Original Article

Stigma and its Correlates among Caregivers of Patients with Bipolar Disorder

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ABSTRACT

Background: Stigma associated with mental illness is multifaceted, and it extends to even those who take care of the afflicted persons. Research shows that stigma has maximal impact on patients who have schizophrenia and their caregivers, but information pertaining to caregivers of patients with bipolar disorder is minimal. Accordingly, this study aimed to evaluate stigma and its correlates among caregivers of patients with bipolar disorder. **Methodology:** This cross-sectional study conducted at a tertiary care hospital purposively enrolled 103 caregivers of patients with bipolar disorder-I. The caregivers were assessed on the stigma scale for caregivers of people with mental illness (CPMI) and the Explanatory Model Interview Catalogue (EMIC) stigma scale. **Results:** The majority of caregivers attributed the illness of the patient to stress (54.4%), chemical imbalance (48.5%), or heredity (29.1%), while nearly one-fourth believed it to be the will of God. The mean weighted scores on various domains of CPMI were comparable [affective domain = 2.24 (standard deviation (SD) = 0.51); cognitive domain = 2.25 (SD = 0.54) and behavioral domain = 2.23 (SD = 0.55)]. The mean score on EMIC was 28.00 (SD = 14.57). Caregivers with low income reported higher stigma in affective and cognitive domains. Also, lesser time spent with the patient correlated with higher stigma in the affective domain. Furthermore, poor functioning of the patient was associated with high caregiver stigma in cognitive and behavioral domains. **Conclusion:** Caregivers of patients with bipolar disorder experience significant affiliate and courtesy stigma, and higher stigma is associated with lower income of the caregivers and lesser time spent in caregiving.

Key words: *Bipolar disorder, caregiver, correlates, stigma*
Key messages: *Caregivers of patients with bipolar disorder experience significant affiliate stigma. Experience of higher affiliate stigma among the caregivers is associated with poor functioning of the patient.*

Stigma is conceptualized as "an attribute that is deeply discrediting" and reduces the bearer "from a whole and usual person to a tainted, discounted one."[1] Stigma associated with mental illnesses is not limited to patients but it also extends to their caregivers. Studies from the different parts of the globe suggest

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that caregivers of patients with severe mental disorders such as schizophrenia experience significant stigma.[2-5]

The stigma faced by the caregivers due to their association with a mentally ill individual is referred to as "associative stigma" or "courtesy stigma."[1,6] Besides this, caregivers can stigmatize themselves (the equivalent of self-stigma in patients themselves), which is known as "affiliate stigma" and is understood as a personal affliction of caregivers by the public stigma that is prevalent in the society.[7] Affiliate stigma is considered to have three components, namely, affective (e.g., feeling of unhappiness), cognitive (e.g., thoughts of helplessness), and consequent behavior (avoidance, alienation, etc.).

Previous research on stigma in caregivers of mentally ill persons suggests that more than half of them suffer from some kind of stigma.[8] Furthermore, the stigma faced by the caregivers of patients with a severe mental disorder is associated with significant psychological distress in caregivers.[9] They also believe that the society devaluates people with mental illnesses and their families, and thus, many a time, caregivers are reluctant to reveal themselves as caregivers of persons with mental illnesses.[10]

In terms of correlates of stigma, available literature suggests that parents of persons with mental illnesses who report higher stigma often conceal hospitalization of the patient. Furthermore, higher stigma was reported by those who do not stay with the patient, by those who have a higher education level, and when the patient was a female.[2] Although a good amount of research is available for stigma in schizophrenia and its impact on the patients and their caregivers, limited information is available for caregivers of patients with bipolar disorder (BD).

As a part of the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD) study, the authors assessed stigma in caregivers of individuals with BD. Stigma was high in Hispanic caregivers of unwell patients with BD-I (vs. BD-II), those with low social support, and those having few social interactions.[11] Similarly, among caregivers of well patients, stigma was more in an adult child of the patient, those educated to college level, those with few social interactions, and those caring for a female patient with BD.[11] Other studies suggest higher perception of stigma by carers, in turn, predicts more depressive symptoms, avoidance, and social withdrawal in them.[12] In a recent multicentric study from India, caregiver stigma was measured using stigma scale for caregivers of people with mental illness (CPMI), and highest level of stigma was reported by the caregivers

of patients with schizophrenia, followed by BD, and the level of stigma was the least in those with recurrent depressive disorder (RDD).[13] In addition, the score was also highest for various components of CPMI, namely, affective, behavioral, and cognitive, for the caregivers of patients with schizophrenia. Interestingly, the caregivers of patient with schizophrenia had lowest General Health Questionnaire scores, and the proportion of those having a psychological morbidity was significantly lower among the caregivers of patients with schizophrenia when compared with the caregivers of patients with BD or RDD.

Notwithstanding the current research on various perspectives of caregiving in mental illness from India, minimal exploration has been done on stigma experienced by the caregivers of patients with BD and its correlates. With the aim of filling this gap, this study aimed to evaluate stigma and its correlates among caregivers of patients with BD.

METHODOLOGY

This was a cross-sectional study, conducted at the Outpatient Department of Psychiatry services at a tertiary care hospital that caters to major part of north India. The study was approved by the Institute Ethics Committee, and the recruitment of patients and caregivers was done after obtaining written informed consent. Using a purposive sampling method, 103 caregivers of patients suffering from BD-I as per the Diagnostic and Statistical Manual, fourth revision, age 18–65 years, and currently in clinical remission were chosen. The caregivers were included only if they were >18 years of age, did not suffer from any psychiatric or chronic physical illness (other than nicotine dependence), and could read and/or understand Hindi. They were also required to be living with and intimately involved in the care of the patient.

The following self-report questionnaires were filled by the caregivers:

Stigma scale for CPMI:[7] It measures the caregiver's internalization of stigma or affiliate stigma in three domains, namely, cognitive, affective, and behavioral domains. Each item of the scale is rated on a 4-point Likert scale from strongly disagree (1) to strongly agree (4). The mean scores are obtained for each domain from the scores obtained on various items included in the particular domain. The scale has a Cronbach's alpha value of 0.95, which reflects excellent internal consistency. Weighted mean scores of each component were calculated to compare the severity of each component. We used the Hindi translated version of

this tool, which has been used in an earlier study from our center[5] and was also used in a multicentric study evaluating stigma in caregivers of patients with severe mental disorders.[13]

Explanatory Model Interview Catalogue (EMIC) stigma scale:[14] It assesses anticipated or perceived stigma in the caregivers. It is a self-report scale which has 15 questions, with four answering options, with a higher score indicating higher perceived stigma.

In addition to these self-report questionnaires, the caregivers were evaluated for their etiological attribution of the illness of the patient. This was done by a semi-structured instrument.

The patients were evaluated on the following scales:

Hamilton Depression Rating Scale (HDRS):[15] The 17-item HDRS was used to evaluate depression in the patients. A cut-off score of 7 was used to define remission.

Young Mania Rating Scale (YMRS):[16] This 11-item scale was used to evaluate the remission of manic illness. A score of <7 was used to define remission in this study.

Global Assessment of Functioning scale (GAF):[17] The GAF scale was used to rate the impact of BD on the patients' functioning. This scale measures how the patients are doing in the domains of psychological, social, and occupational functioning and covers the aspects of positive mental health and severe psychopathology. It is a very simple scale to use and has good reliability and validity.

Data analysis
Data were analyzed using the Statistical Package for the Social Science Version 14 (SPSS for Windows, Version 14.0. SPSS Inc., Chicago, IL, USA). Descriptive analysis was used for continuous and categorical variables. The relationship of stigma with other variables was studied using Pearson's product moment correlation, Student's *t*-test, and Chi-square test.

RESULTS

Sociodemographic profile
Demographic details of the patients are shown in Table 1. The mean age of the patients was 40.83 [standard deviation (SD) =11.56] years, and the mean duration of formal education was 10.63 (SD = 3.98) years. The majority of the patients were married (82.7%) and had a monthly income in excess of 7,000 Indian rupees (INR) (76.7%). Slightly more than half of the patients were unemployed (55.3%), belonged to joint or extended family setup (53.8%), and were from a rural background (52.9%).

Male (57.3%) caregivers outnumbered female caregivers. The mean age of the caregivers was 43.41 (SD = 12.43) years, and the mean duration of formal education of caregivers was 10.59 (SD = 4.14) years. The majority (74.7%) of the caregivers had a monthly income of more than 7,000 INR. There was a nearly equal distribution of caregivers who were on paid employment and those who were not on paid employment. In terms of relationship with patients, nearly half of the caregivers were spouses (54.4%), and this was followed by parents (22.4%). The mean duration of being in the caregiver role was 10.12 (SD = 7.89) years and the mean duration of face-to-face time spent in caregiving was 0.42 (SD = 1.72) hours per day. Caregivers had accompanied the patient for more than 90% of the hospital visits in the past 6 months.

The clinical details of the patients are shown in Table 2. The mean age of onset of illness was 29.63 (SD = 10.18) years, and the mean duration of illness was 131.79 (SD = 98.57) months. The mean duration of remission at the time of assessment was 11.16 (SD = 13.0) months. The mean number of depressive episodes experienced by the patients was 2.61 (SD = 2.55), while that for mania was 3.95 (SD = 3.73) and the mean HDRS and YMRS scores at the time of assessment were 0.75 (SD = 1.44) and 0.29 (SD = 0.92), respectively. The mean number of lifetime episodes was 7.25 (SD = 5.98), and the current GAF score at the time of assessment was 78.21 (SD = 0.36).

No comorbid psychiatric and physical illness were seen in 98 (95.1%) and 95 (92.2%) caregivers, respectively. Alcohol dependence was seen in three patients, three patients also had comorbid tobacco dependence, and opioid dependence syndrome currently in remission was present in one patient. Hypothyroidism was present in three patients, and one each had diabetes mellitus, both hypertension and diabetes mellitus, obesity, epilepsy, and vitiligo.

Attribution of illness (etiological models) by the caregivers
The majority of the caregivers reported the etiology of the illness of the patient to be related to stress (54.4%), chemical imbalance (48.5%), or heredity (29.1%) [Table 3]. Overall, a biological etiological model was attributed by more than three-fourths of the caregivers. Nearly one-fourth of the caregivers (25.2%) attributed the illness to the will of God (25.2%).

Table 1: Sociodemographic profile of the patients (*n*=103) and their caregivers (*n*=103)

Variable	Patients *n* (%)/mean (SD)	Caregivers *n* (%)/mean (SD)
Gender		
Male	61 (58.7)	59 (57.3)
Female	42 (40.4)	44 (42.7)
Marital status		
Single	18 (17.3)	16 (15.5)
Married	86 (82.7)	87 (84.5)
Education		
Up to matriculation	53 (51.5)	53 (51.5)
More than matriculation	50 (48.5)	50 (48.5)
Employment status		
Not working	57 (55.3)	52 (50.5)
Working	46 (44.7)	51 (49.9)
Monthly income (in INR)		
Up to 7000	24 (23.3)	26 (25.3)
More than 7000	79 (76.7)	77 (74.7)
Type of family		
Nuclear	47 (45.2)	47 (45.2)
Joint/extended	56 (53.8)	56 (53.8)
Locality		
Rural	55 (52.9)	55 (52.9)
Urban	48 (46.2)	48 (46.2)
Relation with patient		
Parents	NA	23 (22.4%)
Siblings		11 (10.7%)
Children		13 (12.6%)
Spouse		56 (54.4%)
Mean age (years)	40.83 (11.56)	43.41 (12.43)
Mean years of education	10.63 (3.98)	10.59 (4.14)
Mean duration of being the primary caregiver (years)	-	10.12 (7.89)
Time spent by the caregiver with the patient in a day (h)	-	0.42 (1.72)
Percentage of visits in the last 6 months in which caregiver accompanied the patient	-	91.21 (14.78)

SD: Standard deviation

Table 2: Clinical details of patients

Variable	Mean (standard deviation)	Range	Median
Age at onset of illness (years)	29.63 (10.18)	13-58	30.0
Total duration of illness (months)	131.79 (98.57)	12-456	108.0
Duration of remission (months)	11.16 (13.00)	2-72	6.0
Number of episodes of depression in past	2.61 (2.55)	0-18	2.0
Mean duration of depressive episodes in months	2.47 (1.86)	0-9	2.0
Current HDRS score	0.75 (1.44)	0-6	0
No. of episodes of mania in past	3.95 (3.73)	0-20	3
Mean duration of manic episodes in months	2.53 (1.37)	0-9	3
Current YMRS score	0.29 (0.92)	0-5	0
Number of episodes of hypomania in past	0.60 (2.24)	0-20	0
Mean duration of hypomanic episodes in months	0.14 (0.37)	0-2	0
No. of episodes with mixed features	0.08 (0.34)	0-2	0
Mean duration of mixed episodes in months	0.05 (0.36)	0-3	0
Total number of lifetime episodes	7.25 (5.98)	2-41	5.2
Total number of episodes with psychotic symptoms	2.00 (3.53)	0-18	5
Percentage of episodes with psychotic symptoms	26.41 (28.00)	0-100	20
Total no. of hospitalization	0.38 (0.75)	0-3	0
Mean GAF score	78.21 (10.36)	40-92	80

HDRS: Hamilton Depression Rating Scale; YMRS: Young Mania Rating Scale; GAF: Global Assessment of Functioning Scale

Caregiver's stigma

On CPMI, the mean total (weighted) score was 2.24 (SD = 0.51). In terms of CPMI domains, the mean weighted score was equal for affective (mean 2.25; SD = 0.49) and cognitive (mean 2.25; SD = 0.54) domains, and the mean score for the behavioral domain (mean 2.23; SD = 0.55) was slightly less than the other two domains [Table 4]. Nearly two-thirds of

the caregivers disagreed or strongly disagreed on almost all the items of CPMI, and the rest agreed on most of the items. On the EMIC scale, the mean score was 28.00 (SD = 14.57).

Correlates of caregiver's stigma

The caregivers who had lesser income and who spent lesser time with the patient reported higher stigma in the affective domain of CPMI (Pearson's correlation coefficient -0.237; $P = 0.016*$), as well as had a higher total CPMI score (Pearson's correlation coefficient -0.197; $P = 0.046*$). In addition, higher stigma on the cognitive domain of CPMI was reported by caregivers having lower monthly income (Pearson's correlation coefficient -0.200; $P = 0.043*$) [Table 5]. None of the other sociodemographic variables of caregivers (namely, the age, education, duration of being a caregiver, accompanying the patient during follow-up in past six months, supervising medication, etc.) had a significant correlation with any of the domains of CPMI and total EMIC scores.

The poor functioning level of the patient (as indicated by lower GAF score) was associated with higher caregiver stigma in the cognitive (Pearson's correlation coefficient -0.206; $P = 0.036*$) and behavioral domains (Pearson's correlation coefficient -0.202; $P = 0.041*$) of CPMI and a high total score (Pearson's correlation coefficient -0.199; $P = 0.044*$) as well [Table 5]. However, no correlation was observed with patients' attributes such as age of the patient, gender, duration of illness, duration of remission, number of episodes in the past, scores on HDRS and YMRS, number of follow-ups in the past 3 months, or total number of hospitalizations.

Relationship of etiological models of illness by caregivers with their sociodemographical and stigma-related variables

Depending on the presence or absence of at least one supernatural or magicoreligious etiological model, the caregivers were divided into two groups (45 with a supernatural or magicoreligious etiological model and 58 with none). It was seen that such a belief was more if the caregiver was a female ($P = 0.002$), educated less than matriculation ($P < 0.001$), or was unemployed ($P < 0.01$). However, the two groups did not differ on the various measures of anticipated or affiliate stigma.

DISCUSSION

Recently, the stigma associated with mental illnesses has received significant attention.[18-22] However, the research is still scarce with respect to family stigma or affiliate stigma and perceived stigma among the caregivers of patients with BD. This provided the impetus to conduct this study.

Caregiver's stigma

In this study, nearly one-third of the caregivers of patients with BD "agreed" or "strongly agreed" on statements endorsing courtesy/affiliate stigma. With respect to anticipated/perceived stigma as assessed on

Table 3: Etiological explanations reported by the caregivers

Etiology	*n* (%)
Stress	56 (54.4%)
Chemical imbalance	50 (48.5%)
Heredity	30 (29.1%)
Ghosts	6 (5.8%)
Spirit intrusion (*Upari Kasar*)	9 (8.7%)
Divine wrath (*Devi Devta Prakop*)	6 (7.8%)
Planetary influences (*Grah Nakchatra*)	14 (13.6%)
Sorcery/witchcraft (*Jaadu tona*)	9 (8.7%)
Evil spirits (*Buri atma*)	8 (7.8%)
Bad deeds in past life (*Karma*)	14 (13.6%)
Punishment by God	12 (11.7%)
God's will	26 (25.2%)
Breaching the taboos of God	8 (7.8%)
Number of caregivers with at least one supernatural etiology (i.e., reported at least one of the causes as listed from 4-13)	45 (43.7%)
Number of caregivers with at least one biological etiological model (i.e., reported at least one of the causes as listed from 1-3)	79 (76.7%)

Table 4: Caregivers' stigma as per CPMI scale and Explanatory Model Interview Catalogue

Item	Mean (SD)
CPMI-affective component	2.25 (0.49)
CPMI-cognitive component	2.25 (0.54)
CPMI-behavioral component	2.23 (0.55)
Total CPMI score	2.24 (0.51)
Total EMIC score	28.00 (14.57)

CPMI: Caregivers of People with Mental Illness; SD: Standard deviation; EMIC: Explanatory Model Interview Catalogue

Table 5: Correlation of caregiver's stigma with sociodemographic/clinical variables of caregivers and patients

Variable	Affective component	Cognitive component	Behavioral component	Total CPMI score
Relationship with caregiver variables				
Caregiver income	−0.237* (0.016)	−0.200* (0.043)	-0.148 (0.135)	−0.197* (0.046)
Hours of time/day	−0.263** (0.007)	-0.169 (0.088)	-0.156 (0.116)	−0.198* (0.045)
Relationship with patient variables				
GAF score	-0.168 (0.091)	−0.206* (0.036)	−0.202* (0.041)	−0.199* (0.044)

*$p<0.05$; **$p<0.01$. CPMI: Caregivers of People with Mental Illness; GAF: Global Assessment of Functioning Scale

the EMIC scale for caregivers, 60% of the caregivers endorsed stigma. A higher proportion of caregivers of patients who were single (82%) reported difficulties in getting married due to caring for a person with BD in the family. This finding is in keeping with the cultural and general public attitudes in the Indian society, where the marital alliance is solemnized after an intense screening, and mental illness adversely affects the marriage prospects of the sufferer and siblings.[23] When compared to a recently published study from the same center,[5] which involved caregivers of patients with schizophrenia, the mean scores on affective (2.25 vs. 2.3), cognitive (2.25 vs. 1.9), behavioral domains (2.23 vs. 1.8), and total CPMI (2.24 vs. 2.1) score were slightly higher in the index study. The multicentric study from India, which also used the same scale, reported the highest level of stigma among the caregivers of patients with schizophrenia, followed by BD and least in those with RDD.[13] A study[24] from China also reported the highest affiliate stigma for the caregivers of patients who have schizophrenia, when compared with caregivers of patients with BD. When one attempts to understand the finding of this study and the existing literature, it is evident that the issue is not yet settled with respect to the hierarchy of stigma experienced by the caregivers of various severe mental disorders. It can be said that the caregivers of patients with BD also appear to experience a comparable level of stigma as that reported by caregivers of patients with schizophrenia.

Correlates of caregiver's stigma
In the STEP-BD study, patient characteristics, namely, an early age of onset of illness; a greater number of hospitalizations; suffering from a more severe type of illness; and caregiver attributes of high burden, depressed mood, and low social support, were associated with higher caregiver stigma. On the other hand, in the same study, caregivers of well patients who were females, more educated, and had fewer social interactions reported higher perceived stigma.[11] In this study, caregivers who earned less and spent less time with the patient reported higher affiliate stigma. None of the patient's sociodemographic and clinical variables were associated with perceived stigma in their caregivers. We did not find any association of relationship of caregiver with the patient and perception of stigma. However, in previous research, higher stigma has been reported by an adult child of patient[11] or parents.[24]

In this study, higher stigma in the affective domain (of CPMI) was seen among the caregivers who spent less time with the patient. This finding possibly suggests that caregivers who are less bonded to patients report higher stigma. However, it is also possible that caregivers who experienced more stigma avoided the patient and resultantly spent less time with the patient.

Among the patient variables, stigma had a significant correlation with the level of functioning of the patients, with caregivers of patients with better functioning reporting lower stigma. This finding suggests that clinicians managing patients with BD should not limit themselves to achieving clinical remission only but also address the functioning, as better functioning can possibly lead to lower caregiver burden and resultant stigma.

This study has certain limitations. The assessment of stigma was limited to a single cross-sectional evaluation and a relatively small sample size. The study recruited patients and caregivers attending a tertiary care hospital and patients who were clinically stable. There was a lack of a control group in the study. We did not evaluate other psychological variables such as expressed emotions, coping, and psychological morbidity among the caregivers. Future studies must attempt to overcome these limitations.

To conclude, this study suggests that caregivers of patients with BD suffer from high affiliate and courtesy stigma, which is comparable to that reported by caregivers of patients with schizophrenia. Hence, there is an urgent need to address stigma among the caregivers of patients with BD. Measures such as proper psychoeducation of the patient and their caregivers, access to various social welfare schemes, rehabilitation of the patient, and public awareness programs to mitigate stigma among the patients and the caregivers may help reduce stigma related to BD.

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Conflicts of interest
There are no conflicts of interest.

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