

Caregiver burden in the families of the patients suffering from bipolar affective disorder

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Abstract

Background: Bipolar affective disorder is a disabling illness which causes a considerable degree of burden on the caregivers. Few studies from India have measured the burden of care in bipolar affective disorder and its association with caregiver variables.

Aims: This study aimed to evaluate the burden experienced by the caregivers of patients with bipolar disorder and to evaluate the association with various socio-demographic factors of the caregivers and clinical variables of patients with caregiver burden.

Methodology: 100 caregivers of patients diagnosed with bipolar disorder, aged 18 years or more, of either gender, living with the patient for at least one year were assessed by Family Burden Interview Schedule (FBIS), DUKE-UNC Functional Social Support Questionnaire (FSSQ) and General Health Questionnaire (GHQ-30).

Results: Higher caregiver burden was associated with caregiver variables like female gender, illiterate status, low socioeconomic status, advancing age, being married and having lower social support. Among the clinical variables, longer duration of being involved in the care of patients was significantly associated with higher burden scores. Higher burden was associated with longer duration of illness and higher number of lifetime episodes. Better compliance with medication was associated with lower caregiver burden.

Conclusions: Higher caregiver burden among the caregivers of patients with bipolar disorder is associated with many of the caregiver variables and longer duration of illness. Higher social support is associated with lower caregiver burden.

Keywords: Caregiver burden, Bipolar disorder, Correlates, social support

Abbreviations: FBI: Family Burden Interview; DUKE-UNC FSSQ: DUKE-UNC functional social support questionnaire; GHQ-30: 30-item version of the Goldberg's General Health Questionnaire.

Introduction

Bipolar affective disorder (BPAD) is one of the commonest psychiatric disorders with a lifetime prevalence of about 3% in the general population and is the sixth leading cause of disability worldwide (1,2). This disorder is characterised by repeated episodes in which the patient's mood and activity levels are significantly disturbed. This disturbance consists on some occasions of an elevation of mood and increased energy and activity (mania or hypomania), and on other occasions of a lowering of mood and decreased energy and activity (depression) (3). As the illness starts early in life, i.e., during teens or early adulthood, persons suffering from BPAD have symptoms of illness for the major part of their life (4, 5).

In India, since professional services, both in public and private sectors are not adequately developed due to shortage of trained human resources and infrastructure, the family support system plays a major role in caring for people with mental illnesses (6). The primary caregiver is identified as an adult relative (a spouse, parent or spouse equivalent) living with a patient, who is involved in the care of the patient on a day-to-day basis, takes the responsibility for bringing the patient to the treatment facility, stays with the patient during the inpatient stay,

provides financial support and/or is contacted by the treatment staff in case of emergency (7). Intensive involvement in the care of the patient is often associated with significant caregiver burden.

Caregiver burden can be defined as the presence of problems, difficulties or adverse effects which affect the lives of caregivers of patients with various disorders or illnesses, e.g. members of the household or family (8). Family burden is broadly divided into objective and subjective burden. While the notion of the objective family burden relates to measurable problems (e.g. patients' troublesome behaviours), the idea of subjective family burden is bound to caregivers' emotions arising in response to the objective difficulties (9). Multiple studies across the world have shown that bipolar disorder is associated with significant caregiver burden (10-31). In view of the high caregiver burden, it is now suggested that the emphasis in psychiatric rehabilitation needs to shift from a patient-focused approach to a combined patient and caregiver-focused approach. Although there are studies from different parts of the country, there is a lack of data on caregiver burden from Kashmir, which is often faced with turmoil, which can influence caregiver burden. The present study is an effort in this direction to assess caregiver

burden and its correlates among primary caregivers of patients with bipolar disorder.

Methodology

The present study was conducted on primary caregivers of patients with BPAD. Primary caregivers were defined as those caregivers who were closely involved in the care of the patient during the acute episodes and during the maintenance period in terms of bringing the patient to the hospital, supervising the medications and liaison with the treating team.

The study sample comprised of 100 caregivers of 100 patients diagnosed with BPAD as per the International Classification of Diseases classification of mental and behavioural disorders, 10th revision (ICD-10) (3), attending either the outpatient or inpatient services at the Department of Psychiatry, SKIMS, Bemina, Srinagar. The study was approved by the Ethics Committee of the institute and all the participants were recruited after obtaining written informed consent.

To be included in the study, the caregivers were required to be involved in the care of patients, aged 18 or above, living with the patient for at least 1 year and were a family member taking care of patients without any wages. Caregivers who were diagnosed with psychiatric illness and staying with the patient for less than 12 months were excluded.

The caregivers were assessed by following scales:

Family Burden Interview Schedule (FBIS) (32): This is a semi-structured interview schedule having 24 items, each of which is scored on a 3-point scale, i.e. 0 indicating no burden, 1 indicating a moderate level of burden and 2 suggesting severe burden. The items of the objective burden of the scale are divided into 6 domains, i.e. financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interaction, physical health and mental health. Subjective burden is evaluated by a single item. This scale has been widely used in previous studies from India (26, 33-35).

DUKE-UNC Functional Social Support Questionnaire (FSSQ) (36): The Duke-UNC Functional Social Support Questionnaire (FSSQ) is an 8-item instrument to measure the strength of the person's social support network (36). Responses to each item were scored as 1 ('much less than I would like'), 2 ('less than I would like'), 3 ('some, but would like more'), 4 ('almost as much as I would like') and 5 ('as much as I would like'). The scores from all eight questions are summed (maximum 40) and then divided by 8 to get an average score. The higher score indicates better perceived social support. Cronbach's alpha for this scale is 0.84.

Hindi General Health Questionnaire (GHQ-30) (37): The modified version of Goldberg's General Health Questionnaire (GHQ) (38) was used. This is a screening device for identifying minor psychiatric disorders in the general population and within the community or non-psychiatric clinical settings such as primary care or general medical outpatients. The self-

administered questionnaire focuses on two major areas: the inability to carry out normal functions and the appearance of new and distressing phenomena. In each question of the 30-item GHQ, the caregivers were asked to choose among: Better than usual or same as usual = 0, less than usual or much less than usual = 1. The results were evaluated by the two-step assessment method (0-0-1-1-method). The minimum GHQ-30 total score was 0 and the maximum total score of GHQ-30 was 30. A cut-off of 6 was used to categorize those with and without psychiatric morbidity. Cronbach's alpha value of the GHQ-30 was 0.93. The Kappa coefficient was 0.64 ($p < 0.001$).

The recorded data was compiled and entered into a spreadsheet (Microsoft Excel) and then exported to data editor of SPSS Version 16.0 (SPSS Inc., Chicago, Illinois, USA). Continuous variables were summarised in the form of means and standard deviations and categorical variables were summarised as percentages. Student's independent t-test and Chi-square tests were employed for comparing caregiver burden with different variables.

Results

The study included nearly equal number of male and female patients. About two-thirds of the patients were married (63%). About one-third of the patients had not received any formal education and another third had completed their secondary education and one-fourth had completed graduation (Table 1).

Description of socio-demographic variables of caregivers

The study included nearly equal numbers of male and female caregivers. The majority (55%) of the caregivers were spouses of the patient. The majority of the caregivers were married (93%). Nearly half of the caregivers had not received any formal education (48%), were homemakers (44%) and three-fifths of them were from low socioeconomic status (60%). The majority of caregivers (77%) had been caring for duration of one to five years (Table 1).

Clinical profile of patients.

In the present study, the majority of patients (77%) had duration of illness in the range of 1-5 years, nearly half of them were never hospitalised, the majority (55%) of patients had one to two manic episodes, most of them (64%) had three to five episodes of depression, and the majority (75%) of them never attempted suicide or homicide. The majority of patients (73%) were compliant with medication. (Table 2)

Caregiver burden, social support and psychological morbidity among caregivers

As is evident from Table 3, the highest burden was reported in the financial domain, followed by disruption in family routine activities, disruption of family leisure, disruption of family interactions, effect on physical health of others and least burden was reported in the form of effect on mental health of others. The mean DUKE UNC FSSQ score was 3.17 (SD=0.84) with range 1.75-4.75.

Table 1: Description of socio-demographic variables of caregivers

Variables	Caregiver Frequency (n=100)(%)	Patients Frequency (n=100)(%)
Age (Years)	20-29	11(11%)
	30-39	24(24%)
	40-49	26(26%)
	50-59	34(34%)
	≥ 60	17(17%)
	Mean± SD	43.4 ±11.25
Gender	Male	52(52%)
	Female	48(48%)
Marital Status	Unmarried	7(7%)
	Married	93(93%)
Educational Status	No formal education	48(48%)
	Primary	5(5%)
	Secondary	27(27%)
	Graduate	20(20%)
Occupation	Unemployed	3(3%)
	Labourer	27(27%)
	Student	3(3%)
	House maker	44(44%)
	Employed	23(23%)
Socio-economic Status	Low	60(60%)
	Middle	40(40%)
	High	0(0%)
Relationship of caregiver	Father	11(11%)
	Mother	22(22%)
	Spouse	55(55%)
Duration of care	1-5yrs	77(77%)
	6-10yrs	16(16%)
	>10yrs	7(7%)
	Mean ± SD	4.8±4.16

Table 2: Clinical profile of patients.

Patient Variables	Frequency(n=100)(%)	
Duration of illness	1-5 Yrs	77(77%)
	6-10 Yrs	16(16%)
	11-15 Yrs	5(5%)
	16-20 Yrs	1(1%)
	> 20 Yrs	1(1%)
	Mean±SD	4.83±4.25
Number of hospitalisations	Never	47(47%)
	Once	24(24%)
	Twice	18(18%)
	Thrice	6(6%)
	Four Times	5(5%)
	Mean±SD	0.98±1.16
Number of episodes of mania	1-2	55(55%)
	3-4	39(39%)
	5-6	6(6%)
	Mean±SD	2.61±1.12
Number of episodes of depression	< 3	15(15%)
	3-5	64(64%)
	> 5	21(21%)
	Mean±SD	4.05±1.87
Number of attempts of homicide	0	75(75%)
	1	8(8%)
	2	4(4%)
	≥ 3	5(5%)
	Mean±SD	0.37±0.93
Number of attempts of suicide	0	75(75%)
	1	1(1%)
	2	6(6%)
	≥ 3	2(2%)
	Mean±SD	0.23±0.74
Compliance with medication	Yes	73(73%)

	No	27(27%)
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Table 3: Caregiver burden, social support and psychological morbidity among caregivers

Psychosocial parameters	Mean (SD)	Range
Financial burden	7.01 (2.28)	3-12
Disruption of family routine activities	5.38(1.77)	3-9
Disruption of family leisure	4.12 (1.26)	2-8
Disruption of family interactions	4.04 (1.36)	3-9
Effect on physical health of others	2.28 (0.83)	1-4
Effect on mental health of others	1.51 (0.82)	0-4
Total family burden	24.31 (7.35)	13-44
Objective burden	3	
Score < 12	97	
Score ≥12		
Subjective Caregiver burden score	1.12(0.61)	0-2
DUKE UNC FSSQ	3.17 (0.84)	1.75-4.75
GHQ-30	13.14 (5.65)	2-25
GHQ score < 6	77 (77%)	
GHQ score ≥ 6	23 (23%)	

Table 4: Association of caregiver burden with socio-demographic variables of caregivers

Caregiver Variables	N	Mean	SD	P-value
Age (Years)	20-29	11	20.63	4.860
	30-39	24	22.67	7.409
	40-49	26	25.08	6.211
	50-59	34	26.93	5.839
	≥ 60	5	29.25	6.675
Gender	Male	52	23.60	7.384
	Female	48	27.35	7.309
Marital Status	Married	93	26.97	7.409
	Unmarried	7	21.29	6.211
Educational Status	No formal education	48	28.78	7.772
	Primary	5	27.80	7.596
	Secondary	27	24.69	7.223
	Graduate	20	22.35	5.092
Occupation	Unemployed	3	23.15	7.268
	Labourer	27	25.47	1.399
	Student	3	23.05	6.891
	House maker	44	28.05	6.891
	Employed	23	22.07	7.312
Socio-economic status	Low	60	26.88	7.958
	Middle	40	23.38	5.687
	High	0	0	0
Type of family	Nuclear	82	28.37	5.463
	Joint	18	23.54	6.354
Relationship to patient	Parent Spouse	33	24.47	7.972
	Offspring	55	28.04	7.038
		12	21.57	6.024
Duration of care	1-5 Years	77	22.99	5.644
	6-10 Years	16	33.06	6.027
	> 10 Years	7	35.57	5.996

Table 5: Clinical Profile of patients with bipolar disorder

Disease Profile	No.	Mean	SD	P-value
Duration of illness	1-5 Yrs	77	22.98	5.644
	6-10 Yrs	16	33.07	6.027
	≥ 10Yrs	7	37.01	2.887
Number of Hospitalisations	Never	47	22.21	7.896
	Once	24	25.83	7.438
	Twice	18	26.54	6.527
	Thrice	6	28.50	4.506
	Four Times	5	31.00	6.042
Number of episodes of mania	1-2	55	22.27	5.612
	3-4	39	27.97	6.726
	5-6	6	38.65	2.066

Number of episodes of depression	< 3	15	21.93	7.611	<0.001*
	3-5	64	23.91	5.817	
	> 5	21	32.81	6.615	
Compliance with medication (>75%)	Yes	73	24.51	7.328	0.041*
	No	27	27.94	7.377	

Table 6: Clinical Profile of patients with bipolar disorder

Variables	Objective Burden (Pearson's correlation coefficient)
Age of the patients	0.487(0.039) *
Age of the caregivers	0.391(<0.001)** *
Duration of care	0.510 (<0.001)***
Duration of illness	0.526(<0.001) ***
Number of hospitalisations	0.526(0.045) *
Number of episodes of mania	0.526(<0.001) ***
Number of episodes of depression	0.526(<0.001) ***
Social Support Questionnaire	-0.211 (0.035)*
GHQ-30 total score	0.370 (<0.001)***

Mean GHQ-30 score was 13.14(SD=5.65) with a range of 2-25. Of the 100 caregivers, about one-fourth (N=23) had a GHQ-30 score of 6 or more, indicative of psychological morbidity.

Association of caregiver burden with demographic and clinical variables

As is evident from Table 4, higher caregiver burden was associated with higher age, female gender, lack of formal education, being a homemaker, lower socioeconomic status, a nuclear family set-up, being spouse of the patient and longer duration of being in the caregiver role.

Clinical Profile of patients with bipolar disorder

In terms of clinical variables, higher objective caregiver burden was associated with duration of illness more than 10 years, higher number of hospitalisations and higher number of manic and depressive episodes. Caregivers of patients consuming >75% of the prescribed medications reported lower caregiver burden (Table 5).

Advancing age of patient and caregiver, increasing duration of care, prolonged illness, greater number of hospitalisations and higher number of episodes of either polarity were significantly associated with higher caregiver burden. In terms of association of social support and caregiver burden, higher social support was associated with significantly lower caregiver burden, whereas higher caregiver burden was associated with higher psychological morbidity (Table 6).

Discussion

Families play an important role in care of patients with chronic mental illnesses. In the process of caring for such patients, relatives face a considerable burden.

Findings of the present study suggest that higher burden was seen among the caregivers who were relatively older, of female gender, uneducated or illiterate, homemakers and from nuclear families. Compared to parents and siblings, spouses reported significantly higher levels of caregiver burden. Furthermore, the

caregivers involved in the care of the patient for longer durations reported significantly higher levels of caregiver burden.

In terms of clinical variables of patients, higher caregiver burden was associated with longer duration of illness, higher number of lifetime hospitalisations, higher number of manic and depressive episodes and poor medication compliance. Poor social support was associated with a higher level of caregiver burden. Higher caregiver burden was associated with higher psychological morbidity.

Many previous studies from India have evaluated caregiver burden among caregivers of patients with bipolar disorder (10-32). There is a lack of consensus with respect to caregiver variables and their association with caregiver burden (39). Some of the studies suggest that there is no significant difference in the caregiver burden as reported by caregivers of either gender (6), whereas others suggest that females report higher caregiver burden (13, 40). Our findings support the studies which have reported higher caregiver burden among female caregivers. This finding of ours could have been influenced by the relationship of caregivers with patients. In the present study, spouses of patients formed a large proportion of caregivers and they reported significantly higher burden, in contrast to parents and siblings. Cultural issues like restriction of females to household activities with lower opportunities to vent out their distress, inability to spend time on leisure activities, financial dependency and lack of independence could also be responsible for higher perceived burden. It was noticed that caregivers from nuclear families had higher caregiver burden as compared to those from joint families. The joint family system is considered to promote interdependence and possibly is associated with sharing of caregiver burden and this may explain why caregivers from joint families reported lower caregiver burden. Similar findings have been reported in earlier studies from India (41).

Findings of the association of higher caregiver burden with duration of illness are supported by existing literature (14). This finding suggests that possibly with passing time, frequent

relapses of illness lead to caregiver burnout, which leads to higher caregiver burden. Previous studies have also noted an association of higher caregiver burden with higher numbers of hospitalisation (30). Findings of the present study too support this association. Higher caregiver burden with greater numbers of hospitalisations possibly indicate more severe episodes and hospitalisation associated with more expenditures and loss of earnings. This suggests that all efforts must be made to pick up relapses at the earliest and manage them effectively to minimise the chances of progression to severe episodes and resultant need for inpatient care. Previous studies have also reported association between higher caregiver burden and higher number of episodes, especially manic episodes (14) and more severe manic episodes (42). Manic episodes of the illness are very disruptive to daily life, work and family relationships. Due to this, these episodes place great demands on family members involved in caregiving. These demands can persist even during remission, where residual symptoms are often still present and lead to caregiver burden. Available data from India suggest that in contrast to patients from the West, patients from India have a higher number of manic episodes (43). Taken together, this finding has important implications as this suggests that efforts must be made to prevent frequent relapses in patients with bipolar disorder, especially in the Indian context to reduce the caregiver burden (44).

In the present study, higher burden was also associated with a higher number of depressive episodes and this finding is supported by existing literature (16).

Long-term management of bipolar disorder requires continuation of medications with good compliance. Poor medication compliance has been shown to be associated with many negative patient-related outcomes like higher risk of relapses, suicidality, poor quality of life, higher residual or sub-syndromal symptoms etc (45, 46). The present study adds to this body of literature and suggests that poor medication compliance in patients is also associated with higher caregiver burden and this finding is supported by the existing literature (11).

Among the demographic variables of caregivers, higher age of caregivers was associated with higher caregiver burden. This finding is also supported by existing literature (6). This association possibly suggests that with increasing age, the caregivers possibly experience more burnout, lose hope and also lose physical vigour to take care of the mentally ill relative.

Accordingly, it is important for the mental health professionals to support the ageing caregivers.

To conclude, the present study suggests that BPAD is associated with higher caregiver burden. Higher caregiver burden is associated with clinical variables of the patients and demographic variables of the caregivers. Among the patient-related variables, longer duration of illness, those with a higher number of lifetime episodes of either polarity and poor medication adherence are associated with higher caregiver

burden. Hence, all measures must be taken to minimise relapse in patients with BPAD. Among the demographic variables of caregivers, higher caregiver burden is reported by caregivers who were relatively older, of female gender, uneducated or illiterate, homemakers and from nuclear families.

Our findings highlight the need for additional research on interventions to reduce burden among caregivers of patients with bipolar affective disorder. For better outcomes of disease, more attention needs to be given to the primary caregivers in terms of psycho-education and counselling.

Competing Interests

None

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