77.00
	Middle education	85.00
	Matriculation/H.S	87.50
Family income	Graduate	70.00
	<2,040	80.14
	2,041-6,100	90.47
	6,101-10,160	80.50
	10,161-15,280	0.00
Relationship to patient	15,281-20,360	78.00
	Spouse	93.90
	Parent	82.25
	Sibling	93.66
	Children	88.80
	Others	74.00

Table 8 shows that most commonly employed coping strategies included help seeking (93.33%)

followed by religious coping strategies (83.33%) and external attribution (80%).

Table-8: Different types of coping used by caregivers of Bipolar Affective Disorder

Coping style	Used/Not used	BPAD	
		No	(%)
Positive cognitive	Used	21	70.00
	Not used	9	30.00
Negative cognitive	Used	18	60.00
	Not used	12	40.00
Problem solving	Used	21	70.00
	Not used	9	30.00
Magical thinking	Used	20	66.67
	Not used	10	33.33
Avoidance	Used	9	30.00
	Not used	21	70.00
Distraction	Used	20	66.67
	Not used	10	33.33
Religious	Used	25	83.33
	Not used	5	16.67
Help seeking	Used	28	93.33
	Not used	2	6.67
External attribution	Used	24	80.00
	Not used	6	20.00

Table-9: Comparison of burden with coping in caregivers of Bipolar Affective Disorder

COPING	GROUP A (Burden <80) (n = 6)		GROUP B (Burden >80) (n = 24)		P value
	Mean	SD	Mean	SD	
Positive cognitive	18.70	3.05	13.00	1.49	<0.0001*
Negative cognitive	2.00	0.93	14.57	1.98	<0.0001*
Problem solving	21.00	4.82	13.00	1.49	<0.0001*
Distraction	13.33	1.50	13.33	1.50	1.000
Magical thinking	13.33	1.50	13.33	1.50	1.000
Avoidance	1.00	0.89	3.43	0.41	<0.0001*
Religious	25.00	6.01	19.05	3.43	0.0030*
Help seeking	24.88	5.89	26.67	6.67	0.5534
External attribution	13.33	1.50	22.85	4.97	<0.0001*

[*: p value Significant at <0.05]

Table 9 shows that the caregivers with lower burden in BPAD had resorted to coping strategies like Positive cognitive, Problem solving and Religious coping strategies significantly more than the caregivers with higher burden. On the other hand those with higher burden used coping strategies like negative coping,

external attribution and avoidance significantly more than those with lower burden. There was no significant difference in the use of coping strategies like distraction, magical thinking and help seeking between the two groups.

Table-10: Correlation between Global Assessment of Functioning (GAF) of patients with burden of caregiver in BPAD

TOTAL GAF SCORE	CAREGIVER OF BPAD		“r” VALUE
	Mean BAS score	SD	
21-30	98.50	27.82	r = 0.9421
31-40	90.38	23.10	
41-50	92.83	23.95	
51-60	81.83	19.58	
61-70	95.00	25.08	
71-80	70.00	14.97	

Table 10 shows an “r” value of 0.9421, which is close to 1.00, indicating high positive correlation between caregiver’s burden and level of impairment in functioning of patients of Bipolar Affective Disorder.

Majority of the patients were male in the age group of 18-30 years, Hindus, married, unemployed and belonged to low income families of rural background. Mean age was 38.20 years. Majority of the caregivers were in the age range of 18-30, males, married, educated up to middle education level and belonged to

low income families. Our findings are in contrast with the findings of Jenkins and Schumacker in 1999, who found that women take on a large part of care giving responsibility. Siblings constituted the predominant population among the caregivers. Among caregivers, females, married, those who belonged to poor families and those with duration of care of ten or more than ten years experienced more caregiver burden. Our findings were in line with the findings of Rao *et al.* 2015 who found that females, those from low socioeconomic status, married caregivers and those with longer duration of care and treatment were significantly associated with higher burden scores. Positive correlation was found between the caregiver's burden of illness and patient's impairment in functioning. Our findings are in accordance with the findings of Roy Choudhury *et al.* 1995; and Credo and Parkar in 2006 [30,31]. Among the caregivers of patients of BPAD the most commonly used coping strategies included help seeking (93.33%) followed by religious coping strategies and external attribution. Our findings are in accordance with the findings of Ganguly *et al.* and Chakrabarti *et al.*[26,27] Caregivers with lower burden had resorted to coping strategies like Positive cognitive, Problem solving and Religious coping strategies significantly more than the caregivers with higher burden. On the other hand those with higher burden used coping strategies like negative coping, external attribution and avoidance significantly more than those with lower burden.

CONCLUSION

Thus as the patient's impairment in functioning increases, burden of illness also increases. Caregivers who were females, married, belonged to poorer families and spouses of patients experienced higher burden. Those caregivers with duration of care equal to or more than 10 years experienced more burden than those with shorter duration of care. Most caregivers used help seeking followed by religious coping strategies and external attribution. It was also seen those with lower burden used coping mechanisms like Positive cognitive, Problem solving and Religious coping strategies significantly more than those with higher burden. On the other hand those with higher burden used coping strategies like magical thinking, external attribution and negative cognitive significantly more than those with lower burden.

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